

Understanding and Improving Disability Training for Health Workers in Sub- Saharan Africa



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ABSTRACT

The World Health Organization estimates that 16% of the world's population is disabled. Health worker training in many countries has been described as limited, ineffective, and unsystematic with regard to disability. This insufficiency is likely to be detrimental to the quality of health care that disabled people receive across health systems globally and understanding the training and other mechanisms that help health workers to improve their care for disabled patients could improve health outcomes.

To date, there has been limited research on disability training to health workers in sub-Saharan Africa. Pilot programmes in countries like Ghana have shown promise, but there remain substantial gaps in the literature. This aim of this thesis is to understand how to improve health worker training in sub-Saharan Africa by exploring the current state of health worker training on disability in sub-Saharan Africa and makes recommendations to improve it. The thesis explores these topics through i) a systematic literature review to characterise existing health worker training on disability globally; ii) a document analysis of disability laws and policies in selected countries in sub-Saharan Africa; iii) secondary analysis of regional data to understand how disabled people use health services; and iv) qualitative interviews to explore health workers' perspectives of training on disability in Ghana.

The systematic review found that there are numerous individual interventions to train health workers about disability, but these are usually one-off trainings, with limited evaluation, follow-up, or consistency across settings. Similarly, the document analysis showed some laws and policies required training, but did not provide further details (i.e., curriculum, budget, timing, etc.) necessary for implementation. Furthermore, secondary analysis showed that there were no substantial differences in where disabled people seek care, which emphasized the importance of training every health worker. Finally, the qualitative data demonstrated that training interventions were acceptable and effective in changing the attitudes and behaviour of health workers. However, these interviews, together with the other results of the thesis, show that health worker training must be more robust in its frequency, formality, and follow-up to ensure health workers are all trained to improve health equity for disabled people.

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STATEMENT OF CONTRIBUTIONS

I certify that the work in this thesis is my own. Where others have contributed to the work, their initials are used. The contributions of others are summarised as follows:

Throughout the thesis, Professors Sara Ryan (SR), Sue Ziebland (SZ), Dr Emily McFadden (EM), have provided feedback on the methodology, protocols, and chapter drafts.

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ABBREVIATIONS

ANC – Antenatal Care

aOR – Adjusted Odds Ratio

ARI – Acute Respiratory Infection

BMI – Body-mass Index

CAR – Central African Republic

CI – Confidence Interval

CFM – Child Functioning Module

CPD – Continuing Professional Development

DRC – Democratic Republic of Congo

HIV – Human Immunodeficiency Virus

HTC – HIV Testing and Counselling

ICPD – International Conference on Population and Development

ISCO-08 – International Standard Classification of Occupations

MICS – Multiple Indicator Cluster Survey

MICS6 – Round 6 of the Multiple Indicator Cluster Survey

MiNDBank – More Inclusiveness Needed in Disability and Development

OR – Odds Ratio

SDGs – Sustainable Development Goals

SRH – Sexual and Reproductive Health

SRHR – Sexual and Reproductive Health Rights

SSA – Sub-Saharan Africa

UK – United Kingdom

UN CRPD – United Nations Convention on the Rights of Persons with Disabilities

UN DESA – United Nations Department of Economic and Social Affairs

UNICEF – United Nations Children’s Fund

US – United States of America

WGQs – Washington Group Questions

WHO – World Health Organisation

TABLE OF CONTENTS

ABSTRACT	II
ACKNOWLEDGEMENTS	III
STATEMENT OF CONTRIBUTIONS	V
STATEMENT OF PUBLICATION	VI
STATEMENT OF FUNDING	VII
ABBREVIATIONS	VIII
INDEX OF TABLES	XVI
INDEX OF FIGURES	XVII
1 INTRODUCTION	18
1.1 BACKGROUND	18
1.2 MODELS OF DISABILITY	18
1.3 INEQUITY FOR DISABLED PEOPLE AND THE SDGs	20
1.4 DISABLED PEOPLES' HEALTH STATUS AND OUTCOMES	21
1.4.2 <i>Health Outcomes</i>	23
1.5 HEALTH ACCESS AND SYSTEMS FOR DISABLED PEOPLE	23
1.5.1 <i>Conceptualising Access to Health for Disabled People</i>	24
1.5.2 <i>The Importance of Health Worker Training</i>	26
1.6 WHAT ALREADY EXISTS TO TRAIN HEALTH WORKERS ON DISABILITY?	27
1.7 LITERATURE CONTEXT ON DISABILITY TRAINING FOR HEALTH WORKERS IN SUB-SAHARAN AFRICA.....	29
1.7.1 <i>Sub-Saharan Africa</i>	29
1.7.2 <i>Disability Training in Sub-Saharan Africa</i>	30
1.8 LITERATURE GAPS	31

1.9	THESIS STRUCTURE.....	32
1.9.1	<i>Research Question and Overall Methods</i>	33
1.9.2	<i>Chapter Structure</i>	33
2	THE LEGAL AND POLICY REQUIREMENTS OF DISABILITY TRAINING.....	35
2.1	CHAPTER PURPOSE	35
2.2	BACKGROUND	35
2.3	METHODS.....	36
2.4	RESULTS	38
2.5	DISCUSSION.....	41
2.6	CONCLUSION	42
3	GLOBAL EVIDENCE ON DISABILITY TRAINING FOR HEALTH WORKERS....	44
3.1	CHAPTER PURPOSE	44
3.2	BACKGROUND	44
3.3	METHODS.....	45
3.3.1	<i>Search Strategy</i>	45
3.3.2	<i>Selection Criteria</i>	45
3.4	RESULTS	47
3.4.1	<i>Lecture/Didactic Methods</i>	50
3.4.2	<i>Disabled People as Teachers</i>	50
3.4.3	<i>Case Studies</i>	51
3.4.4	<i>Placements, Experiential, and Community-based Learning</i>	51
3.4.5	<i>Simulations</i>	52
3.4.6	<i>Clinical Encounters</i>	52
3.4.7	<i>Multi-pronged Approach</i>	53
3.4.8	<i>Training Effectiveness</i>	53
3.5	DISCUSSION.....	54

3.5.1	<i>Future Directions</i>	56
4	QUANTITATIVE DATA SOURCE	57
4.1	CHAPTER PURPOSE	57
4.2	UNICEF'S MULTIPLE INDICATOR CLUSTER SURVEY	57
4.2.1	<i>MICS Sampling and Data Quality</i>	57
4.2.2	<i>Interviews</i>	58
4.2.3	<i>Questionnaires and Data Format</i>	59
4.2.4	<i>Washington Group Questions</i>	59
4.3	ETHICAL APPROVAL.....	61
4.4	AIMS OF THE QUANTITATIVE ANALYSES	62
5	ASSOCIATION BETWEEN DISABILITY STATUS AND CARE-SEEKING BEHAVIOUR FOR COMMON CHILDHOOD ILLNESSES	63
5.1	CHAPTER PURPOSE	63
5.2	INTRODUCTION	63
5.3	METHODS.....	64
5.3.1	<i>Data</i>	64
5.3.2	<i>Measure of Impairment</i>	64
5.3.3	<i>Outcomes and Covariates</i>	65
5.3.4	<i>Statistical Analysis</i>	66
5.4	RESULTS	66
5.4.1	<i>Prevalence</i>	73
5.4.2	<i>Care Seeking</i>	74
5.4.3	<i>Health Worker Who Provided Care</i>	75
5.5	DISCUSSION.....	76
5.5.1	<i>Strengths and Limitations</i>	78
5.6	CONCLUSION	79

6	ASSOCIATION BETWEEN DISABILITY STATUS AND USE OF MATERNAL CARE SERVICES.....	80
6.1	CHAPTER PURPOSE	80
6.2	BACKGROUND	80
6.3	METHODS.....	81
6.3.1	<i>Outcomes and Covariates</i>	81
6.3.2	<i>Statistical Analysis</i>	81
6.4	RESULTS	82
6.4.1	<i>Antenatal Care</i>	84
6.4.2	<i>Skilled Birth Attendance</i>	84
6.4.3	<i>Postnatal Care</i>	84
6.4.4	<i>Postpartum Care</i>	84
6.5	DISCUSSION.....	86
6.5.1	<i>Strengths and Limitations</i>	87
6.6	CONCLUSION	89
7	QUALITATIVE STUDY CONTEXT AND METHODS.....	90
7.1	CHAPTER PURPOSE	90
7.2	BACKGROUND	90
7.2.1	<i>Description of the University of Ghana Training</i>	92
7.3	STUDY SETTING	92
7.4	STUDY DESIGN	93
7.5	STUDY PARTICIPANTS	94
7.6	SAMPLING AND RECRUITMENT OF PARTICIPANTS.....	94
7.7	DATA COLLECTION	95
7.8	DATA ANALYSIS	95
7.9	ETHICAL CONSIDERATIONS	96

7.9.1	<i>Ethical Approval</i>	96
7.9.2	<i>Informed Consent</i>	96
7.9.3	<i>Confidentiality and Data Management</i>	97
7.9.4	<i>Compensation</i>	97
7.10	REFLEXIVITY AND POSITIONALITY	97
8	PERSPECTIVES ON HEALTH WORKER TRAINING ON DISABILITY IN GHANA	
	99	
8.1	CHAPTER PURPOSE	99
8.2	INTRODUCTION	99
8.3	METHODS.....	99
8.4	STUDY PARTICIPANTS	100
8.5	FINDINGS.....	101
8.5.1	<i>Challenges with Training</i>	101
8.5.2	<i>Suggested Improvements for Training</i>	104
8.5.3	<i>Theory of Change Model</i>	107
8.6	DISCUSSION.....	109
8.6.1	<i>Strengths and Limitations</i>	111
8.7	CONCLUSION	111
9	THE IMPACT OF DISABILITY TRAINING FOR HEALTH WORKERS	113
9.1	CHAPTER PURPOSE	113
9.2	INTRODUCTION	113
9.3	FINDINGS.....	113
9.3.1	<i>Awareness Raising to Address Stigma and Human Rights</i>	113
9.3.2	<i>Broader Training—Beyond Health Workers is Needed</i>	114
9.3.3	<i>Training is Important, but a Broader Focus on Accessibility is Needed</i>	115
9.3.4	<i>Healthcare Workers Can Be Empowered to Challenge Social Norms</i>	116

9.4	DISCUSSION.....	117
9.4.1	<i>Strengths and Limitations</i>	<i>118</i>
9.5	CONCLUSIONS	119
10	DISCUSSION AND CONCLUSION	120
10.1	SUMMARY OF FINDINGS	120
10.1.1	<i>Objective 1: To Characterise Existing Interventions</i>	<i>120</i>
10.1.2	<i>Objective 2: To Recommend Which Health Workers Should Be Prioritized for Training 121</i>	
10.1.3	<i>Objective 3: To Understand Key Stakeholders' Perspectives of Current Training Initiatives.....</i>	<i>122</i>
10.2	STRENGTHS AND LIMITATIONS	123
10.3	RECOMMENDATIONS.....	125
10.3.1	<i>Recommendation 1: Adopt A Common Framework.....</i>	<i>125</i>
10.3.2	<i>Recommendation 2: Full Curriculum Integration</i>	<i>128</i>
10.3.3	<i>Recommendation 3: Evaluate Training to Develop a More Robust Evidence Base 129</i>	
10.3.4	<i>Recommendation 4: Prepare Health Systems To Train Health Workers on Disability 130</i>	
10.4	FURTHER ACTIONS TO IMPROVE DISABILITY TRAINING	131
10.5	CONCLUSION.....	132
11	APPENDICES.....	134
	APPENDIX 1: LAWS AND POLICIES EXTRACTION TABLE	135
	APPENDIX 2: SAMPLE SEARCH STRATEGY	138
	APPENDIX 3: EXTRACTION SHEET	141
	APPENDIX 4: MICS CHILDREN UNDER FIVE QUESTIONNAIRE - CHILD FUNCTIONING MODULE	159
	APPENDIX 5: MICS WOMEN'S QUESTIONNAIRE - ADULT FUNCTIONING MODULE	161

APPENDIX 6: MULTI-LEVEL MODEL FOR ARI, DIARRHOEA AND FEVER CARE PROVIDER ACCORDING TO CHILD’S DISABILITY STATUS BY COUNTRY, 2017-2020	162
APPENDIX 7: CHAPTER 5 SENSITIVITY ANALYSIS	165
APPENDIX 8: CHAPTER 6 SENSITIVITY ANALYSIS	166
APPENDIX 9: OXTREC ETHICS APPROVAL LETTER	167
APPENDIX 10: GHANA HEALTH SERVICE ETHICS APPROVAL LETTER	169
APPENDIX 11: INTERVIEW GUIDE –TRAINEES	170
APPENDIX 12: INTERVIEW GUIDE – TRAINERS	172
APPENDIX 13: PARTICIPANT INFORMATION SHEET.....	174
APPENDIX 14: QUALITATIVE STUDY CONSENT FORM.....	176
12 REFERENCES.....	177

INDEX OF TABLES

Table 2.1: Summary of Disability-Training for Health Workers Clauses in Disability Laws and Policies in Selected Sub-Saharan African Countries.....	40
Table 3.1: Characteristics of Included Studies.....	49
Table 5.1: Baseline Characteristics of 51,901 Children from 10 Multiple Indicator Cluster Survey (MICS) Countries in Sub-Saharan Africa, 2017-2020.....	68
Table 5.2: Baseline Characteristics by Disability Status, of 51,901 Children from 10 Multiple Indicator Cluster Survey (MICS) Countries in sub-Saharan Africa, 2017-2020.....	69
Table 5.3: Unadjusted and adjusted odds ratios for having and seeking care for Acute Respiratory Infection (ARI), diarrhoea, and fever in children from 10 Multiple Indicator Cluster Survey (MICS) countries in sub-Saharan Africa, 2017-2020.....	71
Table 5.4: Adjusted Odds Ratios for the Care Provider Type from Whom Care is Sought for ARI, Diarrhoea And Fever, According to Disability Status in Children from 10 MICS Countries in Sub-Saharan Africa, 2017-2020.....	75
Table 6.1: Baseline Characteristics, Overall And By Disability Status, of 10,021 Women from 13 MICS in Sub-Saharan Africa, 2017-2020.....	83
Table 6.2: Adjusted odds ratios for antenatal care coverage and provider types for women from 13 Multiple Indicator Cluster Survey (MICS) countries in sub-Saharan Africa, 2017-2020.....	85
Table 6.3: Adjusted odds ratios for the care provider type for various stages of maternal health care for women from 13 Multiple Indicator Cluster Survey (MICS) countries in sub-Saharan Africa, 2017-2020	85
Table 8.1: Participant Characteristics	100
Table 8.2: Training Methods Theory of Change.....	108
Table 10.1: Core components of health worker training	127

INDEX OF FIGURES

Figure 1.1: Missing Billion Health System Framework 26

Figure 3.1: Flow Chart of Selected Studies to Review Health Worker Training on Disability.....48

Figure 7.1: Map of Ghana Regions and Interview Locations 93

1 INTRODUCTION

1.1 BACKGROUND

At some point in our lives, most of us will become disabled,* either temporary or permanently.¹

Congenital impairment, accidents, chronic and terminal illnesses, multimorbidity, or ageing makes it highly likely each person will become part of the 16% of the global population that is currently disabled.² Yet, disability is still viewed as a rarity, extra burden, or individual flaw. Disability is often stigmatized, and disabled people are regularly denied their equal rights to accessible education, health, employment, transportation, and more.³ The juxtaposition between some non-disabled people's current comportment towards disabled people likely contradicts how they would want to be treated if, or when, they become disabled. When disability is reframed as a nearly inevitable, natural part of the human experience, it emphasizes the scale of disability and the importance of expanding knowledge and challenging bias against this human characteristic. Therefore, this thesis seeks to answer the question: 'how can we improve health worker training on disability in sub-Saharan Africa?'

1.2 MODELS OF DISABILITY

To understand contemporary conceptions of disability, one must first understand the largely outdated medical model of disability. This model emphasises the 'problem' with an individual's characteristics and pathology as something that must be prevented or cured.⁴ It views disability as an inherently negative characteristic,⁵ or, more strongly, "personal tragedy for both the individual and her family, something to be prevented, and if possible, cured".⁶ While contemporary models have evolved from this definition, the 'prevention', 'cure' and 'tragedy' paradigms that define the medical model of disability still shape many of the common narratives around disability today.⁵ For instance, many policies or programmes to support disabled people also utilise a medicalised

* This thesis will use identity-first language, in keeping with current UK conventions and to align with the social model of disability.

definition of disability or require a medical examination and certification to access essential services, like social protection programmes or educational supports.⁴ However, the medical model has widely been criticised and abandoned because it lacks the nuance to address the aspects of disability other than an individual's impairment.^{5,7} In an extreme example, the medical model would prioritize spending billions of pounds in research for "curing" Autism, rather than providing people with appropriate social, health, and educational support.

In contrast, the increasingly accepted models of disability emphasize that disability lies within the social environment, rather than as an implicit flaw in an individual. In the view of these models, disability occurs when impairments interact with their environment to disable a person.^{8,9} The social model of disability believes a person is disabled by their environment (physical and social), rather than disability being seen as an innate feature in the individual.^{7,9} For example, entering a building is no longer a disabling experience when a wheelchair user has access to the appropriate assistive technology and stairs are replaced with lifts and ramps. While the societal and environmental factors that lead to disability are captured in the social model, it often appears to disregard the consequences of impairment on an individual, such as chronic pain or other health aspects that are innate to one's impairment.¹⁰ The Nordic Social Model addresses this gap by viewing disability on a continuum of interaction between disability and impairment, with external factors influencing where an individual lies on the continuum.¹¹ In 2001, the World Health Organization expanded on these models to develop the International Classification of Functioning, Disability, and Health.¹² Under this model, the disability is viewed within the personal context of an individual across all activities available to them, with an emphasis on health and functioning. It views an activity within the interaction between personal (i.e., health condition, body structure and function, and participation) and contextual factors (i.e., environmental and personal characteristics) in how an individual can participate in the activity. This reframing accounts for how an individual's impairment, activity limitation, and participation restriction create barriers to inclusion and what supports or interventions might improve an individual's ability to participate in an activity.¹² For example, two people with spinal cord injuries may both have difficulty moving and walking, but the level of their impairment would depend on

the activities they wish to do, in combination with a variety of social factors, such as age, gender, marital status and education. Accordingly, two people with similar spinal cord injuries—a 28-year-old married male who is employed and a 65-year-old single female who is retired—may face different barriers or require different accommodations. This model of disability is also reflected in the 2006 United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)—the seminal UN document that addresses the rights of disabled people around the world that is ratified by 186 countries (as of August 2023). The UN CRPD definition of disability provides a fundamental understanding of disability globally:

“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.”¹³

The emphasis on external factors and equity drives the need to explore what types of support and interventions would improve the lives of disabled people. Most interventions have targeted the built environment to support greater inclusion and accessibility. For instance, most countries have public access laws that support making any public built environment (i.e., schools, health facilities, transport systems, shops, places of workshop, etc.) accessible, but full progress and implementation is lacking in most countries.¹⁴ In addition, the role of individuals’ attitudes and resulting social environment is central to these models of disability, making attitudes and awareness important to address. Yet, most societal-level interventions are aimed at removing the infrastructural, economic, and environmental barriers to disability, rather than societal-level interventions to address the stigma, negative attitudes, and discrimination disabled people face.¹⁵

1.3 INEQUITY FOR DISABLED PEOPLE AND THE SDGs

Many disabled people face substantial barriers to accessing healthcare,¹⁶ education,¹⁷ social support,¹⁸ housing,¹⁹ employment,²⁰ and transportation,²¹ leading to poor health outcomes,²² underemployment and unemployment,²³ poverty,²⁴ and various other social inequities.³ Indeed, these inequities are further exacerbated by intersecting identities, such as gender, race, sexuality, religion, migration status, and location.^{22,24,25}

Within the global health landscape, the Sustainable Development Goals (SDGs)—UN-led global objectives to “end poverty and inequality, protect the planet, and ensure that all enjoy health, justice, and prosperity”²⁶—have renewed focus on health equity within global health and development. At the core of these goals is to ‘leave no one behind’, and while no one goal is specifically about disability, this objective and the inequities disabled people face makes disabled people a cross-cutting group, necessary to achieve each of the goals.²⁷ Disabled people are also included in several targets that measure progress on the goals, including targets for Goal 4 (inclusive education), Goal 8 (inclusive employment), Goal 10 (social, economic, and political inclusion), Goal 11 (accessible cities and transport), and Goal 17 (disability-disaggregated data).²⁸ Many have argued that the global goals will not be met without focusing on the inequities disabled people face, particularly without focus on disability in health-related goals (such as HIV eradication),²⁹ better disability-disaggregation in data and monitoring,³⁰ or full implementation of health-related UN CRPD articles.²⁷

1.4 DISABLED PEOPLES’ HEALTH STATUS AND OUTCOMES

1.4.1 HEALTH STATUS

Disabled people face barriers in the health sector, leading to substantial inequities in health status and outcomes. A 2022 World Health Organisation Report found evidence of several health inequities for disabled people, including higher rates of common chronic conditions such as diabetes, asthma, cardiac disease, osteoporosis, anxiety, and depression.² Quantitative research in the last decade has quantified these differences in health status for disabled people.

In terms of health behaviours and nutritional status, data from South Korea showed that disabled people were three-times more likely to be physically inactive (adjusted Odds Ratio (aOR): 3.06, 95% C.I.: 1.71 – 5.48 for no physical activity; aOR: 1.70, 95% C.I.: 1.19 – 2.43 for insufficient physical activity) compared to non-disabled people.³¹ Disabled people are also significantly more likely to smoke than their non-disabled peers.^{2,32} and have worse oral health, on average, including having an average of 2.5 decayed teeth.³³ While there is also evidence on the gap in access to oral care services,

when people with intellectual disabilities did access care, they were more likely to have teeth extracted rather than restored.^{34,35} Furthermore, disabled people also experience a range of nutritional status disparities. A 2017 systematic review found that disabled children had nearly three times higher odds of being underweight (Odds Ratio (OR): 2.97, 95% C.I.: 2.33 - 3.79) and two times higher odds of being stunted (height for age) or wasted (weight for height) (Stunting: OR: 1.82, 95% C.I. 1.40 - 2.36; Wasting: OR:1.90, 95% C.I.: 1.32 - 2.75) compared to children without disabilities.³⁶ Another study showed that disabled children also have significantly higher mortality rates from severe acute malnutrition than non-disabled children (OR: 6.99, 95% C.I. 3.49 - 14.02).³⁷ In adults, data from South Korea showed disabled people had higher odds of being underweight (aOR: 2.14; 95% C.I.: 1.07 - 4.28)³¹ and disabled women are had higher odds of being obese (OR 1.40, 95% C.I.: 1.38 – 1.41).³⁸

Disabled people also experience disparities in the diagnosis, treatment, and outcomes of a range of non-communicable diseases. A recent systematic review of 29 studies found that disabled women had significantly lower odds of having had screening for breast (OR: 0.78, 95% CI: 0.72-0.84) and cervical cancer (OR: 0.63, 95% CI: 0.45-0.88) than non-disabled women.³⁹ In contrast, a US study found that disabled women are more likely to have breast or cervical cancer screening, despite less access to screening.⁴⁰ A range of studies from South Korea have also highlighted that disabled people are more likely to die from cancer than non-disabled people.⁴¹⁻⁴⁴ In terms of cardiovascular diseases, disabled people are more likely to have congenital heart diseases,⁴⁵ and this condition is particularly prevalent amongst adults with Down syndrome⁴⁶ and intellectual disabilities.⁴⁷ There is also evidence from France that showed disabled older adults have an increased risk of coronary heart disease (aOR: 1.8, 95% C.I.: 1.1 – 2.9) and experience higher mortality from cardiovascular diseases (adjusted Hazard Ratio (aHR): 4.5, 95% 1.8 – 11.3) than non-disabled older adults.⁴⁸

These trends also hold true for communicable diseases. Evidence from South Africa shows disabled people are twice as likely to have tuberculosis⁴⁹ and a systematic review of studies in sub-Saharan Africa showed disabled people have an HIV prevalence of 1.1% to 29%, 1.31 times higher than the general population (95% C.I.: 1.02 – 1.69).^{50,51} Disabled children also have higher rates of diarrhoeal

disease, acute respiratory infection, and fever, compared to non-disabled children, as discussed for sub-Saharan Africa in Chapter 5.^{22,52} Furthermore, recent evidence from Canada showed STIs are more common in disabled women (OR: 1.54, 95% C.I.: 1.27 – 1.86) and men (OR: 1.29, 95% C.I.: 1.03 – 1.62) than non-disabled adults.⁵³

These inequities are also exacerbated along the lines of gender and income. For example, disabled women face an array of barriers in accessing sexual and reproductive health care,⁵⁴ as will be discussed in greater depth in Chapters 6-9. Disabled women who have had children also experienced worse general health (aOR: 6.85), poor mental health (aOR: 4.02) and poor physical health (aOR: 9.34).⁵⁵ Additionally, qualitative research has also shown that disabled people in the lowest income brackets experience particularly substantial challenges with accessing and affording health care, leading to worse self-reported health status.⁵⁶

1.4.2 HEALTH OUTCOMES

These gaps in health status have consequential impacts on mortality and life expectancy. A systematic review and meta-analysis found that disabled people in low- and middle-income countries have a 2.06 times higher mortality rate (95% C.I.: 1.80 – 2.34)⁵⁷ and die 10-20 years earlier than non-disabled people, largely because of preventable health inequities.^{22,58} The poor social and health factors outlined above not only worsen health outcomes, but are also sources of poor health to begin with, leading to a cycle of poor health.⁵⁹ Reinforcing this idea, a recent systematic review found a complicated relationship between the system, interpersonal, and environmental factors that inhibit equal access to healthcare for this population.¹⁶ The data showed several domains—stigma and discrimination, lack of accessible communication and information, and poorer quality services—where better inclusion of disabled people in the health system is needed.¹⁶

1.5 HEALTH ACCESS AND SYSTEMS FOR DISABLED PEOPLE

With these stark differences in health status and outcomes, it is unsurprising that the picture of health access is not markedly better. Disabled people, generally, have three types of health needs: 1) regular health care (i.e., immunisations, sexual health check-ups, etc.), 2) additional general health services

because of poorer health, and 3) Specialist health care related to their impairment (i.e., rehabilitation services, ophthalmologists, neurologists, etc.).⁶⁰ Accordingly, disabled people report having higher utilisation of primary or secondary health services and higher health expenditures.⁶¹ However, despite the increased need for health care, disabled people also report having three times higher unmet needs for health care.⁶² In Sierra Leone, disabled people were less likely to have access to a public hospital than non-disabled people (aOR: 0.36, 95% C.I.: 0.12 – 0.99).⁶³ A UK study found that disabled people often had unmet needs due to distance/transport (aOR: 4.32, 95% C.I. 2.66 – 7.00), long-waitlists (aOR: 2.38, 95% C.I.: 1.96 – 2.89), being unable to afford examinations or treatment (aOR: 3.35, 95% C.I.: 1.94 – 5.80), and affordability of prescribed medicines (aOR: 5.39, 95% C.I.: 2.77 – 10.50).⁶⁴ While the NHS ensures financial protection for the costs of services, these data, and a systematic review, have shown the extra costs associated with seeking care (i.e., transport, carer time, etc.) and out-of-pocket co-payments for medicines are still a significant barrier to accessing care for disabled people.^{64,65}

1.5.1 CONCEPTUALISING ACCESS TO HEALTH FOR DISABLED PEOPLE

The Levesque framework for accessing healthcare provides a concise framework for understanding how the systems, institutional, provider, community, and individual level-factors impact health access.⁶⁶ This framework is important, as it not only provides a framework for the complex concept of health access by integrating the various determinants of health access into a patient journey, but also because it helps conceptualise how patient-centred health systems operate, in practice.⁶⁶ In the framework, there are five dimensions of accessibility (approachability, acceptability, availability and accommodation, affordability, and appropriateness), with five collar dimensions of ability (perception of need, seeking, reaching, paying for, and engaging with care). In this framework, there is an emphasis on how each stage of the healthcare journey may be hampered by barriers. From perceiving health needs to seeking care and receiving adequate treatment, there is evidence that disabled people face substantial barriers in accessing healthcare.¹⁶

A key component of the framework outlined by Levesque includes the relationship with healthcare workers, as past health experiences are seen as a modifying factor in deciding to access healthcare.

Therefore, this framework helps highlights the relationship that can form from negative experiences with health workers. While there is no definitive evidence on the impact of health workers' attitudes towards disabled people and its impact on care-seeking, there is a growing body of evidence that suggests health workers have prejudice or negative attitudes towards disabled people. For example, a 2020 study in the United States found that most health workers believe disabled people have a worse quality of life than non-disabled people (82.4%) and feel tentative when providing care to disabled people (59.3%).⁶⁷ This is echoed in other studies, which suggest physicians perceived caring for disabled people negatively, making them more reluctant to care for disabled people in their practices.⁶⁸ Indeed, in a survey of student members of the American Academy of Family Physicians, nearly 98% of participants wanted more disability training, with only 36% stating that they were well-trained on how to provide care for disabled patients.⁶⁹ Finally, a qualitative study in Ghana found that health workers saw disabled people as anxious, violent, selfish, inconsiderate, lacking self-confidence, and difficult to communicate with—perceptions that likely lead to poor quality and unequal care.⁷⁰ These studies, in conjunction with Levesque's framework, emphasise that, despite disabled people having higher health needs, these negative experiences with health workers when accessing healthcare may hamper individuals' decisions to seek care in the future. This, combined with exclusion from most clinical trials and treatment for novel healthcare interventions,⁷¹ contributes to lower health access, worse outcomes, and higher mortality.

While these studies and frameworks help highlight the barriers and pathway for poor health for disabled people, the Missing Billion Framework (Figure 1.1) offers solutions within a health systems-approach. This framework builds on Levesque's work, as well as other work on health systems frameworks to identify the particular system and service delivery elements that can contribute to building disability-inclusive health systems.⁷² While system-level factors, like governance and leadership, health financing and data and evidence are essential building blocks, service delivery relies on a combination of demand (autonomy and awareness and affordability) and supply (human resources, health facilities, and special services/assistive technology). This emphasis

on human resources for health as part of a systems-level approach to addressing inequities for disabled people underscores the importance of health worker training on disability.



Source: The Missing Billion Initiative

Figure 1.1: Missing Billion Health System Framework⁷²

1.5.2 THE IMPORTANCE OF HEALTH WORKER TRAINING

The evidence on substantial gaps in health status, access, and outcomes for disabled people, as well as frameworks for understanding access to health and disability-inclusive health systems emphasise the role of individual interactions with health workers. Therefore, one solution to close the health gap for disabled people is through training health workers on disability, with the aim of improving their attitudes and skills to better support disabled people in accessing their right to health care. Building capacity of health human resources to improve service delivery is also included in the UN CRPD—the seminal international legal framework on the rights of disabled people—Article 25(d), which specifies health worker training as a means of improving health equity and quality of care for disabled people.¹³ Similarly, the WHO Global Report on Health Equity for Disabled People included health worker training as one of the 40 key actions to reduce these preventable health inequities experienced by disabled people.²

These high-level international commitments, as well as additional empirical evidence on increased barriers to health and higher health needs highlighted above demonstrate that health workers must

understand disability. To achieve greater understanding of disability among health workers, it is first necessary to understand and improve health worker training on disability. Disabled peoples' higher utilisation of services makes it highly likely that health workers interact with this population regularly, making it important to ensure that all cadres are equipped with the relevant skills and etiquette to appropriately support this population. However, there is limited evidence on what constitutes effective disability training and how existing interventions could be further improved and scaled. Furthermore, existing evidence remains concentrated in high-income countries, but 80% of the disabled population live in low- and middle-income countries.⁷³ The evidence of inequities and the literature on the efficacy of existing interventions (covered in Chapter 3) for disabled people demonstrates how health worker training could be a mechanism to improve healthcare for disabled people. Approaching these health inequities via disability training for health workers is not a single solution, but, in conjunction with systemic reforms and other interventions, may support changing awareness and attitude—two of the important drivers of inequities.⁷⁴

1.6 WHAT ALREADY EXISTS TO TRAIN HEALTH WORKERS ON DISABILITY?

Disability training for health workers is poorly characterised because of the unsystematic nature of how training has evolved. Indeed, most documented instances of disability trainings are one-off lectures or seminars to fulfil equity, diversity, and inclusion requirements, or to briefly recognize the needs of this patient population, rather than an integrated part of clinical education. However, over the past three decades, clinical education in the Global North has been transforming, focusing less on the educational process itself, but rather how one can develop a competent clinical learner, equipped with the appropriate tools for professional practice.⁷⁵ This goal has shifted clinical pedagogy away from time-based training and instead emphasised ability, outcomes, and engagement.⁷⁶ Now, new approaches to clinical pedagogy focus on building individual competencies, in specific areas, including knowledge, skills, values, and attitudes.⁷⁶ Switching to a competency-based approach has helped clinical education focus on improving health disparities, including disability-based competency training.

Several articles have already outlined disability-specific competencies for health worker training.⁷⁷⁻

⁸⁰ Given the long history of discrimination for disabled people, there is increasing literature—usually based in the US—that treats disability as a cultural group given the visibility and group-identification aspects of disability.⁸¹ Accordingly, there is literature encouraging health worker training to take disability as a ‘cultural competency’, embedded in clinical education.⁸² To further this, a recent US study identified national priorities for disability competency:

1. Contextual and Conceptual Frameworks on Disability
2. Professionalism and Patient-Centred Care
3. Legal Obligations and Responsibilities for Caring for Patients with Disabilities
4. Team and Systems-Based Practice
5. Clinical Assessment
6. Clinical Care Over the Lifespan and During Transitions⁸³

While these competencies are nationally validated within the United States, the specifics of how these are taught may be less applicable in other contexts, such as low- and middle-income countries, where there are different frameworks about and understandings of disability, levels of health system integration, and legal obligations. Singh et al, for example, describe 52 disability competencies for Indian Medical Graduates based on the various roles a physician takes (clinician, leader, communicator, lifelong learner, and professional),⁷⁹ but these roles are country-specific, rather than globally applicable. Instead, Shakespeare and Kleine offer a globally-oriented view of the US-based recommendations from Kirschner and Curry as:⁸⁰

- “1. Framing disability within the context of human diversity across the lifespan and within social and cultural environments.
2. Skills training for assessment of disability and functional consequences of health conditions, considering implications for treatment and management.
3. Training in general principles concerning etiquette for interactions with persons with disabilities.

4. Learning about roles of other health care professionals forming integrated teams to care for persons with disabilities.
5. Understanding the legal framework of national anti-discrimination legislation, the Convention on the Rights of Persons with Disabilities, relevant ethical standards, and the principles of reasonable accommodation and universal design.
6. Competency in patient-centred care approaches, including patients' perception of quality of life.”⁸⁴

Despite the work done to develop these competencies, their implementation is inconsistent, depending on what individual colleges, health institutions, and countries' licensing requirements decide to use. Instead, a more standardized approach is needed, based on what is most effective in training health workers.

1.7 LITERATURE CONTEXT ON DISABILITY TRAINING FOR HEALTH WORKERS IN SUB-SAHARAN AFRICA

1.7.1 SUB-SAHARAN AFRICA

Sub-Saharan Africa (SSA) refers to the 42 group of countries and six island nations located south of the Saharan desert on the African continent.⁸⁵ Each country in the region has its own distinct culture, languages, health and education systems, and political institutions, though they share a common history in colonial rule, with most countries only gaining independence in the 1950s and 1960s.⁸⁶ Today, these countries are home to nearly 1.2 billion people, most of which are under the age of 15 (42%) and live in rural areas (58%).⁸⁷ Propelled by its youth bulge, development funding, and the recently-established African Continental Free Trade area, SSA has experienced rapid economic growth over the past two decades. However, this growth has been stalled by the impact of the COVID-19 pandemic and has been insufficient to rapidly improve poverty, health, and other development indicators across the continent.⁸⁸ Life expectancy at birth has been increasing in recent decades, but is only 60 years across the continent—20 years less than the European Union average.⁸⁷

All countries in the region are considered low- and middle-income countries, with an average GDP per capita of USD\$ 3,759 (£3,017) per annum, making it the poorest region in the world.⁸⁵

Health systems in the region have also been improving in recent decades, but survey data has found people in SSA have poor self-rated health, affordability of care, and access to healthcare.⁸⁹ Over a third (36%) of all health spending in the region comes from out-of-pocket expenses, which is symptomatic of the low government spending on health in the region (7.2% of GDP).⁹⁰ Health systems in SSA also face system-level pressures from ‘brain drain’ and critical shortage of health workers to high burdens of communicable diseases (i.e., HIV/AIDS).⁸⁹ These challenges are set to increase, as health systems in the region begin to feel the pressures of a shifting disease burden and increased prevalence of non-communicable diseases like diabetes and hypertension increases.⁹¹ The shifting disease burden and critical shortage of health workers have renewed calls for improving human resources for health in the region. Efforts to retain and increase the production of health workers have been coupled with efforts to improve the quality of education health workers receive.⁹² This focus means there are potentially opportunities to strengthen the curricula with regards to disability.

The health systems, disease profile, and challenges are unique to each country within SSA. These data and challenges reflect that of the entire continent, but this thesis only presents data on 13 countries in the region because of limited available data.

1.7.2 DISABILITY TRAINING IN SUB-SAHARAN AFRICA

Laws, policies (Chapter 2), and literature on disability training (Chapter 3) reveal that specific trainings to build these competencies in health workers are implemented unsystematically across health worker training programmes. While this is discussed in further detail in subsequent chapters, there is even less literature on the sub-Saharan African context. Existing evidence shows only specific health worker cadres, geographies, or impairment types are covered in specific trainings. For example, a recent two-day training programme in South Africa focused on training health workers about the intersectionality of HIV and disability. The goal was to improve health workers’

knowledge and skills, particularly related to improving accessibility and reasonable accommodations within HIV services. After the workshop, participants were supposed to develop an action plan for disability inclusion within their health facilities, which was evaluated along with other learning goals through qualitative interviews three months after the intervention. Overall, this example was found to be successful in providing tools for change and that health workers generally implemented the recommendations from the training to improve services for and their attitudes towards disabled people.⁹³ Another study evaluated the efficacy of using the Health Education and Training (HEAT) curriculum for child mental health for community health workers in Ethiopia. The curriculum is a two-week didactic course to teach about facets of child and maternal health, family planning, and non-communicable diseases, among other topics. Child mental health, development, intellectual disabilities, and autism are covered during the training. The study used a mixed-methods approach for its evaluation, including a sample of 104 Ministry-identified health workers to complete a survey and a purposeful sample of 11 HEAT-trained health workers to evaluate their experiences of the training. Overall, the study found that health workers needed greater support in identifying and providing services for children requiring mental health care, and that training should further discuss stigma and discrimination, as well as referral pathways to improve the quality of the training.⁹⁴ While these were the only two published studies on health worker training on disability in Africa, found after an extensive literature search, there was also a protocol for a multi-faceted trial to improve access to sexual and reproductive health (SHR) for disabled women in Ghana that included training health workers on disability and SRH.⁹⁵ This training is used as a qualitative case study in this thesis and described more fully in Chapter 7.

1.8 LITERATURE GAPS

As described above, the evidence relating to disability training for health workers is predominantly located in high-income countries, particularly in the US. While research from high-income countries can be mobilizing for action in low- and middle-income countries, the health system context, cultural factors, and resources available often make these comparisons or adoption difficult. In particular, this geographic distribution also may omit specific health worker groups, such as community health

workers, who are part of efforts to scale up human resources for health in cost-effective, geographically dispersed, and rapid ways. Therefore, more research is needed in low- and middle-income countries to determine what is most effective to train health workers on disability in these contexts.

Similarly, there is a bias towards certain publication types in the existing academic literature. First, many trainings, programmes, or manuals are not published (neither in the academic nor grey literature), so the published evidence is selective. Of the material that is published, most are from studies that examine a one-off intervention that is highly concentrated on a particular health worker school, a specific type of health worker, and/or a specific geography (i.e., a medical or nursing school at one university in one country). This may include some quantitative data evaluating the training intervention, but this is short-term and most existing research to understand efficacy is mixed-methods or qualitative. There are also systematic reviews summarizing evidence on disability training, usually with a specific impairment or type of health worker as their focus.⁹⁶⁻¹⁰⁰ A previous systematic review took a global and cross-disciplinary focus,⁸⁴ but the evidence was collected over ten years ago. Finally, there are several commentaries that call for greater inclusion of disability within health worker training.^{77,78,101,102} While these calls to action provide summaries of evidence and often make some recommendations for training, they are not sufficiently context-specific nor evidence-based to move this area of research forward. Therefore, there needs to be more understanding of the laws and policies around disability training; the current interventions across cadres, geographics and impairments; further understanding of the impact of existing interventions; and some quantitative data analysis showing where there is demand for care to match training appropriately.

1.9 THESIS STRUCTURE

Overall, these gaps highlight the need for more research in sub-Saharan Africa, an updated global systematic review, more quantitative research, and more in-depth understanding of potential core

elements and effects of disability training. Accordingly, these are the gaps in the literature on disability training for health workers that this thesis will seek to fill.

1.9.1 RESEARCH QUESTION AND OVERALL METHODS

My main research question was “how can we improve health worker training on disability in sub-Saharan Africa?”. To answer this, I used a mixed-methods approach, including systematic review, two secondary data analyses, and semi-structured qualitative interviews. Each method was used to address different areas of disability training for health workers and was brought together for overall interpretation of how training could be improved.¹⁰³

1.9.2 CHAPTER STRUCTURE

Chapter 2 analyses the disability laws and policies from the 13 countries in sub-Saharan Africa covered in this thesis to understand the rationale for training. Since there is limited understanding of the laws and policies for disability training in the health sector, this aspect fills this gap in the literature.

Chapter 3 summarizes the literature on existing interventions to train health workers. A previous review was conducted in 2013, but this systematic review updates understanding of the interventions used to train health workers on disability.

Chapter 4, 5, and 6 relate to the secondary analysis on the Multiple Indicator Cluster Survey to understand which health workers we should train about disability based on demand for care. Chapter 4 provides a brief overview on the MICS survey methods. Chapter 5 examines data on common childhood illnesses to understand where caregivers of disabled children seek care and Chapter 6 looks at maternal health seeking behaviours to understand if there is a particular group that should be targeted for training. Given existing examples of training in the literature provide limited rationale for why specific cadres are trained on disability, these analyses may help to understand care-seeking patterns to improve allocative efficiency of training for specific health worker cadres.

Chapter 7, 8, and 9 use qualitative methods to interview trainers and trainees from existing disability training for health workers in Ghana to understand how future training could be improved. Chapter 7 describes the study methods and setting, Chapter 8 offers an analysis of trainers and trainees' perspectives on the disability and sexual and reproductive health training, in which they have participated, to identify what was effective and how future training could be improved. Chapter 9 discusses trainees' perspectives on their behaviour change at an individual-level post-training, and their reports of the broader societal changes that need to happen to improve healthcare for disabled people.

Chapter 10 discusses recommendations to improve training for health workers, developing a framework for future trainings based on the results of the thesis.

By combining the existing evidence from laws, policies, and literature (Chapters 2 & 3), with quantitative data analysis on demand for health care (Chapters 4-6) and qualitative data analysis on how to improve training (Chapters 7-9), this thesis is able to make recommendations (Chapter 10) on how disability training for health workers could be improved in sub-Saharan Africa. My approach allows me to draw on an understanding of the training landscape from legal, policy, household data, and stakeholder levels.

2 THE LEGAL AND POLICY REQUIREMENTS OF DISABILITY

TRAINING

2.1 CHAPTER PURPOSE

The purpose of this chapter is to characterise how countries included in this thesis have included health worker training on disability as part of their disability laws and policies. Understanding these legal provisions is important to help understand the existing training activities within countries, as well as how laws and policies may have shaped action on training health workers, beyond what is published in academic literature.

2.2 BACKGROUND

In the past two decades, international organisations and laws have increasingly called for more disability training for health workers through global pledges and commitments. For example, the World Health Organization includes several specific recommendations on training health workers as part of their 40 actions on achieving health equity for disabled people, released in December 2022.¹⁰⁴ Furthermore, Article 25(d) of the UN CRPD specifies health worker training as a means of improving health equity and quality of care for disabled people.¹³ Regionally, the African Union has protected the rights of disabled people through the African Disability Protocol, which mandates several stipulations in regards to the right to health. Several clauses of Article 17 of the African Disability Protocol address stigma, discrimination, and health worker training, informing the importance of this topic in African countries' disability laws.¹⁰⁵ Accordingly, several countries in sub-Saharan Africa include disability training in their national disability laws, committing to this central component of improving health for disabled people. Countries, therefore, have a domestic and international legal obligation to deliver disability training for health workers by ratifying these treaties and protocols. However, there remains a persistent gap between ratification and implementation.

Progress on disability-inclusion is important to contextualize within legal institutions, because disability-inclusion may only begin after laws and policies have changed to reflect increasing acceptance of disabled people.⁸ That is, underlying negative attitudes and actions towards disabled people have often changed after advocacy and activism have focused on enactment of anti-discrimination laws and policies as one of the main mechanisms for improving disability-inclusion.^{7,8} Solidifying these efforts with laws becomes a particularly important tool for enacting and enforcing these changes, since there is often a void or resistance to enact elements of anti-discrimination laws. This socio-legal approach to social change demonstrates the importance of understanding the legal and policy context for disability inclusion in health worker training. Legislation on training may be an opportunity to integrate disability into curricula or competency requirements. By enacting a law that mandates training for healthcare workers on disability, it ensures that health professionals are equipped with the necessary knowledge and skills to understand and address the needs and challenges faced by disabled patients. This training may encompass disability awareness, communication strategies, providing culturally competent care, and ensuring accessible health facilities.⁸⁴ Ultimately, such a law aims to promote inclusivity and equitable health services for disabled people, fostering a more compassionate and accommodating healthcare environment for all patients.

This makes it important to examine how disability law deals with disability training for health workers, if at all. Similarly, examining how national disability strategies have mentioned disability training can be insightful for how countries implement policy in practice and how individual governments have conceptualised their obligations under UN CRPD. To date, most analysis of disability laws has focused on how these laws support inclusive education for disabled children.¹⁰⁶ However, very little research has examined the right to health within these laws or determining countries' obligations to deliver health worker training.

2.3 METHODS

Using the READ approach¹⁰⁷ for document analysis, which involves systemically selecting and extracting data according to a framework, I examined the laws and policies of the 13 countries included in the quantitative section of the thesis (Chapters 3-6). Countries included were: Central African Republic, Chad, Democratic Republic of Congo, The Gambia, Ghana, Guinea-Bissau, Lesotho, Madagascar, Malawi, Sao Tome et Principe, Sierra Leone, Togo, and Zimbabwe. The laws, policies, and strategies were sourced from several pre-determined reference frames that were thought to have comprehensive records of existing disability laws: WHO MiNDBANK (More Inclusiveness Needed in Disability and Development) and UN Department of Economic and Social Affairs (UN DESA) webpages. First, I searched for each country's page on the WHO MiNDBank,¹⁰⁸ which includes countries' national policies, strategies, and laws on mental health, substance abuse, disability, general health, human rights, and development. I cross-referenced this database with the UN DESA Disability Strategies and Action Plans by Country webpage,¹⁰⁹ as well as their Disability Laws and Acts by Country webpage.¹¹⁰ These existing databases provided a standardized way of accessing recorded laws, policies, and strategies, to reduce bias from using other search engines unsystematically or encountering potential language or geographic biases. There were no date or language restrictions applied. The databases did not provide date of updates, but since the databases were cross-referenced, they were assumed to be up to date.

An extraction framework was developed to count mentions of 11 specific aspects of training, including: 1) legal requirement 2) costs, 3) time, 4) competencies, 5) staging (i.e., when training is delivered in curricula), 6) methods, 7) impairment type, 8) cadres, 9) benefits of completion, 10) objectives, and 11) evaluation and monitoring. These categories were developed using the key elements of the trainings that were described in the systematic review (Chapter 3). Second, I translated four French documents into English. Then, each document was saved on the date of access and reviewed only by me. I reviewed each law twice and extracted any key phrases that pertained to the 11 aspects of training in the extraction framework. Finally, the extracted data were analysed to infer trends in inclusion of disability training for health workers in disability laws, policies, and strategies.

2.4 RESULTS

Of the 13 countries included in the sample, three had no disability laws (Central African Republic, Guinea-Bissau, and Sao Tome et Principe),¹⁰⁸⁻¹¹⁰ policies, or strategies in any of the databases. In total, 15 documents were eligible for inclusion across 10 countries (Table 2.1 presents a summary; full results in Appendix 1).¹¹¹⁻¹²⁵ Most countries had disability policies from post-UNCRPD implementation (i.e., 2006), while three only had documents from before 2000 (DRC, 1973;¹²³ Madagascar, 1998;¹²⁴ and Zimbabwe, 1992¹²¹). Malawi had the most documents at four, while most other countries had only a law.

In terms of content, only five countries commented on whether the training was recommended or mandatory, and only three countries (Gambia, Ghana, and Malawi) had clauses that required some form of disability training for health workers in their most recent law.^{111,113,117} Lesotho and Togo had some recommendation to train health workers about disability, but this was not required. Similarly, only The Gambia, Ghana, Lesotho, and Malawi had further details on the shape these trainings should take. For example, in The Gambia, the law specifically mentioned integrating disability training into health programmes curricula and continuing professional development (CPD) for all current health and rehabilitation staff.¹¹² Ghana's laws highlighted the importance of including training on general health and rehabilitative care for disabled people within training for health professionals and health care programs.¹¹³

Sign language was highlighted as a competency that should be included in training in Lesotho and Malawi, but only Lesotho's policy specifically included that health service providers such as nurses, doctors, and HIV testing and counselling (HTC) counsellors should be trained on sign language.¹¹⁴ Few countries mentioned specific impairment types, except for Malawi (albinism)¹¹⁸ and Lesotho (people with intellectual disabilities and d/Deaf and hard of hearing individuals).¹¹⁴ Malawi and Lesotho also had plans within the policies to evaluate their laws. For example, Malawi stated they would aim to have 3 new curricula for health personnel; 41 physiotherapists trained; 100 rehabilitation technicians trained¹¹⁸ while Lesotho's plan was broader and focused on providing sign

language skills to health service providers including nurses, doctors, HTC counsellors, and other health workers.¹¹⁵ These specifics were not found in any other countries' policies or laws, making these the most specific examples of commitment and monitoring of the laws studied in this section.

Malawi had the greatest number of laws, policies, UN CRPD reports, and strategies, as well, as substantial details about the specifics of training. For example, Malawi's National Disability Mainstreaming Strategy and Implementation Plan 2018-2023 had the highest score of all documents analysed, with specific details in 73% of categories included in the framework (n = 8). This document emphasized disability training for health workers since access to health services was selected as one of the priority areas for the government. Accordingly, the policy specifies the budget (50 million MK; nearly £50,000 in 2018) to train health workers across all stages of their training. The policy also lists specific competencies (sign language, causes of disability, early intervention, assessment, and referral services), disabilities (albinism), health cadres (physiotherapists, orthopaedics, Dermatologists and ophthalmologists, HTC service providers), and objectives of the training (highlighted above).

Table 2.1 also shows categories where fewer countries had details or no country had specified anything on this topic. For instance, no country had details on the length, methods, or benefits of training. Only two countries (Malawi and Sierra Leone) included details on the costs of training, which were predominantly related to specific budget lines for training¹¹⁸ or in-principle support for health worker institutions that conduct training,¹²⁰ respectively. All three laws that were pre-CRPD implementation had none of the criteria related to disability training for health workers.

Table 2.1: Summary of Disability-Training for Health Workers Clauses in Disability Laws and Policies in Selected Sub-Saharan African Countries

Country and Law/Policy Name	Language	Date	Requirement	Cost	Length	Competencies	Staging	Methods	Impairment Type	Cadres	Benefits	Objectives	Monitoring and Evaluation
Chad - Law No. 007/PR/2007 Bearing Protection for Disabled Persons	French	2007											
DRC - Code de la Personne - Chapitre III sur les Handicapes, Infirmes et Prodiges	French	1973											
The Gambia - Persons with Disabilities Bill	English	2020	Mandatory										
The Gambia - Integrated National Disability Policy	English	2009-2018	Recommended										
Ghana - Persons with Disability Act, 2006 (Act 715)	English	2006	Mandatory										
Lesotho - National Disability Mainstreaming Plan	English	2019	Recommended										
Lesotho - National Disability and Rehabilitation Policy	English	2011	Recommended										
Madagascar - Loi sur les personnes handicapées	French	1998											
Malawi - CRPD Initial and Second State Party Reports	English	2016											
Malawi - Disability Act	English	2012	Mandatory										
Malawi - National Disability Mainstreaming Strategy and Implementation Plan	English	2018-2023	Recommended										
Malawi - National Policy on Equalisation of Opportunities for People with Disabilities	English	2006	Recommended										
Sierra Leone - The Persons with Disability Act	English	2011											
Togo - Loi Togolaise Relative a La Protection Sociale des Personnes Handicapees	French	2011	Recommended										
Zimbabwe -Disabled Persons Act	English	1992											

2.5 DISCUSSION

Since many actions around disability-inclusion are instigated by laws, policies, and strategies, these documents can provide insight into progress on disability-inclusion. To date, there is no published evidence on how disability laws and policies include health worker training. Most analyses of disability laws in sub-Saharan Africa have focused on inclusive education¹⁰⁶ and none have looked at the right to health or other health-related clauses.

While these documents provided some evidence that there has been some attention to training to improve health equity for disabled people, the majority of these inclusions were minimally modified articles of UN CRPD. This boiler-plate approach can provide some basis for action. For example, in Ghana, the language of their Disability Act is similar to UN CRPD, yet there have been various individual trainings and interventions.⁹⁵ However, these fail to integrate this training into curricula systemically, even though that could be expected from implementing such a law. Therefore, having further documents that delineate plans, budget, and evaluation (i.e., Malawi's mainstreaming strategy) can support actual integration into the health worker education system. On the other hand, nearly half of the countries had either no disability laws or ones that were over 20 years old. The lack of up-to-date laws make it challenging to assess the state of disability rights, particularly what the health system is doing to adequately train health workers on treating disabled patients.

Furthermore, most of the countries only listed information about the requirements for training, rather than in-depth content. The absence of disability action plans or policies adjacent to the laws showed the laws themselves did little to advance these goals. Furthermore, even when laws stated it was required, this requirement does not necessarily translate to high-quality disability training. Countries that had more detailed descriptions of their training within the laws do not necessarily translate to better trained health workers. For example, Lesotho's focus on sign language competency can be exceptionally beneficial for d/Deaf and hard of hearing patients, but this requires that health education systems have the capacity to teach all these individuals sign language. There is also an opportunity cost to investing in training for only one impairment type, since this focus would not

translate to support for other impairment types (i.e., supporting blind and visually impaired people). Adopting a competency approach—which was not done in most laws—may be a more optimal route for systematically training health workers.

Finally, there is a broader question of whether laws and policies are the appropriate place for such detailed inclusions. Given these laws and policies were enacted several years ago, it is highly likely there are new governments in power, likely with different priorities around disability-inclusion and disability training for health workers. Laws and policies can be essential to trigger implementation and funding, or may be aspirational, without sufficient actions, meaning that their utility is undermined. For example, Malawi's multitude of documents outlined a clear picture of the training topics, budget, and ministerial responsibilities for accountability. Since this level of commitment and planning was rare in these documents, integration of disability competencies into health worker certification may be the more appropriate mechanism for improving health worker competency. Intervention at this level could enable certified health workers to be trained, examined, and refreshed on their competency in treating disabled patients. Therefore, further research should examine whether these competency, licensing, and Ministry of Health budget documents have greater potential for inclusion of disability than these laws. This is particularly important since experimenting with this approach to licensing may trigger more stringent implementation of disability training for health workers.

2.6 CONCLUSION

Laws, policies, and action plans often signal a country's intent to change, provide background on specific interventions, or demonstrate values. While mandating, or even including disability training for health workers in laws, policies, and strategies may not necessarily translate into better health outcomes for disabled people, it can be an important step for further action. The policies of many countries in the sub-sample of sub-Saharan African countries have included clauses on disability training, but these lightly recommended actions with limited follow-up plans, strategies, or public funding mean that further work in this area is needed. Policies with specific implementation and

monitoring plans need to be developed to financially support and expand health worker training on disability. Examining whether there are licensing requirements related to some form of disability-training would be helpful to understand how countries are implementing these laws.

3 GLOBAL EVIDENCE ON DISABILITY TRAINING FOR HEALTH WORKERS

3.1 CHAPTER PURPOSE

Building on the understanding of training activities within the legal and policy space, this chapter helps characterise examples of interventions that have been documented in the academic literature. This is important to understand what interventions already exists to train health workers on disability.

3.2 BACKGROUND

This systematic review directly builds on a review by Shakespeare and Kleine that explored health worker training on disability between 2000 and 2011.⁸⁴ Their review found that, while there are numerous interventions to teach health professionals about disability, there are few common philosophical underpinnings, insufficient hands-on experience, and more opportunities to incorporate disability across the curriculum.⁸⁴ Since this review, additional systematic reviews have examined health worker training on disabled people for certain populations of health workers^{98,100} or certain impairments.¹²⁶ The existing fragmented approach to disability inclusion in curricula limits the understanding and goal of having all health workers trained on disability. The broader definition of cadre, impairment, and geography used in this review is necessary to understand the full scope of best practices within health worker training on disability. In addition to these reviews, there have been several calls to action to strengthen curricula around disability,^{127,128} yet a concerted effort to integrate disability training into health worker curricula around the world is still needed.

Given renewed international commitments to health worker training on disability and country-level plans in Australia¹²⁹ and the UK¹³⁰ to train health workers on specific impairments, it is important to update Shakespeare and Kleine's review⁸⁴ and outline the types of training interventions to improve health worker's knowledge, confidence, self-efficacy, and competence in treating disabled patients. This study sought to understand how all types of health workers are trained on disability. By

understanding what training is already provided to health workers, we can understand the current landscape and possible opportunities to further improve training. Ultimately, this review will help to understand the types of training that currently exist, the impact of training, and how it has been evaluated.

3.3 METHODS

3.3.1 SEARCH STRATEGY

Electronic searches were conducted for the EMBASE, Global Health, Medline, CINAHL, ASSIA and Web of Science databases between 18-19 January 2021. Search terms were developed in three domains: i) disability and impairment, ii) health education, and iii) health workers. Disability terms were general, focusing on various types of impairments; health education terms targeted aspects of health training (i.e., ‘core competency’, ‘patient encounter’, ‘standardized patient’, etc.); and health worker terms were developed using key terms from WHO’s International Classifications of Health Workers.¹³¹ Terms were developed using MeSH, keywords, or equivalent as well as from other reviews on similar topics and searches were limited to papers in English, French, or Spanish. A full sample search strategy can be found in Appendix 2. These parameters and strategy were agreed upon by the authors and a research librarian before the search was conducted to ensure there were adequate words to capture articles across the three domains examined. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement was followed for conducting and reporting the review (PROSPERO Registration: CRD42021231120). All studies identified by the review were exported into an EndNote database (version X20, Clarivate Analytics, Philadelphia, PA, US) and then exported into Rayyan (Qatar Computing Research Institute, Qatar) for screening.¹³²

3.3.2 SELECTION CRITERIA

My search strategy sought to replicate Shakespeare and Klein’s search strategy and identify peer-reviewed articles from around the world published between January 2012 and 2021. Given the previous systematic review covered this topic until 2011,⁸⁴ the search included articles published

from 2012-January 2021 and included all health worker types, health education levels, and disability globally. The inclusion criteria required that studies were:

- 1) qualitative and/or quantitative in methods;
- 2) included a complete description of the intervention;
- 3) explicit evaluation of the training's impact (i.e., pre- and/or post-training evaluations, follow-up surveys, etc.); and
- 4) had a particular focus on improving disability competency, knowledge, confidence, self-efficacy, curricula, or teaching methods.

Studies examining health worker attitudes towards disabled people were excluded on the basis that a positive attitude does not necessarily guarantee improved competency or care outcomes. Studies that measured attitudes alongside other criteria were included. Finally, given the abundance of articles on training health workers about mental health and psychosocial disabilities, the authors decided that this topic merited further, independent exploration, and, therefore, we excluded papers that trained health workers on this topic.

All data were extracted into a spreadsheet developed for this review. 78 full-text articles were included, following a title, abstract, and full-text review by two reviewers (SR and DRG). Three reviewers (SR, AW, and RL) extracted data related to the general study information, setting, country, health worker cadre, number of participants, type of disability, features of the intervention, impact measurement, outcomes, and study design. The extraction was double-checked by a second reviewer and collectively checked again by the extractors (SR, AW, and RL). Any conflicts in inclusion or extraction were resolved through discussion with a third and/or fourth member of the review team.

Given the wide array of study instruments and outcomes used to assess training impact, a meta-analysis was not deemed appropriate, and a narrative synthesis was conducted instead. Quality and bias assessments were conducted by at least two reviewers in accordance with the SIGN50 (Scottish Intercollegiate Guidelines Network Checklists). In-line with these guidelines, the papers were assessed on their study design; sampling method and sample size calculation; clearly defined and

reliable measure of impact; disability definition; response rate; presence of confidence intervals and significance; and whether confounders/limitations were considered. In addition, case-control studies were assessed on whether or not the cases and controls were clearly defined and comparable.^{133,134} Studies were rated as ‘low bias’, if all or almost all, of the criteria were fulfilled, and those that were not fulfilled were thought unlikely to alter the conclusions of the study; ‘medium bias’, if some of the criteria were fulfilled, and those not fulfilled were thought unlikely to alter the conclusions of the study; or ‘high bias’, if few or no criteria were fulfilled, and the conclusions of the study were thought likely or very likely to alter with their inclusion.

3.4 RESULTS

The preliminary search identified 5,665 articles for title and abstract screening, after 1,527 duplicates were removed. Following screening, 247 articles were included for full-text review. Twelve studies were excluded because full texts could not be retrieved. A further 154 studies did not meet the inclusion criteria, as shown in Figure 3.1, and 3 articles included in the review were excluded during extraction because of an unclear intervention (n=1) and sampling a different population group (n=2).¹³⁵ Included studies (n=78) represented a range of geographies, health workers, and intervention types (Table 3.1). Among these, there were studies from 19 countries, including seven low- and middle-income countries.¹³⁶ Most studies took place in the United States (n=35), followed by the United Kingdom (n=13). Among the studies included, 30 were rated as low, 43 as medium, and five as high risk of bias. Studies varied in whether they were mandatory or optional; free or paid; and for certification or elective; however, many studies did not include this information. Various cadres of health workers were included in the study; doctors, medical students, or residents (n=37), and nurses or nursing students and occupational/physical therapists (n=17) were the main recipients of training. These health workers were generally trained in the pre-qualification stage (n=52), though there were several in-service (n=7) and continuing professional development (CPD) programs (n=19). The review included studies across impairment types; the most common focus was training about people with intellectual and developmental disabilities (n=41), followed by general programs about disabled people (n=16).

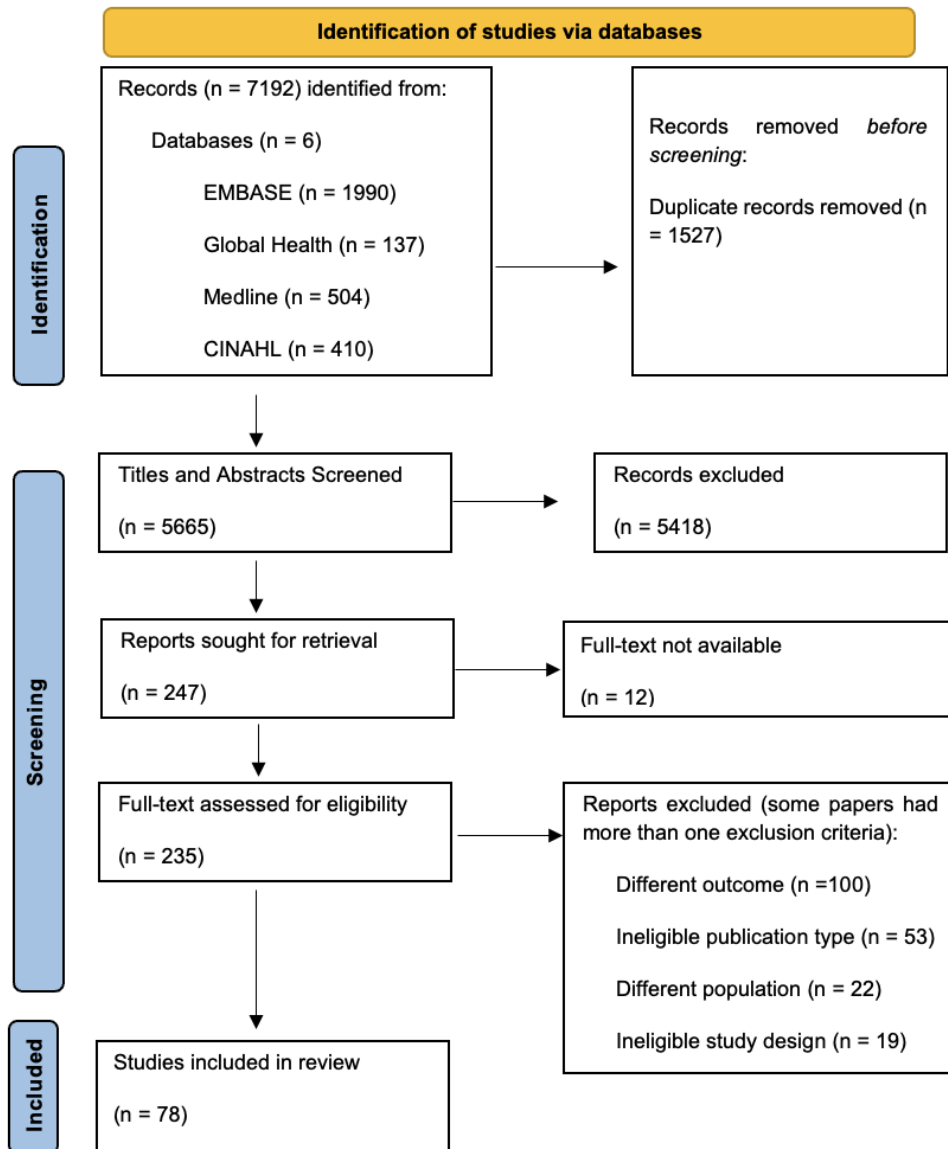


Figure 3.1: Flow Chart of Selected Studies to Review Health Worker Training on Disability

Table 3.1: Characteristics of Included Studies

Variable	Number	Percentage (%)
Training Location		
North America	40	51.2
Europe	22	28.2
Asia	6	7.7
Oceania	4	5.1
Africa	4	5.1
South America	2	2.5
Disability Focus of Training*‡		
Intellectual and developmental	41	51.9
All types of disabilities/unspecified	16	20.3
Physical/motor	13	15.2
Communication	9	11.4
D/deaf and hard of hearing	8	10.1
Visual impairment	3	3.8
Sensory impairment	2	2.5
Health Worker Type*‡		
Medics	37	35.2
Nurses	17	16.2
Occupational and Physical Therapists	17	16.2
Allied Health Professionals	8	7.6
Dentists	7	6.7
Audiologists and Speech Language Pathologists	6	5.7
Psychologists	4	3.8
Personal Care Workers	5	4.8
Community Health Workers	2	1.9
Pharmacists	2	1.9
Teaching Method*		
Lecture/didactic methods	65	34.7
Case study	28	14.9
Clinical encounter	26	13.9
Placements, experiential, and community-based learning	25	13.4
Simulation	24	12.8
People with disabilities as a teacher	19	10.1
Intervention Outcomes*		
Knowledge	57	28.4
Competence	42	20.9
Attitudes	31	15.4
Confidence	24	11.9
Comfort	15	7.5
Communication skills	12	6.0
Self-Efficacy	11	5.5
Other related outcomes	9	4.5
Study design		
Quasi-experimental	41	52.6
Randomised control trial (RCT)	9	11.5
Qualitative	8	10.3
Cross-sectional	7	9.0
Mixed methods	6	7.7
Cohort	4	5.1
Case-control	3	3.8

*Total number is greater than 78 because studies included multiple variables. ‡Categories include students and residents who are in training to become fully qualified as this type of health worker.

Most studies measured improvements in knowledge (n=57) and competence (n=42) outcomes, yet most studies used a self-designed evaluation instrument (n=54). The majority of included studies used a quasi-experimental design (n=41) where they compared pre- and post- intervention scores. There was a wide variety of techniques to train health workers about disability, including lectures or other didactic methods (n=65), and case studies (n=28); the majority of studies (n=58) used multiple teaching modalities (Appendix 3).

3.4.1 LECTURE/DIDACTIC METHODS

Most (n=65) studies included lectures or didactic methods, such as videos, multi-media formats, or online coursework. Many studies used these opportunities to introduce health professionals to the topic of disability from a rights-based perspective to enhance attitudes, awareness, and knowledge about disability. Some studies also taught particular skills that could be applied in-practice, such as an elective sign language class for medical and pharmacology terms¹³⁷ to improve skills for engaging with d/Deaf or hard of hearing individuals. Lectures were often combined with some other intervention (case study or simulation) to apply knowledge learned from the lecture. Participants in combined programs identified the content to be quite engaging and contributed to greater improvements in key outcomes. However, for those who only completed lecture or didactic-based methods, there were still improvements in the general outcomes, but it was often less substantial than studies that combined multiple methods.^{135,138,139} Finally, some programs utilized novel, innovative technology and multimedia tools to teach about disability in a more engaging method than traditional lectures or didactic methods. For example, one study designed multi-media tools (MMLTs) to teach medical students about common visual impairments and compared the knowledge scores with those who had read a textbook. The findings highlight the importance of using engaging material, as while there was no significant difference in knowledge (except for cataract recognition), the MMLT took less time and 87% of individuals found it more enjoyable than reading textbooks.¹⁴⁰

3.4.2 DISABLED PEOPLE AS TEACHERS

Recognizing the important role of self-advocates and patients as educators,⁸⁴ several studies (n=19) invited disabled people to share their experiences in the health system, portray standardized patients,

or give a lecture. Some universities hired disabled people to participate in simulated patient programs, while others asked patients to participate voluntarily. Many others found creative ways of engaging with disabled people. Cardiff University, for example, hired a self-advocacy theatre group to run a simulation and icebreaker activity.¹⁴¹ These activities added a non-clinical dimension to medical training about disability, as it allowed participants to explore disability outside the health worker-patient relationship and engage in dialogue. Studies that involved disabled people as teachers and also measured participants comfort and attitudes, demonstrated that non-clinical interactions could enhance comfort and attitudes towards disabled people.^{142,143}

3.4.3 CASE STUDIES

Case studies are a common tool in health education to prepare health workers holistically for their education; typically, these involve presenting a patient's medical history (without the person being present). Case studies have a clear structure, details, and clinical observations to teach students about the topic.¹⁴⁴ Accordingly, many included papers used case studies (n=28) as a way of learning how to improve care for disabled people. These tools were especially common in continuing professional development, as some programs ask patients to bring case examples to review anonymously to improve care^{145,146} or were to spur reflection on their own work. Several case studies were conducted through online learning or innovative interactive methods. For example, the City University of London created CitySCaPE for nursing students, which is a multi-media simulation of different patient cases of people with intellectual disabilities.¹⁴⁷ These types of case studies that blended the traditional case study and simulation aspects created opportunities for engagement in settings where in-person or clinical encounters were not possible. Most of the evidence on case studies was generated by studies that utilised some form of pre- and post-intervention evaluation, providing good evidence that this method can improve the outcomes evaluated in this review.

3.4.4 PLACEMENTS, EXPERIENTIAL, AND COMMUNITY-BASED LEARNING

Placements, experiential, and community-based learning (n=25) methods were sustained opportunities (i.e., multiple clinical sessions with patients, a term placement, or residential program) to engage with disabled people in clinical and alternative settings that were common to in-service

and pre-qualification training. For example, some studies examined the impact of clerkship placements in specialized clinics for disabled people,¹⁴⁸ while others looked at improvements for nurses and occupational therapists who participated in a week-long summer camp for disabled children.¹⁴⁹ In the clinical setting, several qualitative studies found that students improved their skills because they were able to engage with disabled people for extended periods, rather than a single interaction. Furthermore, the out-of-clinic engagement, such as at camps, schools, or residential settings helped illustrate the non-medical and everyday lives of disabled people.

3.4.5 SIMULATIONS

Simulations were single-session events that either used disabled actors or volunteers to act as patients in a devised scenario to support skill development and learning outside of health worker-patient interactions. Many speech-language pathology, nursing, and medical student programs used simulations (n=24) as tools to develop confidence and communication skills when treating patients with communication disorders.¹⁵⁰⁻¹⁵² In addition, several medical schools integrated disability training into existing clinical simulation skills labs to improve care for disabled people. For example, at the University of Gothenburg medical students were videotaped during a simulated patient exercise to reflect on improving communications skills, particularly for the simulated patient with an acquired communication disorder.¹⁵² Most studies evaluating simulations used quasi-experimental, cohort, or RCT designs, generating a higher degree of evidence that the simulations were useful tools for improving knowledge, comfort, and competency in a low-pressure environment that is applicable to serving disabled people.

3.4.6 CLINICAL ENCOUNTERS

Many programs (n=26) included singular clinical encounters with disabled patients as part of their disability training. These were often day-long programs to familiarize students with providing care in a clinical setting, often under supervision of a fully qualified doctor or expert and were predominantly focused on improving knowledge and competency.¹⁵³ Most students who participated in these programs were advanced (i.e., penultimate or final year students) who had previously had some education on providing care to disabled people. These opportunities focused on practicing

clinical skills to treat disabled patients, and, despite the short exposure, did affect participant's key outcome scores across several RCT (n=4) and quasi-experimental studies (n=15). For instance, clinical encounters used in CPD, such as in Rwanda, where instructors in a physiotherapist training program went to participants' clinics to provide immediate feedback on their practice.¹⁵⁴

3.4.7 MULTI-PRONGED APPROACH

Few studies utilised only one method of instruction for their intervention, with most using multiple teaching methods. This is becoming increasingly common in clinical education, as didactic methods are being replaced with more learner-centred education.¹⁵⁵ Of all the papers included, only two utilised all teaching methods we examined in this review. For example, in a quasi-experimental study, two State University of New York medical colleges demonstrated the importance of integrating disability across health worker curricula, as all participants significantly improved their knowledge, attitudes, and core competencies in treating disabled patients.¹⁵⁶ Similarly, the University of South Florida had a 12-week clinical clerkship that involved classroom simulations, lectures, case studies, disabled people as teachers, and a twice-weekly placement in a community clinic that served disabled people. This quasi-experimental case-control study showed these types of immersive experiences can help improve knowledge, attitudes, and comfort.¹⁵⁷

3.4.8 TRAINING EFFECTIVENESS

While the diversity of outcome measures did not allow us to conduct a meta-analysis,¹⁵⁸ it is important to note that almost all papers included in this review improved the outcomes they measured. Given most of these were quasi-experimental or RCTs with low or medium risk of bias, there is evidence that it is possible to change the outcomes measured through training interventions. Since intervention had improvements in at least one outcome of interest, we examined how intervention effectiveness varied by outcome of interest for each study that included it. All included studies that sought to improve and measure confidence, communication skills, and competence demonstrated that the intervention improved these outcomes. Studies that looked at knowledge demonstrated improvements in 94.7% of studies, while comfort improved in 93.3% and self-efficacy

improved 90.9% of studies. Studies that included participants' attitudes as an outcome had the lowest number of studies with improvements at 80.6% of studies.

Only seven studies looked at long-term follow-up (three months or more after the intervention). None of the studies showed that there was increase in the outcome between post-test and follow-up. While 51.7% of these studies sustained learning at the long-term follow-up point, 42.9% reported lower follow-up scores than post-test scores.

3.5 DISCUSSION

Numerous studies and examples serve as successful models to train health workers about disability and improve knowledge, competence, skills, self-efficacy, and confidence to treat disabled patients. All teaching methods had some positive impact on the outcomes measured in this study, regardless of health worker type, location, or training stage, though the most used training methods were lecture/didactic methods and case studies. While the multi-pronged approach may have helped the effectiveness, the heterogenous nature of these interventions show a missed opportunity to integrate disability training systematically into training. Similarly, there were very few studies that showed sustained knowledge three months after the original intervention. This is exemplified by the two studies that utilized all teaching interventions to mainstream disability in their institutions health curricula, either through sustained engagement in a curricula¹⁵⁶ or an intensive placement.¹⁵⁷ However, limited information about commonalities in curricula could be extracted from the data, given the diversity of interventions methods and topics.

It is important to note that these findings are not substantially different from the 2011 review.⁸⁴ Similar methods are still used to teach health workers on disability and each example is highly localized, within either a certain school or region, other than two studies that examined national-level training programs.^{154,159} The limited evidence of systemic integration of disability training within health worker practices is concerning in this context as the current status of training appears to depend on where you received your training, where you live, or where you work. Enacting systemic-level change to ensure all health workers have the same level of high-quality training on

disability will contribute to providing consistent, high-quality care and outcomes for disabled people. Ultimately, a lack of disability competency results in a patient safety issue, as the provider is ill-equipped to provide an adequate standard of care. Approaching training on disability with the same standards, competency requirements, and rigor as patient safety can be a critical step in improving outcomes for disabled patients.

Similarly, there was limited standardization in study design and evaluation methods for disability training interventions. Of the 78 studies, nearly 70% designed their own instruments, and only two studies included the same standardized measure of outcomes.^{160,161} Few studies measured the longevity of the intervention's impact, though those that did demonstrated both sustained or decreases in the outcomes measured. Sustained approaches that mainstream disability should help to ensure learning is not performative for post-intervention evaluation, but actually change practice. This finding was previously noted,⁸⁴ yet there has been little improvement in the past decade, likely because of a lack of comparability in settings where this research would occur and funding for these evaluations. The diversity of tools to assess impact of training limits our ability to assess effectiveness and compare training methods across geography, health worker cadres, and training stages hampers progress on this important topic. Developing—and using—a common, standardized cross-disability tool or protocol for evaluating immediate and long-term intervention impact may help support monitoring and evaluation efforts to further refine and improve training.

While the review uncovered many examples of disability training, one of the main limitations of the study is that it only includes published examples of studies, which can leave out unpublished examples. Since nonsignificant or negative findings are unlikely to be published in academic journals, there is likely some publication bias in this review. This is particularly evident with the didactic methods, where there are plausibly hundreds of other interventions or examples that are integrated into the health curricula around the world, but, perhaps, with less promising or measured results. Furthermore, without greater follow-up evaluation or standardization in evaluation, it is difficult to assess the longevity and quality of impact to understand impact of training definitively. On the other hand, this review reveals some adaptable examples of how to integrate disability

training into all stages of health worker training and development, which can serve as models for inclusion efforts around the world.

3.5.1 FUTURE DIRECTIONS

Ultimately, this review shows a piecemeal approach to training health workers on disability, as well as a lack of progress on training since Shakespeare and Kleine's review, demonstrating the need for further work in this area. In particular, there are three main gaps that should be explored to improve health worker training on disability. First, there is limited documentation of what constitutes good training or what is required legally as part of disability laws or for licensing. The fragmented nature of disability training contributes to disparities in provider competency and quality health care for disabled people around the world. While focusing on training by impairment is useful, there is also a need to have holistic disability training. Improving the standardization of core competencies that training on disability should address and measures of impact for disability training can further improve progress in this area.

Second, there is limited evidence why training is provided to specific health worker cadres. This and our limited understanding of health seeking behaviour among disabled people, limits our ability to focus health worker training on specific cadres that intersect more frequently with disabled people.

Finally, the limited evidence on long-term efficacy points to declining outcomes with time. Therefore, it is important to examine what more efficacious training would look like and how this could be achieved. Conducting qualitative research with individuals who have previously undertaken training could contribute to answering these key questions (i.e., how training could be more effective, memorable, and applicable; what training is lacking from the current curricula; how regularly should training be refreshed; and when training should happen for maximum impact). Therefore, working to include disability in training and better understand its impact through standardized outcomes are key areas to improve integration of disability training for health workers.

4 QUANTITATIVE DATA SOURCE

4.1 CHAPTER PURPOSE

The second section of the thesis seeks to understand if it is possible to use large data sources to understand which health workers should be prioritized for training. This chapter details the data source used for these analyses, the Multiple Indicator Cluster Survey.

4.2 UNICEF'S MULTIPLE INDICATOR CLUSTER SURVEY

UNICEF's Multiple Indicator Cluster Survey (MICS) is a population-based, cross-sectional survey that has collected critical health and development in 118 low- and middle-income countries for over 25 years. It has become one of the largest, most representative, and comparable data sources in low- and middle-income countries.^{162,163} Compared to other household surveys, the relative methodological rigour, comparability, open accessibility, sample size, and scope of questions make the MICS an important source for policymakers and development agencies to track progress on many of the Sustainable Development Goal indicators, which were discussed in the introduction.¹⁶³⁻¹⁶⁵

4.2.1 MICS SAMPLING AND DATA QUALITY

The MICS are household surveys that are representative at the national and first subnational (i.e. regional) levels.^{164,166} While sampling methods may vary slightly for each country depending on priorities, indicators, budgets and time, each survey involves the same multistage sample design, including the following steps:

1. The MICS starts with an existing sample frame, such as a census, recent national survey, or other suitable master sample frame that has defined geographic units.¹⁶³
2. Once the existing sample frame data are assessed for quality (duplication, completion, and recency), the MICS uses probability proportional to size sampling methods to develop census enumeration areas.¹⁶³

3. Within these enumeration areas, surveyors update the list of households to make sure any changes in size (i.e., recent births, deaths, or movement) are accounted for, unless the listing is from the past 12 months.¹⁶³
4. Using random systematic sampling within each enumeration area, 20-25 households are selected from the enumeration area to form clusters. Each household that is randomly selected is invited to participate in the survey.

The household questionnaire is then completed by the household head and specific individuals from the household participate in their individual questionnaires. All household individuals participate in the relevant questionnaires (i.e., women's, men's, children under five, children five to 17 questionnaires), except only one child aged five to 17 is randomly selected to reduce sample size and interview burden.¹⁶³ Individuals who cannot participate are reported as 'incapacitated'.¹⁶⁷

Each respondent has an anonymized identifier, including a cluster number, household number, and line number.¹⁶³ Given that many of the indicators that measure progress on Universal Health Coverage are focused on the health of children under five, sampling techniques are used to ensure sufficient quality and sample size, especially as there is significant variation in fertility rates across MICS settings.^{163,165} One such technique is to collect information about age during the household questionnaire and select a larger sample of children under five for the second round of the survey based on this information.^{163,168} In each country, there are approximately 10,000 households included to achieve sufficient sample size for most indicators.¹⁶⁵ However, this 'household' approach to sampling has some potential sources of bias—such as anyone who is unhoused or who lives in group living quarters would not be included and rarer indicators, such as disability, can be difficult to analyse because of insufficient sample size.¹⁶⁵

4.2.2 INTERVIEWS

Data are collected through face-to-face interviews and responses are entered directly into data management systems via tablet computers.^{163,169} Data collection for each national survey takes approximately 2-3 months to complete.¹⁶³ Interviewers undergo significant training to ensure

consistency and quality, and a multi-faceted team supports robust data collection.^{163,165} Interviewers visit households in teams comprised of a supervisor who coordinates activities and quality control; a driver; three to five interviewers to complete all the appropriate questionnaires; and a measurer for anthropometric measurements and water quality testing.¹⁶³ Data quality testing is ongoing, allowing for corrections to the sampling approach to take place while interviewers are already in the field. Full reports on data quality are published alongside the MICS reports, outlining sampling errors, response rates, and other key indicators to describe the surveys' performance.¹⁶³ MICS response rates vary by country but are typically high: household, women's, and child surveys typically have response rates of 90-95 percent, while the men's individual survey has a response rate of 70-85 percent.¹⁶³ It is not possible to calculate response rate by disability status.

4.2.3 QUESTIONNAIRES AND DATA FORMAT

The MICS have a core set of indicators that can be customized to meet countries' specific needs, but each survey generally has a combination of modules that produce the following data files: household, insecticide-treated nets, individual women, birth history, individual men, children aged 5–17 years, and children under age 5 years.^{165,170} Questions within modules are customized to country-specific contexts (i.e., names of health worker roles, food names, health system organisation, etc.), but are recoded in a similar way to assist standardization.¹⁶³ Anyone over 18 years of age can provide information for the household questionnaire, whereas individuals 15-49 years of age provide the data for their respective individual surveys. Data for children aged 0-14 years (within the 0-4 years and 5-17 years questionnaires, respectively) comes from the child's mother or primary caregiver (if the mother is deceased or does not live in the household) or the 15-17 year olds can respond themselves.^{163,171,172}

4.2.4 WASHINGTON GROUP QUESTIONS

The complexity and cultural relativity of disability has led to an array of definitions and measurements over the past few decades.^{164,173,174} Accordingly, the Washington Group on Disability Statistics was formed to develop standardized, validated tools to measure disability across research projects, national household surveys, and censuses.¹⁶⁶ The Washington Group Questions (WGQs)

are internationally recognized questions that were created to have a global standard definition and measure of disability that is comparable across surveys and contexts.^{164,166,169,175} UNICEF has worked alongside the Washington Group to integrate WGQs into the MICS data.¹⁶⁴ The adult functioning module and child functioning module (CFM) in the men's, women's, and children's modules provide estimates of disability so that all MICS data can be stratified by disability status.¹⁶⁹ Since these questions were incorporated as modules in 2016, 47 countries have publicly available data that can be stratified by disability status, including 13 in sub-Saharan Africa,¹⁷⁶ when the data were downloaded for this doctoral study in January 2021.

MICS uses two methods to assess disability, depending on the age group of interest. The Child Functioning Module was used to calculate the exposure—disability—in Chapter 5, while the Adult Functioning Module was used for Chapter 6.

4.2.4.1 CHILD FUNCTIONING MODULE

The CFM was specially developed to improve on a previous measure of disability (the Ten Questionnaire Survey Instrument) by expanding the breadth of functional difficulties a child may experience at various stages of their development, particularly in intellectual functioning, affect, and behaviour.¹⁶⁴ The CFM has two versions tailored to the various development stages: one is for children two to four years old and the other for children five to 17 years old. The questions measure impairment across various functional domains in alignment with the International Classification of Functioning, including vision, hearing, mobility, communication/comprehension, behaviour, and learning (all children two-17). Caregivers of children aged two to four years of age are asked about dexterity and playing, while caregivers of children aged five to 17 years are asked about self-care, remembering, focusing attention, coping with change, relationships and emotions.^{164,172} Questions across these domains assess the level of difficulty the individual child has with each task (Appendix 4).¹⁷⁴ For example, caregivers are asked “Compared with children of the same age, does (name) have difficulty playing?”, to which they could respond “no difficulty”, “some difficulty”, “a lot of difficulty” or “cannot play at all”. As per the Washington Group guidelines, a child is considered disabled when they answer “a lot of difficulty” or “cannot [insert relevant functional domain] at all”

in one or more functional domains. Children are considered non-disabled when their caregivers respond “no difficulty”, “some difficulty” to all questions.^{169,174} Children with missing data for all CFM questions are not included, while those with data for some functional domains are recoded in the relevant groups (i.e., if they answer “a lot of difficulty” or “cannot [insert relevant functional domain] at all” for a domain, they are considered disabled for that domain).¹⁶⁹ All caregivers of children two to 17 years of age who complete the CFM are also asked about assistive technology usage, but this question does not impact whether or not a child’s data would be recoded as indicating any functional difficulty.¹⁷⁷ The entire survey takes about 20-25 minutes to complete¹⁷³ and underwent several rounds of testing and validation across settings.^{164,169,174}

4.2.4.2 ADULT FUNCTIONING MODULE

The adult functioning module is based on the Washington Group Module Short Set, and includes questions on: vision, hearing, walking or climbing steps, remembering or concentrating, self-care, and communication (Appendix 5).¹⁶⁹ Adults aged 18-49 years of age are asked the level of difficulty they experience with each task, ranging from “no difficulty” to “cannot [insert relevant functional domain] at all”. As per the Washington Group guidelines, adults are considered disabled when they answer “a lot of difficulty” or “cannot [insert relevant functional domain] at all” in one or more functional domains. Adults are considered non-disabled when they respond “no difficulty”, “some difficulty” to all questions.¹⁶⁹ The adult functioning module must be responded to by the individual, not a proxy,¹⁷⁸ however; this can limit the ability of adults with severe impairments to participate (i.e., d/Deaf adults, adults with communication/speech disabilities, etc.).

4.3 ETHICAL APPROVAL

Publicly available, de-identified data were obtained from UNICEF via their online portal (<http://www.mics.unicef.org/>).¹⁷⁶ Ethical clearance was the responsibility of the institutions that administered the survey. MICS data were collected from eligible respondents following informed consent by each national UNICEF-partner institution administering the survey. This study was therefore exempt from University of Oxford ethics review.

4.4 AIMS OF THE QUANTITATIVE ANALYSES

These two quantitative studies examine from whom caregivers of disabled children and disabled women seek care for common childhood illnesses and maternal health care, respectively. Child and maternal health were selected as case studies to illustrate whether there are differences in where disabled people seek care for several reasons. Notably, maternal and child health are central to global health priorities,¹⁷⁹ making it an area where there has not only been substantial investment in health access and equity for marginalised populations, but also extensive data and monitoring to explore how different populations access this care. Furthermore, these two case studies are good examples of regular healthcare that every person is likely to require at some point in their lives, making it less likely to be biased by disease- or geography-specific factors that would complicate the results.

Examining this data may reveal two possible relationships that will be explored further in the qualitative section of this thesis. First, it is possible that disabled people already seek care from well-trained or more accessible providers at differential rates than non-disabled people. However, without any causal data (i.e., questions on why caregivers or women chose to seek from a specific health worker), it is impossible to investigate this relationship. Alternatively, if disabled people seek care from specific health worker cadres, it is an important indication of which health workers should be prioritized for training. Currently, the unsystematic nature of disability training within health workers curricula means that there is no clear rationale for why each cadre of health worker is trained about disability, when they receive the training in the span of their education and career, or if this training is aligned with where there is demand for health care from disabled people. This relationship is important to understand since effective training for health workers may help disabled people have better quality care and feel more respected within the health system.^{74,180} Therefore, generating these insights are helpful to understand how to prioritize cadres within efforts to expand current training initiatives.

5 ASSOCIATION BETWEEN DISABILITY STATUS AND CARE-SEEKING BEHAVIOUR FOR COMMON CHILDHOOD ILLNESSES

5.1 CHAPTER PURPOSE

This chapter serves as the child health case study and provides evidence on where caregivers of disabled children seek care for common childhood illnesses, as a way of measuring where there is higher demand for care among disabled children. The aim of this analysis is to understand if there are trends in where disabled children received care as a way of prioritising training efforts. Since most existing training programmes have not examined if there is particular demand among certain types of health workers to warrant a prioritization of those cadres trained, this analysis seeks to fill this gap.

5.2 INTRODUCTION

There are approximately 70 million disabled children living in sub-Saharan Africa (SSA),¹⁸¹ though this figure is expected to increase because of population growth, increased childhood survival, conflict, climate change, and inequity on the continent.^{73,182,183} Childhood disability is closely linked with poverty²⁴ and health system failures, since limited access to skilled birth attendance and routine immunizations can result in acquired impairments.^{182,183} Improving access to healthcare services can not only assist in primary prevention of acquired impairments, but also better support all disabled children who often face barriers in accessing healthcare.¹⁸⁴ Limited specialised services, under-trained health workers, poverty and economic barriers, physical inaccessibility, and stigma may all contribute to worse outcomes for disabled children.¹⁸⁵

The Sustainable Development Goals (SDGs) have renewed focus on decreasing the high burden of neonatal, infant, and child mortality, as well as improving child health overall.^{186,187} While 80% of under-five mortality still occurs in South Asia and SSA, there are limited data on the health status and outcomes of disabled children in these regions. Round 6 of the UNICEF-supported Multiple-

Indicator Cluster Surveys (MICS6) is one of the only sources of data both on disability status¹⁶⁶ and three of the five leading causes of child mortality: acute respiratory infection (ARI), diarrhoeal disease, and fever (used as an indicator of malaria).

The purpose of this study was to examine if there are differences in where caregivers of disabled children seek care for common childhood illnesses. Understanding these potential differences could help improve disability training for health workers by providing evidence on where there is demand. That is, evidence on differences in care seeking behaviour might identify who should be trained to support the higher number of disabled children they already see, among other considerations. To understand this, I first examined the odds ratios for having these illnesses, and care-seeking behaviour for them, as reported by caregivers of disabled and non-disabled children. For caregivers who sought care for their child, I also described the type of health worker they saw to examine whether care-seeking patterns differ between disabled and non-disabled children.

5.3 METHODS

5.3.1 DATA

The data source is fully described in Chapter 3. For this analysis, I used individual participant data from MICS6 conducted between 2017-2020 for 10 countries in the sub-Saharan African region (Central African Republic, Chad, Democratic Republic of Congo, Gambia, Ghana, Lesotho, Madagascar, Malawi, Sierra Leone, and Togo) that were available as of January 2021. MICS6 data are available for Guinea-Bissau, São Tomé and Príncipe, Zimbabwe, but are not included as there were fewer than 25 disabled children in the denominator for the outcomes of interest. The threshold of 25 was set to align with published MICS reports and found to be more reasonable than a more standard cut-off (i.e., 5) since the surveys are nationally-representative.¹⁶²

5.3.2 MEASURE OF IMPAIRMENT

This study included children aged two to four years whose caregivers responded to the CFM, since that was the overlapping age group for the outcomes of interest. For this age range, the CFM measures impairment across eight functional domains, including vision, hearing, mobility,

communication/comprehension, behaviour, learning, dexterity, and playing.^{166,172} As discussed in Chapter 4, children with “a lot of difficulty” or “cannot [insert relevant functional domain] at all” for at least one domain, but have one or more other domains missing, are still included, as per the Washington Group Syntax.¹⁸⁸ While data may not be missing at random, it was not possible to assess this with the measured variables and our complete case analysis is unlikely to bias the logistic regression estimate.¹⁸⁹ A sensitivity analysis where missing individuals (n=78) were recoded as disabled was conducted to see the impact of missing data (Appendix 7).¹⁹⁰

5.3.3 OUTCOMES AND COVARIATES

For each of the three illnesses that were measured in the database (ARI, diarrhoea, and fever) included in this analysis, outcomes considered were: having the illness, whether care was sought, and the care provider type. Variables for diarrhoea and fever were based on caregiver responses to direct questions on the incidence of the respective illnesses in the two weeks before the survey interview. ARI was based on caregiver responses to questions on illness with a cough, accompanied by rapid or difficult breathing, and symptoms of a chest problem, with or without congestion. Caregivers were asked whether they sought care for these illnesses and, if they had, to list the source(s) where they sought care. Interviewers were trained to ask where the caregiver sought care for the child and check off caregivers’ responses from a pre-determined list.

Provider type was grouped into qualified health providers (physicians and public and private community health workers), non-professional providers (relative/friend, shop/market/street, traditional practitioner), and unspecified health facility workers (public or private hospital, health centre, health post, pharmacy, or clinic), based on mapping provider options in the MICS6 to WHO’s International Standard Classifications of Occupations (ISCO-08).¹⁹¹ These groupings were chosen because physicians and community health workers typically undergo some form of training to be qualified, according to ISCO-08, while those in the non-qualified health providers category did not. Similarly, while many in the unspecified ‘health facility workers’ category might have undertaken training, the lack of specificity on who the child saw for care made it important to create this specific

category to answer the objective of this analysis (i.e., from whom do caregivers of disabled children seek care?)

Covariates were age, sex, wealth, and location (urban/rural). Age and sex were based on caregiver-reported responses. Location was marked by the interviewer according to how the cluster was designated by UNICEF or country statistical offices. Wealth indices were constructed using household characteristics, including ownerships of goods, living situation, water and sanitation, and other assets (included as a cleaned variable in the data I downloaded from UNICEF).¹⁹² Given data on co-morbidities, non-standardized BMI scores, and individual-level ethnicity data were not in the dataset, I could not include them as covariates.

5.3.4 STATISTICAL ANALYSIS

Analyses were completed using R 4.2.2. Baseline summary statistics (means and standard deviations or numbers and proportions) were calculated for covariates and summarised by country, and overall, and by disability status.

Logistic regression was used to examine the relationship between disability status and the prevalence of each illness (diarrhoea, fever, and ARI), and whether care was sought, in each country and overall.

Multinomial logistic regression was used to examine the relationship between disability status and care provider type for each illness separately. Analyses are presented for all countries combined and by country. All analyses were adjusted for age, sex, location, and wealth; analyses presenting all countries combined were also adjusted for country. All models accounted for the clustered survey design (i.e., country, cluster, household numbers, and sample weights) and used robust standard errors for the confidence interval calculations.

5.4 RESULTS

There were 51,901 children, aged 2-4 years, sampled in the 10 countries in sub-Saharan Africa. Table 5.1 shows baseline characteristics by country and overall. The number of children sampled ranged from 1,335 in Lesotho to 9,697 in Chad. The overall prevalence of disability was 7% (n=3,550) and

ranged from 4% (n=247) in Malawi to 11% (n=423) in Central African Republic. Half the sample were girls (n=26,013, 50%). The mean age of the sample was 3.4 years old (SD $\pm$ 0.6), though this was younger in Sierra Leone (3.0 $\pm$ 0.8) and Togo (3.0 $\pm$ 0.8). Table 5.1 also shows the total disability prevalence and prevalence of disability for each functional domain. Learning (42%) and controlling behaviour (38.5%) were the most common functional domains where caregivers reported functional difficulty, while seeing (6.2%) was the least frequently reported type of functional difficulty. These small sample sizes did not allow for disaggregation by functional domain. The missing data on disability was found not to have impacted results in the sensitivity analysis and I thus considered the results robust (Appendix 7).

Table 5.2 shows baseline characteristics by disability status. There were more disabled boys than girls (n=1,952, 55% in boys; n=1,598, 45% in girls). The mean ages of disabled children and non-disabled children were 3.3 $\pm$ 0.6 years and 3.4 $\pm$ 0.6 years respectively. A lower proportion of disabled children lived in urban areas than in rural areas (24% vs. 26%, respectively). In most countries, there were fewer disabled children in the top income quintile compared to non-disabled children. The prevalence of ARI, diarrhoea and fever was generally higher in disabled children (28% vs. 33%; 13% vs. 16%; and 26% vs. 29%, respectively), though absolute differences were small, overall.

Table 5.3 shows odds ratios for having the illness and care seeking behaviours for each illness according to disability status for all countries combined as well as for each country. Table 5.4 shows odds ratios for the type of provider from whom care was reportedly sought for each illness according to disability status for all countries combined; multivariate analyses stratified by country are shown in (Appendix 6) but had insufficient data to interpret results.

Results will be discussed for each illness, by the type of analysis:

1. the prevalence of each illness, by disability status will be described,
2. differences in seeking care for each illness, by disability status,
3. types of health workers who provide care, for each illness, by disability status.

Table 5.1: Baseline Characteristics of 51,901 Children from 10 Multiple Indicator Cluster Survey (MICS) Countries in Sub-Saharan Africa, 2017-2020

	All countries combined	Central African Republic	Chad	Democratic Republic of Congo	Ghana	Lesotho	Madagascar	Malawi	Sierra Leone	The Gambia	Togo
Number of children	51,901	3,701	9,697	8,598	3,678	1,335	4,648	5,947	7,092	4,225	2,980
Survey Year	2017-2020	2018-2019	2019	2017-2018	2017-2018	2018	2018	2019-2020	2017	2018	2017
Female (n, %)	26,013 (50)	1,868 (51)	4,801 (50)	4,427 (52)	1,864 (51)	667 (50)	2,288 (49)	3,031 (51)	3,572 (50)	2,054 (49)	1,441 (48)
Age (Mean ± SD)	3.40 (0.6)	3.49 (0.5)	3.51 (0.5)	3.48 (0.5)	3.49 (0.5)	3.52 (0.5)	3.50 (0.5)	3.49 (0.5)	3.00 (0.8)	3.48 (0.5)	3.01 (0.8)
Urban (n, %)	13,431 (26)	1,308 (35)	1,713 (18)	2,298 (27)	1,471 (40)	331 (25)	1,099 (24)	691 (12)	2,064 (29)	1,541 (37)	915 (31)
Wealth quintile (n, %)											
1 (bottom)	15,257 (29)	1,501 (41)	2,352 (24.3)	2,822 (33)	1,128 (31)	428 (32)	1,464 (32)	1,285 (22)	1,998 (28)	1,539 (36)	740 (25)
2	11,462 (22)	0 (0)	2,313 (23.9)	2,271 (26)	722 (20)	317 (24)	1,111 (24)	1,267 (21)	1,771 (25)	1,033 (24)	657 (22)
3	10,434 (20)	732 (20)	1,896 (19.6)	1,788 (21)	685 (19)	225 (17)	910 (20)	1,238 (21)	1,593 (23)	755 (18)	612 (21)
4	8,101 (16)	799 (22)	1,546 (15.9)	1,176 (14)	583 (16)	199 (15)	646 (14)	1,143 (19)	975 (14)	520 (12)	514 (17)
5 (top)	6,647 (13)	669 (18)	1,590 (16.4)	541 (6)	560 (15)	166 (12)	517 (11)	1,014 (17)	755 (11)	378 (9)	457 (15)
Disabled (n, %)	3,550 (7)	423 (11)	786 (8.1)	500 (6)	296 (8)	89 (7)	320 (7)	247 (4)	451 (6)	236 (6)	202 (7)
Type of impairment											
Seeing	219 (6.2)	22 (5.1)	69 (8.8)	30 (6.0)	8 (2.7)	17 (19.1)	22 (6.9)	28 (11.3)	9 (2.0)	5 (2.1)	9 (4.5)
Hearing	306 (8.6)	41 (9.5)	148 (18.8)	38 (7.6)	6 (2.0)	7 (7.9)	14 (4.4)	21 (8.5)	12 (2.7)	11 (4.7)	8 (4.0)
Walking	417 (11.7)	49 (11.3)	158 (20.1)	63 (12.6)	10 (3.4)	4 (4.5)	12 (3.8)	36 (14.6)	46 (10.2)	15 (6.4)	24 (11.9)
Behaviour	1,368 (38.5)	157 (36.3)	231 (29.4)	186 (37.2)	179 (60.5)	58 (65.2)	98 (30.6)	109 (44.1)	96 (21.3)	154 (65.3)	100 (49.5)
Playing	396 (11.2)	36 (8.3)	125 (15.9)	43 (8.6)	6 (2.0)	6 (6.7)	39 (12.2)	38 (15.4)	78 (17.3)	13 (5.5)	12 (5.9)
Learning	1,490 (42.0)	209 (48.4)	328 (41.7)	203 (40.6)	100 (33.8)	11 (12.4)	165 (51.6)	67 (27.1)	277 (61.4)	60 (25.4)	70 (34.7)
Communication	314 (8.8)	36 (8.3)	101 (12.8)	43 (8.6)	4 (1.4)	9 (10.1)	26 (8.1)	9 (3.6)	65 (14.4)	9 (3.8)	12 (5.9)
Fine Motor	316 (8.9)	24 (5.6)	138 (17.6)	53 (10.6)	19 (6.4)	2 (2.2)	8 (2.5)	18 (7.3)	37 (8.2)	4 (1.7)	13 (6.4)
ARI prevalence (n, %)	14,704 (28.3)	1,221 (33)	2,876 (29.7)	2,162 (25)	1,137 (31)	486 (36)	1,347 (29)	2,500 (42)	1,245 (18)	1,023 (24)	707 (24)
Diarrhoea Prevalence (n, %)	6,739 (13)	638 (17)	1,815 (18.7)	821 (10)	488 (13)	87 (7)	402 (9)	866 (15)	488 (7)	686 (16)	448 (15)
Fever Prevalence (n, %)	13,357 (26)	1,114 (30)	2,645 (27.3)	2,377 (28)	919 (25)	219 (16)	674 (15)	2,249 (38)	1,436 (20)	876 (21)	848 (29)

Table 5.2: Baseline Characteristics by Disability Status, of 51,901 Children from 10 Multiple Indicator Cluster Survey (MICS) Countries in sub-Saharan Africa, 2017-2020

	All countries combined		Central African Republic		Chad		Democratic Republic of Congo		Ghana		Lesotho	
	non-disabled	disabled	non-disabled	disabled	non-disabled	disabled	non-disabled	disabled	non-disabled	disabled	non-disabled	disabled
Number of children (n, %)	48,351 (93)	3,550 (7)	3,278 (89)	423 (11)	8,911 (91.9)	786 (8.1)	8,098 (94)	500 (6)	3,382 (92)	296 (8)	1,246 (93)	89 (7)
Female (n, %)	24,415 (51)	1,598 (45)	1,655 (51)	213 (50)	4,422 (50)	379 (48)	4,208 (52)	219 (43.8)	1,728 (51.1)	136 (45.9%)	632 (50.7)	35 (39.3)
Age Mean (SD)	3.4 (0.6)	3.3 (0.6)	3.5 (0.5)	3.4 (0.5)	3.5 (0.5)	3.5 (0.5)	3.5 (0.5)	3.47 (0.5)	3.49 (0.5)	3.49 (0.5)	3.52 (0.5)	3.56 (0.5)
Urban (n, %)	12,568 (26)	863 (24)	1,179 (36)	129 (31)		154 (19)	2,159 (26.7)	139 (27.8)	1,373 (40.6)	98 (33.1)	307 (24.6)	24 (27)
Wealth quintile (n, %)												
1 (bottom)	14,160 (29)	1,097 (31)	1,307 (40)	194 (46)	2,177 (24)	175 (22)	2,645 (32.7)	177 (35.4)	1,030 (30.5)	98 (33.1)	398 (31.9)	30 (33.7)
2	10,688 (22)	774 (22)	0 (0)	0 (0)	2,124 (24)	189 (24)	2,142 (26.5)	129 (25.8)	658 (19.5)	64 (21.6)	301 (24.2)	16 (18)
3	9,691 (20)	743 (21)	655 (20)	77 (18)	1,723 (19)	173 (22)	1,692 (20.9)	96 (19.2)	626 (18.5)	59 (19.9)	212 (17)	13 (14.6)
4	7,569 (16)	532 (15)	709 (22)	90 (21)	1,433 (16)	113 (14)	1,109 (13.7)	67 (13.4)	537 (15.9)	46 (15.5)	183 (14.7)	16 (18)
5 (top)	6,243 (13)	404 (11)	607 (19)	62 (15)	1,454 (16)	136 (17)	510 (6.3)	31 (6.2)	531 (15.7)	29 (9.8)	152 (12.2)	14 (15.7)
ARI prevalence (n, %)	13,542 (28)	1,162 (33)	1,029 (31)	192 (45)	2,621 (29)	255 (32)	2,018 (24.9)	144 (28.8)	1,030 (30.5)	107 (36.1)	446 (35.8)	40 (44.9)
Diarrhoea prevalence (n, %)	6,176 (13)	563 (16)	549 (17)	89 (21)	1,666 (19)	149 (19)	758 (9.4)	63 (12.6)	442 (13.1)	46 (15.5)	75 (6)	12 (13.5)
Fever prevalence (n, %)	12,343 (26)	1,014 (29)	945 (29)	169 (40)	2,449 (28)	196 (25)	2,228 (27.5)	149 (29.8)	827 (24.5)	92 (31.1)	194 (15.6)	25 (28.1)

Table 5.2 (continued)

	Madagascar		Malawi		Sierra Leone		The Gambia		Togo	
	non-disabled	disabled	non-disabled	disabled	non-disabled	disabled	non-disabled	disabled	non-disabled	disabled
Number of children (n, %)	4,328 (93)	320 (7)	5,700 (96)	247 (4)	6,641 (94)	451 (6)	3,989 (94)	236 (6)	2,778 (93)	202 (7)
Female (n, %)	2149 (49.7)	139 (43.4)	2,935 (51.5)	96 (38.9)	3,369 (50.7)	203 (45)	1,956 (49)	98 (41.5)	1,361 (49)	80 (39.6)
Age Mean (SD)	3.51 (0.5)	3.43 (0.5)	3.49 (0.5)	3.46 (0.5)	3.02 (0.81)	2.66 (0.79)	3.48 (0.5)	3.49 (0.5)	3.02 (0.82)	2.85 (0.8)
Urban (n, %)	1,038 (24.0)	61 (19.1)	676 (11.9)	15 (6.1)	1,935 (29.1)	129 (28.6)	1,495 (37.5)	46 (19.5)	847 (30.5)	68 (33.7)
Wealth quintile (n, %)										
1 (bottom)	1,373 (31.7)	91 (28.4)	1,231 (21.6)	54 (21.9)	1,876 (28.2)	122 (27.1)	1,428 (35.8)	111 (47)	695 (25)	45 (22.3)
2	1,028 (23.8)	83 (25.9)	1,205 (21.1)	62 (25.1)	1,651 (24.9)	120 (26.6)	964 (24.2)	69 (29.2)	615 (22.1)	42 (20.8)
3	832 (19.2)	78 (24.4)	1,181 (20.7)	57 (23.1)	1,478 (22.3)	115 (25.5)	721 (18.1)	34 (14.4)	571 (20.6)	41 (20.3)
4	600 (13.9)	46 (14.4)	1,101 (19.3)	42 (17)	916 (13.8)	59 (13.1)	511 (12.8)	9 (3.8)	470 (16.9)	44 (21.8)
5 (top)	495 (11.4)	22 (6.9)	982 (17.2)	32 (13)	720 (10.8)	35 (7.8)	365 (9.2)	13 (5.5)	427 (15.4)	30 (14.9)
ARI prevalence (n, %)	1,250 (28.9)	97 (30.3)	2,370 (41.6)	130 (52.6)	1,160 (17.5)	85 (18.8)	961 (24.1)	62 (26.3)	657 (23.7)	50 (24.8)
Diarrhoea prevalence (n, %)	378 (8.7)	24 (7.5)	798 (14)	68 (27.5)	451 (6.8)	37 (8.2)	640 (16)	46 (19.5)	419 (15.1)	29 (14.4)
Fever prevalence (n, %)	628 (14.5)	46 (14.4)	2,126 (37.3)	123 (49.8)	1,338 (20.1)	98 (21.7)	814 (20.4)	62 (26.3)	794 (28.6)	54 (26.7)

Table 5.3: Unadjusted and adjusted odds ratios for having and seeking care for Acute Respiratory Infection (ARI), diarrhoea, and fever in children from 10 Multiple Indicator Cluster Survey (MICS) countries in sub-Saharan Africa, 2017-2020

	Country	All countries	CAR	Chad	DRC	Gambia	Ghana	
ARI	Having the illness	n	1162	192	255	144	62	107
		OR	1.34	1.96	1.19	1.09	0.64	1.42
		[95% C.I.]	[1.17, 1.53]	[1.44, 2.66]	[0.93, 1.54]	[0.64, 1.87]	[0.40, 1.04]	[0.89, 2.27]
	Seeking care for the illness	aOR	1.33	1.94	1.21	1.1	0.68	1.48
		[95% C.I.] [§]	[1.16, 1.52]	[1.43, 2.64]	[0.94, 1.56]	[0.65, 1.88]	[0.42, 1.10]	[0.93, 2.37]
		n	351	52	54	48	†	49
	Having the illness	OR	0.90	0.51	2.20	0.71	†	1.07
		[95% C.I.]	[0.69, 1.18]	[0.29, 0.91]	[1.15, 4.19]	[0.26, 1.96]		[0.4, 2.85]
		aOR	0.90	0.50	2.05	0.74	†	1.23
	[95% C.I.] [§]	[0.69, 1.19]	[0.27, 0.90]	[1.01, 4.18]	[0.26, 2.11]		[0.46, 3.30]	
Diarrhoea	Having the illness	n	558	89	149	63	46	46
		OR	1.30	1.50	1.09	1.3	1.03	1.07
		[95% C.I.]	[1.14, 1.47]	[1.12, 2.01]	[0.86, 1.38]	[0.84, 2.02]	[0.68, 1.57]	[0.69, 1.65]
	Seeking care for the illness	aOR	1.27	1.44	1.07	1.29	0.98	1.07
		[95% C.I.] [§]	[1.12, 1.44]	[1.07, 1.94]	[0.84, 1.36]	[0.83, 2.00]	[0.64, 1.49]	[0.68, 1.67]
		n	290	39	82	32	29	33
	Having the illness	OR	1.07	1.02	1.88	0.73	1.27	0.57
		[95% C.I.]	[0.85, 1.36]	[0.60, 1.72]	[1.23, 2.87]	[0.33, 1.58]	[0.58, 2.78]	[0.24, 1.36]
		aOR	1.06	0.98	1.93	0.71	1.21	0.55
	[95% C.I.] [§]	[0.84, 1.34]	[0.58, 1.67]	[1.26, 2.95]	[0.33, 1.55]	[0.56, 2.59]	[0.23, 1.33]	
Fever	Having the illness	n	1114	169	196	149	62	92
		OR	1.21	1.85	0.99	1.09	1.12	1.49
		[95% C.I.]	[1.08, 1.35]	[1.45, 2.36]	[0.79, 1.23]	[0.77, 1.54]	[0.77, 1.63]	[1.07, 2.08]
	Seeking care for the illness	aOR	1.19	1.83	0.98	1.09	1.11	1.43
		[95% C.I.] [§]	[1.06, 1.33]	[1.43, 2.34]	[0.79, 1.22]	[0.77, 1.54]	[0.76, 1.6]	[1.02, 1.99]
		n	533	66	81	66	34	69
	Having the illness	OR	1.06	0.91	1.47	1.42	1.02	0.89
		[95% C.I.]	[0.87, 1.29]	[0.61, 1.34]	[1.01, 2.13]	[0.80, 2.52]	[0.55, 1.92]	[0.46, 1.72]
		aOR	1.07	0.91	1.48	1.5	1.06	0.90
	[95% C.I.] [§]	[0.88, 1.30]	[0.62, 1.33]	[1.02, 2.16]	[0.84, 2.69]	[0.56, 1.99]	[0.47, 1.73]	

Table 5.3 (continued)

		Country	Lesotho	Madagascar	Malawi	Sierra Leone	Togo
ARI	Having the illness	n	40	97	130	85	50
		OR	1.86	1.34	1.47	1.66	1.14
		[95% C.I.]	[0.88, 3.93]	[0.89, 2.02]	[1.02, 2.10]	[1.11, 2.50]	[0.61, 2.13]
		aOR	2.05	1.32	1.42	1.55	1.07
		[95% C.I.] [§]	[0.98, 4.28]	[0.87, 2.00]	[0.99, 2.04]	[1.03, 2.33]	[0.58, 1.97]
	Seeking care for the illness	n	†	25	73	50	†
		OR	†	0.49	0.67	1.02	†
		[95% C.I.]	†	[0.24, 0.98]	[0.35, 1.29]	[0.37, 2.84]	†
		aOR	†	0.45	0.71	1.06	†
		[95% C.I.] [§]	†	[0.22, 0.92]	[0.36, 1.40]	[0.39, 2.85]	†
Diarrhoea	Having the illness	n	†	31	68	37	29
		OR	†	0.82	2.31	1.45	1.4
		[95% C.I.]	†	[0.5, 1.35]	[1.54, 3.47]	[1.00, 2.1]	[0.77, 2.53]
		aOR	†	0.81	2.34	1.35	1.41
		[95% C.I.] [§]	†	[0.49, 1.32]	[1.55, 3.52]	[0.93, 1.95]	[0.78, 2.55]
	Seeking care for the illness	n	†	†	49	26	†
		OR	†	†	1.17	0.92	0.64
		[95% C.I.]	†	†	[0.56, 2.45]	[0.41, 2.04]	[0.22, 1.85]
		aOR	†	†	1.18	0.76	0.63
		[95% C.I.] [§]	†	†	[0.56, 2.46]	[0.32, 1.79]	[0.22, 1.81]
Fever	Having the illness	n	25	46	123	198	54
		OR	1.82	0.93	1.46	1.17	0.77
		[95% C.I.]	[1.02, 3.23]	[0.64, 1.37]	[1.04, 2.05]	[0.89, 1.53]	[0.52, 1.15]
		aOR	1.88	0.92	1.38	1.11	0.78
		[95% C.I.] [§]	[1.05, 3.36]	[0.63, 1.35]	[0.98, 1.96]	[0.84, 1.46]	[0.53, 1.15]
	Seeking care for the illness	n	†	26	91	69	31
		OR	†	0.78	1.03	0.92	0.68
		[95% C.I.]	†	[0.38, 1.57]	[0.63, 1.68]	[0.54, 1.56]	[0.35, 1.33]
		aOR	†	0.78	1.05	0.91	0.69
		[95% C.I.] [§]	†	[0.39, 1.55]	[0.64, 1.71]	[0.54, 1.54]	[0.34, 1.38]

† = based on fewer than 25 cases unweighted.

§ = adjusted for age, wealth, sex, and location. All countries estimate is also adjusted by country.

* = adjusted for country only

5.4.1 PREVALENCE

Disabled children had small overall absolute differences (5%) in reported ARI prevalence compared to non-disabled children (Table 5.2). However, this varied by country, from nearly 14% higher prevalence in disabled children in Central African Republic and Malawi to 1.3% in Sierra Leone. Disabled children had higher odds of having had an ARI in the past two weeks than non-disabled children (Table 5.3: aOR = 1.33, 95% C.I. 1.16 to 1.52). When analysed by country, disabled children had higher odds of having had an ARI in the past two weeks than non-disabled children in Central African Republic (aOR = 1.94, 95% C.I. 1.43 to 2.64) and Sierra Leone (aOR = 1.55, 95% C.I. 1.03 to 2.33). Results from other countries were imprecise, for example, in Lesotho, disabled children had between 0.98 lower odds and 4.28 higher odds of having had a recent ARI compared with non-disabled children (aOR = 2.05, 95% C.I. 0.98 to 4.28).

I also observed similarly small absolute differences in diarrhoea (3%) between disabled and non-disabled children (Table 5.2). Non-disabled children had a higher prevalence of diarrhoea and small absolute differences in Madagascar and Togo (by 1.2% and 0.7%, respectively), while disabled children had larger absolute differences in Lesotho (7.5%) and Malawi (13.5%). Using logistic regression models, I found disabled children had higher odds of diarrhoea in the past two weeks than non-disabled children overall (Table 5.3: aOR = 1.27, 95% C.I. 1.12 to 1.44), in Central African Republic (aOR = 1.44, 95% C.I. 1.07 to 1.94), and in Malawi (aOR = 2.34, 95% C.I. 1.55 to 3.52). Other countries had imprecise estimates because of small numbers, such as in Democratic Republic of Congo, where disabled children had between 0.83 times lower to 2.00 times higher odds of having diarrhoea compared with non-disabled children (aOR = 1.29, 95% C.I. 0.83 to 2.00).

Finally, disabled children also had small absolute differences (3%) in reportedly having a fever in the past two weeks compared to non-disabled children (Table 5.2). Malawi had the largest absolute difference between disabled and non-disabled children (12.5%), while non-disabled children had higher rates of fever and smaller absolute differences in Chad (3%), Togo (1.9%), Madagascar (0.1%). Overall, disabled children had a higher odds of fever in the past two weeks than non-disabled children (Table 5.3: aOR = 1.19, 95% C.I. 1.06 to 1.33). When analysing by country, disabled

children had a higher odds of fever than non-disabled children in Central African Republic (aOR = 1.83, 95% C.I. 1.43 to 2.34), Ghana (aOR = 1.43, 95% C.I. 1.02 to 1.99), and Lesotho (aOR = 1.88, 95% C.I. 1.05 to 3.36). No association was seen in other countries, though results were imprecise with wide confidence intervals.

5.4.2 CARE SEEKING

When all countries were combined, in children who had an ARI, there was no evidence that caregivers of disabled children had a different odds of seeking care than caregivers of non-disabled children (Table 5.3: aOR = 0.90, 95% C.I. 0.69 to 1.19). When analysed by country, there was some evidence caregivers for disabled children in Chad had a higher odds of seeking care for ARI than for non-disabled children (aOR = 2.05, 95% C.I. 1.01 to 4.18). Conversely, in Central African Republic (aOR = 0.50, 95% C.I. 0.27 to 0.90) and Madagascar (aOR = 0.45, 95% C.I. 0.22 to 0.92) there was some evidence that caregivers of non-disabled children had lower odds of seeking care for ARI than caregivers of non-disabled children. Some estimates were imprecise, for example, in Ghana, the odds of seeking care in children with diarrhoea were between 0.46 times lower and 3.30 times higher for disabled children compared with non-disabled children (aOR = 1.23, 95% C.I. 0.46 to 3.30).

For all countries combined, there was no evidence that caregivers of disabled children had a higher odds of seeking care for the child's diarrhoea than caregivers of non-disabled children (Table 5.3: aOR = 1.06, 95% C.I. 0.84 to 1.34). When analysed by country, caregivers for disabled children in Chad had a higher odds of seeking care for ARI than for non-disabled children (aOR = 1.93, 95% C.I. 1.26 to 2.95), while other countries had imprecise estimates because of small numbers, including in The Gambia (aOR = 1.21, 95% C.I. 0.56 to 2.59) and Malawi (aOR = 1.18, 95% C.I. 0.56 to 2.46).

In children who had a fever, the combined estimate for all countries showed no evidence that caregivers of disabled children had higher odds of seeking care for the child's fever than caregivers of non-disabled children (Table 5.3: aOR = 1.07, 95% C.I. 0.88 to 1.30). Similar results were seen when analysed by country, with no evidence that caregivers of disabled children had a higher odds of seeking care for fever than caregivers of non-disabled children, except for some evidence in Chad

(aOR = 1.48, 95% C.I. 1.02 to 2.16). Other countries had imprecise estimates, with wide confidence intervals.

Table 5.4: Adjusted Odds Ratios for the Care Provider Type from Whom Care is Sought for ARI, Diarrhoea and Fever, According to Disability Status in Children from 10 MICS Countries in Sub-Saharan Africa, 2017-2020

Care provider type (vs unspecified Health Facility worker) and disability status (vs non-disabled)						
	Unspecified health facility worker		Trained health worker		Non-health professional	
	N	OR Disabled	N	OR [95% CI] Disabled	N	OR [95% CI] Disabled
Country-adjusted only						
ARI care provider	264	1.00	45	2.43 [1.44, 4.10]	81	1.78 [1.12, 2.84]
Diarrhoea care provider	198	1.00	42	1.41 [0.81, 2.44]	70	1.09 [0.79, 1.49]
Fever care provider	364	1.00	81	1.5 [1.04, 2.16]	91	1.13 [0.83, 1.54]
Multivariate (adjusted)*						
ARI care provider	264	1.00	45	2.50 [1.47, 4.25]	81	1.89 [1.19, 2.98]
Diarrhoea care provider	198	1.00	42	1.35 [0.78, 2.32]	70	1.08 [0.75, 1.56]
Fever care provider	364	1.00	81	1.49 [1.03, 2.14]	91	1.14 [0.84, 1.54]

* Adjusted for country, wealth, age, location, and sex

5.4.3 HEALTH WORKER WHO PROVIDED CARE

For all three illnesses, there was insufficient data to analyse by country, so countries were pooled to be analysed regionally. The odds of seeking care for ARI from a trained health worker compared to from an unspecified health facility worker were higher for caregivers of disabled children than for caregivers of non-disabled children (aOR = 2.50, 95% C.I. 1.47 to 4.25). The odds of seeking care for ARI from a non-health professional compared to from an unspecified health facility worker were also higher for caregivers of disabled children compared to non-disabled children (aOR = 1.89, 95% C.I. 1.19 to 2.98). However, there was no evidence that the odds of caregivers of disabled children seeking care for diarrhoea from a trained health worker, or from a non-health professional, compared

to an unspecified health facility worker, differed compared to caregivers of non-disabled children (Table 5.4: aOR = 1.35, 95% C.I. 0.78 to 2.32 and aOR = 1.08, 95% C.I. 0.75 to 1.56, respectively). Caregivers of disabled children had a slightly higher odds of seeking care for fever from a trained health worker than from an unspecified health facility worker compared to caregivers of non-disabled children (Table 5.4: aOR = 1.49, 95% C.I. 1.03 to 2.14). The odds of seeking care for fever from a non-health professional compared to from an unspecified health facility worker were between 0.83 times lower and 1.54 times greater for caregivers of disabled children compared to non-disabled children (aOR = 1.14, 95% C.I. 0.83 to 1.54).

5.5 DISCUSSION

The aim of this study was to examine if there were differences in reported care seeking behaviour among caregivers of disabled and non-disabled children, which could then be used to help identify how to better match healthcare staff training needs with care seeking. In this study of 51,901 children aged two to four years from 10 countries in SSA, the odds of having ARI, diarrhoea and fever in the past two weeks were higher in disabled children than in non-disabled children, although the absolute differences were small overall (between 3 to 5%). There was no evidence that caregivers of disabled children had higher or lower odds of seeking care for ARI, diarrhoea, or fever, than caregivers of non-disabled children. However, this trend diverged in Chad, where caregivers of disabled children had higher odds of seeking care for all illness, and in Central African Republic and Madagascar where caregivers of disabled children had lower odds of seeking care for ARI. Caregivers of disabled children had higher odds of seeking care for the child's ARI and fever from a trained health worker or non-health professional than from an unspecified health facility worker, compared to caregivers of non-disabled children, but no association was seen for diarrhoea.

Existing literature suggests inequities in care seeking behaviour for disabled children, but our study, based on caregiver reports, did not echo these findings. Much of the existing literature suggests that disabled children see non-health professionals more often due to cultural associations with disability and stigma.^{183,185} For example, parents of children with neurodisabilities in Malawi were encouraged

by their communities to see traditional healers because of stigma and disability being associated with curses, punishment, and bad luck.^{185,193} In a qualitative study in Senegal, few caregivers of disabled children knew of specialized services, and instead reported relying predominantly on traditional doctors or religious healers.¹⁸³ In contrast, our study suggests that caregivers of disabled children sought care for ARI from non-trained health professionals, but also saw trained health professionals more often than caregivers of non-disabled children for ARI and fever. I was not able to analyse where parents sought health care in relation to the impairment itself, nor the severity of the illness, as these data were not included in the survey.

This chapter found further differences with existing literature and conceptions of health inequity for disabled children, including that, in most countries, there were no observed differences in reported care seeking between caregivers of disabled and non-disabled children. There are several possible reasons that contribute to this. First, the sample has notable differences with existing literature on the demographic distribution of disabled children—existing literature suggests disability is more common in older and male children, whereas disabled children were, on average, younger, and more likely to be female. While the analysis was adjusted for sex and age, there are cultural norms around gender that further impact care seeking behaviours (i.e., preference for male children can sometimes result in prioritising them for limited resources),¹⁹⁴ treatment, and quality of care. Moreover, impairment itself may be a risk factor for these illnesses. For example, some impairments may dispose children to particular illnesses, such as children with neuromuscular conditions have been found to have higher rates of ARI.¹⁹⁵ Similarly, disabled people, overall, have been shown to have poorer health status, potentially because of poorer access to health care, limited access to education, and other factors, which may predispose them to more infections.¹⁹⁶

In addition, disability status is often associated with family poverty,²⁴ which can lead disabled children to be exposed to poor water supply, sanitation, and hygiene (WASH)¹⁹⁷ or have limited health access. While adjusting for wealth may capture some of this interaction, disabled children may also be more exposed to poor sanitation because of lack of accessible WASH facilities,¹⁹⁸ which could contribute to higher rates of illness observed in this study.¹⁹⁹ These results on whether care

was sought at different rates are inconclusive, with small numbers and wide confidence intervals. It is possible that differences in health systems, connections to the health system for specialised disability care, cultural conceptions of illness and care-seeking, or severity of illness, may affect care-seeking behaviour and from where care is sought. For example, if health systems have robust insurance programmes, local urgent care clinics, or other support for disabled children (i.e., transportation subsidies, home health visits, etc.) to address the system-level barriers to health care for disabled children, it could explain why there were differences in ARI care seeking for Chad, Central African Republic, and Madagascar but not for other countries. However, with the available data, I could not examine the health system-level factors that may have impacted these results.

5.5.1 STRENGTHS AND LIMITATIONS

This study provides novel analysis on critical indicators for child health for disabled children in the MICS6. While other studies have used proxies for disability in previous rounds of the MICS,²⁰⁰ this is the first study to use the CFM to examine these crucial indicators. Since disability disaggregation is routinely missing from SDG monitoring, this study provides critical evidence on differences in having common childhood illnesses and care seeking for disabled and non-disabled children. Furthermore, few studies have examined trends in which health workers provide care, making the finding that caregivers usually seek the health advice of trained health workers for ARI and fever, a key contribution to the literature.

However, I was not able to present planned analyses for every county where data were available or conduct the multinomial logistic regression analyses for each individual country due to small numbers (Appendix 6). While I adjusted for country, I was not able to study the prevalence of other diseases, such as malaria, and health systems measures (i.e., routine vaccination programs) that may impact prevalence of illness or care-seeking patterns. In addition, despite the robustness of the MICS data, disabled children are likely under-sampled in the questionnaire due to the lack of cultural and language-specific adjustments to the survey and, generally, different cultural conceptions of disability.¹⁶⁴ The results may also be affected by recall bias, as all data included in this study are self-reported by the caregiver. Since caregivers may be unwilling to suggest that their child is disabled

or report that they would treat a disabled child differently, this may have increased reporting of care-seeking behaviour among caregivers of disabled children. Furthermore, the sample should be considered in context, since the distribution of baseline characteristics, including age and sex differs from other published data in which disability is more common in girls and increases with age.⁷³ While this may not substantially impact results, since all estimates were adjusted for age and sex, this may be a limitation of conducting a secondary analysis with the MICS dataset. Finally, there are other variables for which I was not able to adjust, such as family size, broader socio-economic context not captured by 'wealth', and severity of illness, that affect illness and care-seeking behaviour. The lack of data on severity, the quality of care, and clinical outcomes after illness limited further exploration of these important factors.

5.6 CONCLUSION

In summary, this study provides evidence of higher prevalence of common childhood illnesses—ARI, diarrhoea, and fever—among disabled children compared with non-disabled children in sub-Saharan Africa, although the absolute differences were small for the overall sample. While it provides no evidence of different reported care seeking patterns by caregivers overall, there were differences in where caregivers of disabled children sought care for ARI and fever, compared to non-disabled children in all countries. Sample sizes limited our ability to understand these differences at the country-level, but this suggests that more targeted data collection is needed to investigate the dynamics of care-seeking behaviour among caregivers of disabled children in sub-Saharan Africa. On the whole, this case study shows that disabled children have higher prevalence of common childhood illnesses, but since there is no strong evidence that caregivers of disabled children have substantially different care-seeking patterns across all three illnesses it suggests that all health workers should be trained about disability. Further, the fact that disabled children have a higher prevalence of these illnesses reinforces the idea that all health workers need disability training, as disabled children will make up a large number of patients because of this relative difference in prevalence.

6 ASSOCIATION BETWEEN DISABILITY STATUS AND USE OF MATERNAL CARE SERVICES

6.1 CHAPTER PURPOSE

This chapter serves as the maternal health case study and builds on Chapter 5, by examining where there are demands for maternal health care. I used additional data from disabled women to provide more insight into the care decision-making pathway, since disabled children's caregivers may mitigate some of the barriers disabled women encounter in accessing care. Ultimately, this chapter seeks to understand whether disabled adults have higher demand for care from certain health worker cadres. Understanding this relationship can help to advance training prioritisation efforts for maternal healthcare providers.

6.2 BACKGROUND

Quality maternal health care is central to the Sustainable Development Goals (SDGs) efforts to reduce maternal mortality.¹⁷⁹ Increasing access to routine antenatal care (ANC), skilled birth attendance, postnatal, and postpartum care can help address high rates of pregnancy-related mortality, particularly in sub-Saharan Africa where maternal mortality remains unacceptably high.²⁰¹⁻²⁰³ Critical shortages of health workers have become barriers to expanding maternal health services at sufficient rates,²⁰⁴ which has led to a renewed focus on inequities in maternal health care across socio-economic,²⁰⁵ urban/rural,²⁰⁶ and educational²⁰⁷ axes. Despite 15.4% of the sub-Saharan African population experiencing disability in some form,⁷³ there remains limited quantitative data on maternal care inequities for disabled women in sub-Saharan Africa.

Disabled women face similar barriers in seeking maternal care as they do for healthcare more broadly.^{196,208,209} While there is some evidence of the maternal care experiences of disabled women in particular settings,²⁰⁸⁻²¹⁷ quantitative research on maternal care for disabled women is severely lacking in sub-Saharan Africa. The inclusion of the Washington Group Short Set (WG-SS) in Round

6 of the UNICEF-supported Multiple Indicator Cluster Surveys (MICS) provides an opportunity to investigate inequities in key maternal care indicators and access to trained health workers for disabled women.^{163,165,178} Understanding more about where disabled women seek care could help to identify where to prioritise disability training for health workers. Accordingly, I analysed data from 13 countries in sub-Saharan Africa with available MICS6 datasets (as of January 2022) to compare disabled women's patterns in seeking antenatal care, and from whom they sought antenatal care, skilled birth attendance, and postnatal and postpartum checks.

6.3 METHODS

Background on the MICS and the methods for sampling were covered in Chapter 4.

6.3.1 OUTCOMES AND COVARIATES

Antenatal care attendance was measured by whether a woman saw any provider (trained or untrained) for antenatal care during a pregnancy in the last two years. Variables measuring the provider type for antenatal care, skilled birth attendance, and post-natal check-ups were grouped into i) nurses/midwives, physicians, ii) community carers (traditional birth attendant, community health worker) and iii) untrained individuals or no one (relative/friend, no one) based on mapping provider options in the MICS survey to WHO's International Standard Classifications of Occupations (ISCO-08).¹⁹¹ These groupings were selected based on the WHO guidelines for maternal health care that encourage task-shifting from physicians to trained health workers for maternal care, such as nurses/midwives.²¹⁸ Community health workers were included in the community carers second group as the WHO guidelines recommend their participation, but prefer skilled birth attendance from a physician, nurse, or midwife for comprehensive care.²¹⁸

6.3.2 STATISTICAL ANALYSIS

Analyses were completed using R 4.2.2. Baseline summary statistics (means and standard deviations or numbers and proportions) were calculated for covariates and summarised by country, and overall, and by disability status.

Logistic regression was used to examine the relationship between disability status and antenatal care attendance for the region overall. This was adjusted for age, wealth, country, and location (urban/rural). Multinomial logistic regression was used to examine the relationship between disability status and the care provider type for antenatal care, skilled birth attendance, and post-natal checks. Analyses are presented for all countries combined, given small sample sizes. A sensitivity analysis was conducted to understand the impact of missing disability data but was found not to have impacted the findings (Appendix 8). Given the skip pattern of the data embedded in the survey design, each indicator has a unique denominator, as some data are missing at random and some data are missing due to the survey design. This method is preferable to imputation because it is difficult to distinguish what data are missing at random compared to missingness due to the survey design. All analyses were adjusted for country, age, wealth, and location (urban/rural). All models accounted for the clustered survey design (i.e., country, cluster, household numbers, and sample weights) and used robust standard errors for the confidence interval calculations.

6.4 RESULTS

This study included 10,021 women between the ages of 18-49 years, who had reported a live birth in the past two years, from 13 countries in sub-Saharan Africa. Table 6.1 shows the baseline characteristics overall and by disability status. The mean age was 27.8 ± 6.4 years in non-disabled women and 28.7 ± 6.9 years in disabled women. Fewer disabled women lived in urban areas than non-disabled women (28.4% vs. 31.7%). The proportion of disabled women in the lowest wealth category was higher than in non-disabled women (37.9% vs. 30.4%). Overall, the prevalence of disability was 3.1% (n = 306). The proportion of women receiving at least one ANC visit from any provider type was high at 95.4% (n = 9,030); and there were small absolute differences between disabled and non-disabled women (91.8% vs. 95.5%). Nurses and midwives were the most common category of provider type for non-disabled and non-disabled women (qualified ANC: 86.9% vs. 84.2% vs. 86.9%; skilled birth attendance: 67.0% vs. 60.4% vs 67.0%; postnatal check: 83.7% vs. 81.2% vs. 83.7%; and postpartum check: 82.1% vs. 78.9% vs. 82.1%), though there were small absolute differences.

Table 6.1: Baseline Characteristics, Overall and By Disability Status, of 10,021 Women from 13 MICS in Sub-Saharan Africa, 2017-2020

	Overall	Non-disabled	Disabled
N (%)	10,021	9,715 (96.9)	306 (3.1)
Age (mean (SD))	27.8 (6.5)	27.8 (6.4)	28.7 (6.9)
Urban	3,171 (31.6)	3,084 (31.7)	87 (28.4)
Disability prevalence	306 (3.1)	-	-
Wealth Quintiles			
1 (bottom)	3,069 (30.6)	2,953 (30.4)	116 (37.9)
2	2,245 (22.4)	2,184 (22.5)	61 (19.9)
3	1,879 (18.8)	1,821 (18.7)	58 (19.0)
4	1,602 (16.0)	1,559 (16.1)	43 (14.1)
5 (top)	1,224 (12.2)	1,196 (12.3)	28 (9.2)
Antenatal care attendance			
At least one visit	9,030 (95.4)	8,773 (95.5)	257 (91.8)
Missing	558	532	26
Qualified ANC provider			
Nurse/Midwife	7,573 (86.9)	7,370 (86.9)	203 (84.2)
Doctor	1,106 (12.7)	1,069 (12.6)	37 (15.4)
Community Health Provider	40 (0.5)	39 (0.5)	1 (0.4)
Missing	1,302	1,237	65
Skilled birth attendance			
Nurse/Midwife	6,265 (66.8)	6,099 (67.0)	166 (60.4)
Doctor	1,131 (12.1)	1,088 (11.9)	43 (15.6)
Community Health Provider	1,195 (12.7)	1,155 (12.7)	40 (14.5)
No one/friend	789 (8.4)	763 (8.4)	26 (9.5)
Missing	641	610	31
Postnatal check on baby			
Nurse/Midwife	3,961 (83.7)	3,853 (83.7)	108 (81.2)
Doctor	339 (7.2)	330 (7.2)	9 (6.8)
Community Health Provider	301 (6.4)	290 (6.3)	11 (8.3)
Friend/relative	133 (2.8)	128 (2.8)	5 (3.8)
Missing	5,287	5,114	173
Postpartum check on mother			
Nurse/Midwife	3,034 (82.0)	2,948 (82.1)	86 (78.9)
Doctor	244 (6.6)	238 (6.6)	6 (5.5)
Community Health Provider	243 (6.6)	230 (6.4)	13 (11.9)
Friend/relative	180 (4.9)	176 (4.9)	4 (3.7)
Missing	6,320	6,123	197

6.4.1 ANTENATAL CARE

Table 6.2 shows odds ratios for ANC coverage and provider types. There was no evidence that disabled women had different rates of ANC compared to non-disabled women (aOR = 0.64, 95% C.I. 0.39 to 1.05) or that disabled women saw different types of ANC providers compared to non-disabled women (doctors: aOR = 1.25, 95% C.I. 0.81 to 1.91; community health providers: aOR = 0.51, 95% C.I. 0.06 to 4.28), though these estimates were imprecise, with wide confidence intervals.

Table 6.3 shows odds ratios for care being provided by nurses/midwives, doctors, community health providers or a friend/no-one for different stages of maternal care. Results are discussed by stage of care and include skilled birth attendance, postnatal and postpartum care.

6.4.2 SKILLED BIRTH ATTENDANCE

There was no strong evidence disabled women had different birth attendants than non-disabled women (Table 6.3: doctors: aOR = 1.52, 95% C.I. 0.99 to 2.33; community health workers: aOR = 0.70, 95% C.I. 0.41 to 1.18; no-one/a friend: aOR = 0.72, 95% C.I. 0.42 to 1.25). However, there was some evidence that disabled women more often had their births attended to by doctors.

6.4.3 POSTNATAL CARE

There was no evidence of a difference in care provider for disabled and non-disabled women for the postnatal checks on their babies (Table 6.3: doctors (aOR = 0.89, 95% C.I. 0.40 to 1.99), community health providers (aOR = 0.77, 95% C.I. 0.30 to 2.00), no one or friend/relative (aOR = 0.79, 95% C.I. 0.19 to 3.26)).

6.4.4 POSTPARTUM CARE

Care provider types for postpartum care for disabled and non-disabled women also showed no differences between the groups (Table 6.3: doctors (aOR = 0.95, 95% C.I. 0.34 to 2.67), community health providers (aOR = 1.38, 95% C.I. 0.51 to 3.75), no one or friend/relative (aOR = 0.46, 95% C.I. 0.87 to 1.38)).

Table 6.2: Adjusted odds ratios for antenatal care coverage and provider types for women from 13 Multiple Indicator Cluster Survey (MICS) countries in sub-Saharan Africa, 2017-2020

Provider Categories	Country-adjusted only OR [95% C.I.] Disabled	Adjusted* OR [95% C.I.] Disabled
Antenatal care coverage	0.64 [0.39, 1.05]	0.64 [0.39, 1.05]
Antenatal care provider type		
Nurse/midwife	1.00	1.00
Doctors	1.23 [0.82, 1.88]	1.25 [0.81, 1.91]
Community Health Provider	0.57 [0.07, 4.71]	0.51 [0.06, 4.28]

* Adjusted for country, wealth, location, and age

Table 6.3: Adjusted odds ratios for the care provider type for various stages of maternal health care for women from 13 Multiple Indicator Cluster Survey (MICS) countries in sub-Saharan Africa, 2017-2020

Indicator	Country-adjusted OR [95% C.I.] Disabled				Adjusted* OR [95% C.I.] Disabled			
	Nurse or midwife	Doctors	Community Health Provider	No one or friend/ relative	Nurse or midwife	Doctors	Community Health Provider	No one or friend/ relative
Skilled birth attendance	1.00	1.40 [0.93, 2.11]	0.86 [0.51, 1.45]	0.90 [0.53, 1.53]	1.00	1.52 [0.99, 2.33]	0.70 [0.41, 1.18]	0.72 [0.42, 1.25]
Postnatal health checks on baby	1.00	0.99 [0.44, 2.20]	0.88 [0.32, 2.46]	0.80 [0.19, 3.26]	1.00	0.89 [0.40, 1.99]	0.77 [0.30, 2.00]	0.79 [0.19, 3.26]
Postpartum health checks on mother	1.00	0.82 [0.29, 2.34]	1.58 [0.57, 4.35]	0.35 [0.84, 1.48]	1.00	0.95 [0.34, 2.67]	1.38 [0.51, 3.75]	0.35 [0.87, 1.38]

* Adjusted for country, wealth, location, and age

6.5 DISCUSSION

This study sought to inform training priorities by examining any differences in key maternal care indicators and from which providers disabled and non-disabled women have sought care in sub-Saharan Africa. In the sample of 10,021 women, estimates for antenatal care attendance, qualified antenatal care provider, postnatal, and postpartum checks, showed small absolute and no relative differences between disabled and non-disabled women, though these estimates were imprecise, with wide confidence intervals. There was some evidence that disabled women were more likely to have been attended to by doctors than non-disabled women (aOR: 1.52, 95% C.I.: 0.99 – 2.33).

These findings are in-line with other household data findings, but largely diverge from other literature, which shows substantial inequities for disabled women. For example, our data echoes evidence from Pakistan's Demographic and Health Survey, which did not show inequities in use of antenatal care between disabled and non-disabled women²¹³ and UK research that has shown that disabled women have satisfactory access to antenatal care.²¹⁴ However, as with the previous chapter, access does not necessarily indicate the same level or quality of care and disabled women in the UK have been shown—in a national survey and qualitative study—to lack the support to make maternal care and childbirth a safe and supportive experience.^{214,215} Other qualitative studies of maternal health care for disabled women have also shown considerable barriers to accessing care and receiving high-quality, rights-based care. A systematic review²⁰⁹ and studies in Uganda²⁰⁸ and Ghana²¹⁶ found that disabled women faced barriers in communication/support, transportation, accessible health facilities, basic needs during delivery, and stigma/discrimination from health workers throughout the birth process. In Canada, disabled women were shown to have worse neonatal outcomes than non-disabled women, highlighting the need for more care for this population.²¹⁰ While the differences in care providers for other forms of maternal care were inconclusive, the small sample size highlights the need to expand disability disaggregation in other maternal health surveys. The lack of inclusion of disability status in core SDG indicators, including maternal health care, impacts our ability to understand inequities for disabled women.

This study highlights that the relationship between disabled women and the health system is complex and should be evaluated in context. For example, our results suggest disabled women may have higher odds than non-disabled women of skilled birth attendance from doctors (aOR = 1.52, 95% C.I. 0.99 to 2.33). Having a doctor as a skilled birth attendant may indicate a health centre or hospital birth, which may be appropriate since previous research has suggested higher risks of complications for both the mother and the baby.^{210,212} This understanding of birth outcomes for disabled women may encourage more to have facility-based births, but this should not necessarily be mistaken for better quality care. A mix of qualitative and quantitative studies have found that disabled women feel they are less likely to be adequately supported during birth or by healthcare professionals than non-disabled women.^{208,214,219,220} Other research has shown that the infantilisation of disabled women can prevent them from becoming pregnant or receiving adequate care during pregnancy.^{215,221} These factors, along with the other social factors such as poverty and poor education make disabled women more susceptible to adverse outcomes.²⁰⁵ Moreover, facility-based births might not be in-line with a woman's desired birth plans and the data do not allow us to explore whether the nature of a woman's impairment led to the choice for a facility-based birth. Qualitative studies around the world have also shown that women with physical impairments report their maternal care is not often aligned with their desires or adaptable and responsive to their wishes.^{208,209,222} Given that autonomy and quality of care were not examined in this study, my findings cannot be interpreted as suggesting that care has improved, but do suggest that there is a need for this issue to be examined more fully in further research on maternal outcomes of disabled women.

6.5.1 STRENGTHS AND LIMITATIONS

This study provides novel evidence on maternal health seeking behaviours of disabled women in sub-Saharan Africa, using data from a large, nationally representative household survey. While other studies have used Demographic and Health Surveys²¹³ or been conducted in other countries,^{210-212,214,222} this study provides data on critical SDG indicators across multiple countries in sub-Saharan Africa. Further, specifically examining which types of health workers disabled women reported

seeking care from provides important data on which care may be most accessible and where further efforts to improve access and quality could be focused to reach disabled women.

This study was limited by the relatively small proportion of disabled women compared to other estimates of disability prevalence,⁷³ which translated to imprecise estimates and an inability to stratify results by country and impairment type. While this study did control for country in the analysis, the lack of country disaggregation potentially masks important country-specific trends or system-level factors, such as health insurance coverage, transport subsidies, and outreach programmes that may impact country-level results. However, even at a regional level, there was a small sample size and the proportion of disabled women in this study substantially differs from previous estimates (3% in this study vs 15.4% in the literature),⁷³ including other age groups in the MICS. This is likely because the domains included in the Washington Group Short Set are limited in comparison to those included in the MICS Child Functioning Module and WHO Model Disability Surveys, which have a broader definition of functioning and functional domains, resulting in substantially higher prevalence of disability.²²³ The small sample size also hampered my ability to analyse the data by impairment type, which would be useful to provide greater understanding of the types of impairments health workers would expect to interact with as well as improve health policy and planning around accommodations, such as sign language interpreters. Moreover, since this is self-reported data on disability and there are no published details on accessibility considerations in the survey design (i.e., interpreters, accessible formats, etc.), the sample may be biased by non-response, narrow definitions of disability, and only include individuals with lower thresholds of impairment who can participate in the survey without accommodations.¹⁶⁷ This is an important limitation, particularly in relation to the findings that suggest fewer than expected differences for disabled women.

Additionally, the survey bases questions on biological sex, rather than gender identity, and therefore may not be fully inclusive of people who have given birth in the past two years, although this is unlikely to have a major impact on my results. Finally, the data provide no indication on the quality of care disabled women received after seeking care, including how their wishes around birth were

respected, which is a consistent issue in the literature on healthcare for disabled people. Further research is needed to understand these trends in the context of high-quality care and respect for women's preferences.

6.6 CONCLUSION

In summary, these results show no evidence of differences between disabled and non-disabled women for antenatal attendance, antenatal care provider, and postnatal and postpartum check-up providers. It provides some evidence that disabled women have higher odds of having the birth attended by a doctor. These findings can help ensure training efforts are equally focused across all health worker cadres who interact with disabled women for maternal care, since the data did not show specific cadres who interact more often. The study was limited by a smaller than expected proportion of disabled women and no data on the quality of care or outcomes, but they still emphasise the importance of training all health workers on this topic.

7 QUALITATIVE STUDY CONTEXT AND METHODS

7.1 CHAPTER PURPOSE

While other chapters have helped advance understanding of existing training and improving the prioritisation of training, the following section provides evidence from existing training to inform improvements to training methods, operationality, and impact. This section builds on previous chapters to understand the context of training by examining trainer and trainee's experiences of an existing training intervention, to understand what may influence effects of the training and what could be improved. By understanding these perspectives, it may help to inform the development, implementation, and evaluation of future trainings.

The following chapters describe a qualitative study in Ghana, and this chapter provides the relevant background on Ghana, the training intervention discussed, and other study practicalities (i.e., methods, ethics, etc.).

7.2 BACKGROUND

Other literature has highlighted that more progress is needed to improve the sexual and reproductive health rights (SRHR) of disabled women.^{54,95,208} Indeed, many studies have noted that disabled women are widely ignored in SRH research, reflecting the erroneous belief that disabled people are asexual.^{54,63,224,225} While there has been greater attention to addressing the stigma disabled people face in accessing SRH, there are still gaps in health policies and research.²²⁴ At the seminal 1994 International Conference on Population and Development (ICPD) in Cairo, there was increasing emphasis on extending SRH and family planning policies to better include disabled people²²⁶ and recent ICPDs have also identified the lack of health worker training on disability and SRH as a major barrier to full implementation of disabled peoples' SRHR.²²⁷ Furthermore, even where there is disability training for health workers included in laws and policies (Chapter 2), the text usually focuses on a broader definition of disability, not specifically focused on SRH care. Despite the sizable population of disabled people globally, health professional's curricula are often unsystematic

and insufficient with regards to disability training, particularly on SRHR.^{95,228} Accordingly, health workforces often lack the adequate knowledge and skills to deliver high-quality SRH care to disabled people. The omission from training and national policies on SRH improvement creates a notable gap in care for disabled women.²²⁴ As population ageing, climate change, disease transition, and conflict increase the prevalence of disability, the lack of health workers adequately trained on disability and SRH is an increasingly important barrier to achieving high-quality SRH care for all and other global health goals.¹⁹⁶

Ghana, however, has emerged as a leader on research and health worker training on disability and SRH in sub-Saharan Africa, because of the training pilots described in this chapter. The 2010 Population and Housing Census estimates that 737, 743 people are disabled in Ghana—approximately 3% of the population.²²⁹ Other estimates suggest the true prevalence of disability is closer to 7-12% of the population, or 1.55 to 2.2 million people,²³⁰ though prevalence varies across different demographic groups. Disability prevalence is higher among women (10.6%) than men (6.2%).²³⁰ For women of reproductive age (15-49 years), the prevalence of disability is 10.2%.²³¹ While there is diversity within disability, the most common impairment types are physical, visual, and hearing/speech impairments.^{229,230}

Recognizing this gap in health worker training, the Government of Ghana has included disability training for health workers as part of its disability laws, the Persons with Disability Act, 2006, as discussed in Chapter 2.²³² Article 32 states:

“The Ministry of Health shall include the study of disability and disability related issues in the curricula of training institutions for health professionals to develop appropriate human resources to provide general and specialised rehabilitation services.”

Substantial research has been conducted on disability and SRH for disabled people, including piloting several trainings on disability and SRH for health workers. Most of this work has been done academically, as recent study of key health documents found that governments have done little to advance disabled peoples’ SRH in the past thirty years since ICPD, including on training.²²⁴ The

study showed key health documents had limited considerations for inclusion, such as accessibility of outreach and documents, budget to conduct training, and explicit mentions of disability in policies, which has hampered improvements in SRH for disabled women.²²⁴ For training specifically, the lack of specificity has resulted in an implementation gap, as relevant authorities and health worker training schools have not delivered on their obligations under the Ghana Disability Act.^{54,232} Therefore, most training for health workers happens outside of government-focused programs, with academic institutions and Disabled Persons Organisations (DPOs) leading the development and implementation of disability and SRH training for health workers.

7.2.1 DESCRIPTION OF THE UNIVERSITY OF GHANA TRAINING

Since 2017, researchers at the University of Ghana have been involved in developing and delivering a disability and SRH training for in-service health workers through various grants. The training aimed to improve Ghana Health Service frontline health workers' understanding of disability and skills to provide family planning and contraceptive services for disabled women and girls. The training was delivered as a one-off two-day course in the Northern District for over 300 health workers either in 2017 or 2021. The course introduced disability, disabled peoples' rights, and addressed common misconceptions about disabled people. Facilitators also spoke about SRH through a disability lens, including discussing appropriate accommodations for exams, possible contra-indications based on impairments, and appropriate maternal care. Theory-based lectures, role-play and simulations, and disabled people sharing their experiences were the main methods used in the trainings. The success of the course was initially evaluated using pre-intervention, post-intervention, and follow-up surveys.⁹⁵ However, there have been no in-depth interviews about what trainees and trainers think of the training, its lasting impact, or how others can learn from this example to improve disability trainings in other contexts. Therefore, in Chapters 8 and 9, I report findings from thematic analysis of semi-structured qualitative interviews with trainees and trainers (including representatives from DPOs, NGOs, government officials, etc.)

7.3 STUDY SETTING

The study was conducted in several settings across Ghana. First, I interviewed key stakeholders in Accra (Greater Accra Region) and Kumasi (Ashanti Region) who had been trainers on previous courses on disability and SRH training, as well as two trainees who took part in a week-long placement at a school for disabled children. The trainers who were interviewed as part of this stage had taken part in a broad array of disability trainings, while all trainees took part in the same training. To interview health workers who had been through the specific disability training run by the University of Ghana, I went to Savelugu District (Northern Region) and Buiepe (Savanah Region) (Figure 7.1) where there were several trainers and trainees who had been involved.

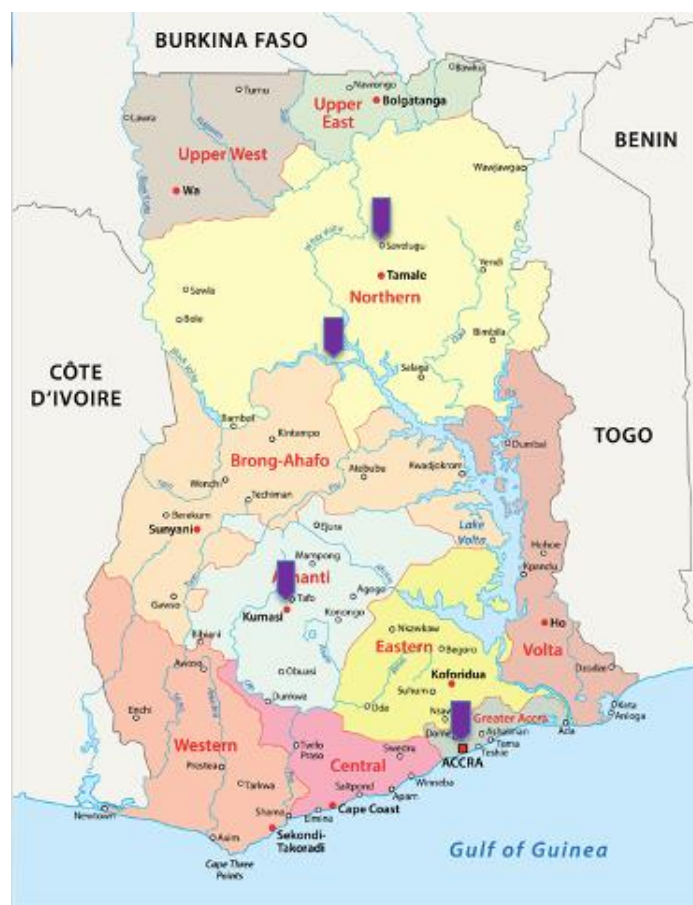


Figure 7.1: Map of Ghana Regions and Interview Locations

7.4 STUDY DESIGN

In-depth, semi-structured interviews were chosen for this study, as they generated rich, detailed data about peoples' perspectives on training. These interviews were audio recorded and transcribed

verbatim before being coded and thematically analysed, as described below (see Section 7.7 Data Analysis).

7.5 STUDY PARTICIPANTS

Interview participants came from two groups: i) trainers and ii) trainees. Trainers included anyone who has been involved in designing and/ or providing a disability training for any cadre of health worker. Trainers included disabled people aged 18 years or older from government agencies such as the Ghana Health Service; DPO representatives; health workers; NGOs; and academics. Trainees were from any cadre of health worker (qualified or in-training), whose role maps onto the WHO classification of health workers, who had been involved in the University of Ghana training about disability in 2017 or 2021. These two groups represent key stakeholders for health worker training on disability and may provide insights into how to improve it further.

7.6 SAMPLING AND RECRUITMENT OF PARTICIPANTS

Given the qualitative nature of this research, the sample size was dictated by saturation of data within the key analytic themes rather than a target sample size. Notwithstanding, I endeavoured to interview approximately 30-40 individuals to collate perspectives from a broad array of stakeholders. Mason showed that qualitative PhD studies had a mean of 31 interviews and recommended that the minimum acceptable sample is 15.²³³ This is echoed by Guest et al. who showed that saturation on a single question is usually reached after 12 interviews.²³⁴ Since this study is looking at two distinct groups, health workers and stakeholders, 30-40 interview participants allow for at least 15-20 interviews in each group.

In total, I conducted 32 interviews with 33 participants (including one joint interview). To capture diverse interview participants, purposeful, snowballing, and convenience sampling methods were used to sample and recruit interview participants. For instance, I approached the Ghana Health Services, DPOs, NGOs and other individuals affiliated with universities and hospitals who we knew had undertaken training and asked them to participate in the study. I was also given previous training

rosters and contacted people who had previously attended the training. Several trainers also identified training participants and contacted them for interviews, which allowed me to source individuals beyond the list of training participants provided by the University of Ghana. This sampling approach meant I was able to interview nearly all training participants in these districts, reducing the risk of only having training participants who were recommended since they could provide positive feedback on the training they attended. However, since the training had been conducted at least a year before the interview, some trainees were no longer working in the districts I visited and were therefore not invited to participate.

7.7 DATA COLLECTION

Semi-structured interviews were conducted in February 2023 and were all in-person, apart from one interview, which was conducted via WhatsApp audio call. Interview questions were devised in two parts: 1) the training they attended/led and 2) the improvements/recommendations they would make for others trying to implement training. A semi-structured interview guide was designed to last 20-30 minutes (Appendix 11 and Appendix 12) was used. Interviews were conducted with the interview participant directly in English and with the appropriate accessibility measures in place (i.e., sign language interpreter for one interview). My North American accent was difficult to understand for some interview participants, and so for some interviews another interviewee sat in to provide clarification. With consent, interviews were audio recorded and transcribed.

7.8 DATA ANALYSIS

Data were analysed using thematic analysis, as outlined by Ziebland and McPherson.²³⁵ Thematic analysis was chosen, as it provided a rigorous method for capturing the underlying meaning within the data and easily comparing and contrasting different participants' experiences with training. Audio recordings were transcribed verbatim. Next, these transcripts were checked against the recording for accuracy. The transcripts were then coded in NVivo, a software package to help organize qualitative data analysis. Codes were developed inductively within the data, as well as drawing on the literature and the researcher's understanding of the topic, to group similar

perspectives that recurred in the data, such as training frequency, methods, and learnings. The transcripts were read multiple times to ensure the coding was consistent throughout the data. The ‘One Sheet of Paper’ method was used to organise each coding extract to summarise the content of the codes and identify patterns across the codes to develop themes inductively within the data. This analysis was guided by the overarching question: “what do stakeholders think about the disability training for health workers in which they have been involved?”, as well as existing literature and prior knowledge. Themes that were similar were combined or grouped into sub-themes, if they pertained to certain groups or sub-sets of data (i.e., disabled persons’ organisation’s role and the cost of training were combined since they both pointed to how these organisations struggled with the informality of training). Throughout the analysis process, I reflected on my personal views, values, and positionality, to challenge any assumptions I was making within the data. The final themes were then drafted and checked by supervisors (SRy and SZ) and rearranged for greater clarity and flow.

7.9 ETHICAL CONSIDERATIONS

7.9.1 ETHICAL APPROVAL

The study was approved by the Oxford Tropical Research Ethics Committee (OxTREC Reference: 534-22) at the University of Oxford (Appendix 9) and the Ghana Health Service Ethics Review Committee (Reference: GHS-ERC 005/12/22) (Appendix 10).

7.9.2 INFORMED CONSENT

Each study participant was given a participant information sheet and consent form before the interview began. These documents (Appendix 13 and Appendix 14) covered the rationale of the study, procedures, and potential benefits and risks. All information was reviewed with interview participants before beginning the interview. Consent forms were distributed and signed by interview participants either in-person or via email. The records were scanned and stored in a secure cloud location.

Participation was voluntary, and participants could choose to withdraw consent at any time from their interview, without any negative personal consequences. During the process, participants were reminded that they could refuse to answer any question.

7.9.3 CONFIDENTIALITY AND DATA MANAGEMENT

Study participants were assigned an anonymized ID number and not identified by name in interview recordings, transcripts, or other documentation. All study records are kept in an encrypted folder and consent forms, or other non-digitized documents were scanned and uploaded. The list linking participant IDs and source records was kept in a password-protected file in a separate digital folder. Any publications that arise from this research will ensure participants are only identified by their anonymous ID. Records of consent and contact details for research purposes were stored on a password protected, University IT network and deleted from the device. Audio recordings of the interviews were downloaded and then transferred from the local computer to the secure University IT network as above.

7.9.4 COMPENSATION

Participants were not paid for their interview and no incentives were offered. Since I travelled to interview each participant, travel expenses were not offered.

7.10 REFLEXIVITY AND POSITIONALITY

All interview participants were aware that I was a white, North American woman. I introduced myself as a DPhil student at the University of Oxford conducting research on disability training for health workers. As some interview participants were connected through my former employer, the World Bank, they were aware of my professional background, and some also said they had Googled me. These factors, in addition to the fact that interview participants knew the original funding for the training pilot was provided by a UK-based organisation, may have impacted the dynamic of interviews.

The impact of these dynamics can be both positive and negative. For example, as a white woman coming from a UK university and having little connection to organisations within Ghana, there may have been some bias towards offering more positive perspectives, as this connection may have had interview participants thinking positive answers may result in future funding for their programmes. This is a potential source of bias, as participants were aware previous funding for the programme came from the UK. However, my status as an outsider may have also made interview participants more comfortable in openly discussing the shortcomings of the Ghanaian training system. Similarly, not revealing my personal disability status may have made certain interview participants—particularly non-disabled health workers—more open about their attitudes towards disabled people, whereas disabled people and DPO members may have felt more comfortable and open, if they had known I was also disabled. My personal interest in this topic often came up in post-interview conversations and disabled participants often seemed more enthusiastic and willing to engage afterwards because of this connection, making me reflect on whether it would have been good to share this in my self-introduction.

The decision to travel to Ghana to conduct the interviews in-person provided invaluable context and is especially helpful in counteracting some of the potential cultural or contextual factors I may have otherwise overlooked. For example, the Accra Rehabilitation Centre hosts all the main DPO offices, allowing for easy collaboration and communication between various DPOs. Without visiting these offices in-person, I might have not realized the proximity nor how they function together for greater advocacy, particularly on advocating for more health worker training. Similarly, choosing to travel by car across the country also helped me to understand the local variations in health system delivery. For instance, in Accra, I visited health workers at large regional hospitals, while in Savelugu, I visited health workers in Community Health Planning and Services (CHPS) compounds. Seeing the variation in size and geographic distribution also helped contextualize the diversity of settings and potential challenges in scaling training across these settings.

8 PERSPECTIVES ON HEALTH WORKER TRAINING ON DISABILITY IN GHANA

8.1 CHAPTER PURPOSE

This chapter examines trainers and trainees' perspectives on the health worker training in which they have been involved. This chapter helps identify the major challenges with existing training and how to improve future training initiatives.

8.2 INTRODUCTION

The study context (Chapter 7) highlights both the legal requirements and the need to train health workers on disability in Ghana. There have been several one-off interventions to train health workers on disability, but most are either undocumented in the literature or have long-term evaluations.¹⁸⁰ The unsystematic, informal nature of disability training, despite legal requirements, makes Ghana an interesting location in which to examine what other countries can do to improve their efforts to develop disability training for health workers. An analysis of in-depth qualitative interviews with trainers and trainers led me to identify several themes related to disability and SRH health worker training in Ghana. As described in Chapter 7, the aim was to understand how to improve disability and SRH training for health workers by understanding health worker and other key stakeholders' perspectives on current training on SRH and disability.

8.3 METHODS

The methods used in this chapter are described fully in Chapter 7. In brief, 32 qualitative interviews were conducted by SR in February 2023 in Ghana. Interviews were transcribed verbatim and coded inductively. The data were analysed using thematic analysis guided by the overarching question: “what do stakeholders think about the disability training for health workers in which they have been involved?”.

8.4 STUDY PARTICIPANTS

I interviewed 17 women (Table 8.1: 51.5%) and 16 men (48.5%), with most coming from the Ghana Health Service or disabled persons organisations (DPOs). Of the 19 health workers I interviewed, there was diversity of cadre, though most were community health nurses. The distribution of trainers and participants was even (17 vs. 16, respectively) and the sample included several disabled participants (9, 27.3%).

Table 8.1: Participant Characteristics

N	33
Gender, n (%)	
Female	17 (51.)
Male	16 (48.5)
Place of employment, n (%)	
Ghana Health Service	18 (54.5)
DPO	7 (21.2)
Academia	4 (12.1)
Hospital	2 (6.1)
Government	1 (3.0)
NGO	1 (3.0)
Health worker cadre (n=19), n (%)	
Community Health Nurse	6 (31.5)
Health Volunteer	4 (21.1)
Community Health Officer	2 (10.5)
Midwife	2 (10.5)
Paediatric Nursing Resident	2 (10.5)
Municipal Public Health Nurse	2 (10.5)
District Director	1 (5.3)
Role in training, n (%)	
Trainer	17 (51.5)
Trainee	16 (48.5)
Disability status, n (%)	
Non-disabled	24 (72.7)
Disabled	9 (27.3)

8.5 FINDINGS

Participants generally reported being pleased with the training they received but suggested it should come sooner in a health workers' educational journey. Overall, they expressed several ideas for models of good training and suggestions for improvements. While questions discussed all aspects of the trainings and the nexus of disability and SRH training, most participants spoke separately about the disability and SRH aspects, making the bulk of results relevant to general disability training, rather than disability and SRH-specific training.

8.5.1 CHALLENGES WITH TRAINING

Participants expressed several concerns with the status quo of disability training for health workers in Ghana, namely with regards to the insufficiency, informality, sign language requirements, cost, and lack of coordination to deliver current approaches to training.

8.5.1.1 INSUFFICIENCY OF CURRENT TRAINING APPROACHES

Most trainers and trainees had been involved in a training for continuing professional development (CPD). However, depending on the health workers' cadre and school, initial basic disability training varied considerably. The below quotes from a midwife and two nurses demonstrate the variation in training programmes.

“In midwifery, it is kind of in passing. You are there to learn things about the gynaecological conditions...they just mention it... [disabled people] are not the majority group in the population so much was not mentioned.” – Trainee 7, Female, Midwife

“Yes, it was actually in the nursing education we had. There was a topic on disability – how to identify a disabled person, their weaknesses, and strengths, how to rehabilitate them. But you know because those are always sub-topics, they are not going to really make it so lengthy” – Trainee 16, Female, Community Health Nurse

“Interviewer: Did you learn about disability in your curriculum?”

Interview Participant: Actually no, I didn't learn.” – Trainee 14, Female, Community Health Nurse

These quotes highlight the variation that leaves some frontline health workers with inadequate training, despite often serving as the main gatekeepers for accessing other health services. In

particular, the variation in nurses' responses—one saying it was mentioned, another saying it was included as a sub-topic and another that there was none—suggests that the amount of training varies depending on the institution attended or that it is too limited to remember.

8.5.1.2 CONSEQUENCES OF INFORMALITY

Several interview participants also highlighted that the lack of integration into the curriculum and it was difficult to implement as sessions were run outside of a formal role. Rather, most participants volunteered their time or had small grants to support the initiative. Trainings were ad-hoc and unsystematic, often run by individuals or DPOs who had some professional knowledge or lived experience, making them an informal aspect of the health education system. Most trainers raised that cost was a substantial challenge in organising training, particularly since most participants were coming to the major city in the district from various sub-districts and venue, food, lodging, and transportation had to be arranged. Some felt that delivery was impacted by the costs:

“I think it is the resources that was making it difficult for us because when you bring them [to Tamale], some are far. They can't come and go that same day. Because of that we just have to hurry up. We start early so they can go home, but I wish we would have been able to extend the training days” – Trainer 11, Female, Public Health Nurse

Interview participants also spoke about the challenge of sustainable funding for training. For example, in one programme interview participants discussed, training was part of an integrated intervention, where participating health volunteers were given motorbikes to help improve disabled peoples' access to health and transportation to health facilities. However, when the programme ended, health volunteers lost access to their motorbikes, as there was no funding available to continue the program. This had consequences for both health volunteers and disabled people who had benefitted from the programme:

“Even up to now they are calling, ‘are you people coming to, are you coming again?’ We say, ‘oh no, the project has ended, so maybe unless our boss says we should start again.’ So, they are complaining because some of them, when they want to go to hospital, they will call you ‘Oh can I get help from you to send me to hospital’ so if the program continues it would have been good.” – Trainee 5, Male, Health Volunteer

Moreover, many trainers noted that the lack of formal recognition from the health education system made it frustrating and difficult to attract attendees outside of their clinical responsibilities. Some DPOs also noted it was hard to get responses when they wanted to run trainings because of this lack of integration:

“We sent a letter to [name of hospital] saying we want to come in and offer trainings. They’ve never responded. But I also noticed that when the letters are coming from their top bosses, quickly you get a slot to talk about it. So, can we have this very formalized where we know that ‘ooh okay this is a letter coming from Ministry of Health that [name of organisation] will be doing a training?’ I think that works, instead of us writing to them directly because sometimes it has to go through a certain process, and you wait, and you get tired, and you stop. So, if you can formalize the trainings that will be useful.” – Trainer 5, Female, NGO

While several participants highlighted the organisation challenges with informal trainings delivered on an ad-hoc basis, some felt that even when the training had been co-organised with the Ghana Health Service, there was a lack of formality that impacted how the training was evaluated:

“After the training what happens next? Were you able to follow up? Do we really have somebody charged and supported to ensure that the discussion is moved forward? That is a big deficit...so most of the trainings we do—not just on disability—appears to end on the shelf or the training room, even including guidelines that we developed.” – Trainer 2, Male, Ghana Health Service

These extracts highlight that the informality of training leads to challenges with transportation, costs, recognition, timelines, and evaluation. In particular, trainers said that these challenges affected their ability to conduct more training or reach a broader audience of health workers.

8.5.1.3 SIGN LANGUAGE IMPLEMENTATION

Many participants also discussed recent efforts to teach sign language to increase communication skills for health workers in Ghana, which was some trainees only exposure to prior disability training. However, without formal implementation, the approach was not seen as likely to achieve the goal of expanding communication skills for d/Deaf patients. For example, many health workers said that they had learned basic sign language, but without incentives nor opportunities to practice, often

forgot the skills they learned. This was echoed by a trainer who questioned the time and financial investment he put into training health workers:

“We finished the training for 6 months for mental health nurses and I went to the psychiatric hospital... communicating only in sign language. I could not get a single nurse who could understand my language. So, the question I was asking myself was ‘why did the person come here to spend six months after the lunch, after the water, after the refreshment and coming every week for six good months – 24 weeks – and you still cannot communicate in the basic sign language?’. You are really not helping the institution.” – Trainer 6, Male, Disabled Persons Organisation

This shows the need for a more comprehensive approach to maintaining skills if the goal is to have all health workers capable of communicating in sign language. For instance, one participant shared that they were studying sign-language again after forgetting the little they had learned in school:

“We did sign language in school but not into detail, you know as students we were doing it just to pass our exams and go. But, coming on the field, you realise that you really need the sign language to be able to communicate with them, so I think yes, I am now learning it currently.” – Trainee 15, Female, Community Health Officer

These extracts demonstrate there are efforts to improve sign language capabilities but recognize the challenges of scaling up sign language learning for all health workers, particularly if it is not embedded in practice or examined as part of competency and licensing requirements.

8.5.2 SUGGESTED IMPROVEMENTS FOR TRAINING

Participants also highlighted various aspects of the training that worked well or could be improved. Trainers and trainees said that more external motivation, collaborative approaches to training, disability-led training, and embedding the training in the health worker curriculums could support increased uptake and efficiency.

8.5.2.1 EXTERNAL MOTIVATION

Several trainees who had been part of the integrated intervention said that the motorbikes they were provided were effective motivators for them to provide services. They felt it not only helped them better provide services and access both clients and facilities, but it also served as an important recognition of their work and role in the community. The loss of the motorbike after the programme finished made it difficult for them to complete their jobs and took away any incentives or transport

to visit disabled people at their homes. Several participants noted that having some form of formal evaluation or incentive for sign language would motivate trainees to attend more training:

“Those with sign language should attract some sort of allowance, you know, additional allowance and it will serve as an inducement.” – Trainer 16, Female, Government

These tangible incentives were seen as useful tools to facilitate better uptake of health worker training and delivery. In addition, many participants mentioned that having more policy-focused incentives would be useful. For example, some participants suggested having a training course on disability as part of the licensing requirement or annual CPD requirements for recertification for professional development. Overall, monetary, transport, and certification-focused incentives were seen by participants as being effective tools to improve the uptake of and incentives for health worker training on disability. Moreover, the strategy to select two participants from each facility also seemed to have an effect on participants’ motivation and interest in the training. Many participants shared that they felt ‘special’ to have been chosen to learn about disability and be empowered to train others about the knowledge they gained at the training. While this method of selection was not intended to have this impact, it is interesting to note that this selection method may have played a role in motivating participants, as well.

8.5.2.2 COLLABORATIVE EFFORTS TO HELP IMPROVE QUALITY

Several trainers had been involved in developing their own curricula and targeting specific organisations to train their health workers. In approaching training this way, they identified two areas where collaborative approaches could strengthen their efforts.

Firstly, many trainers from DPOs mentioned that working with the Ghana Health Service or subject-matter experts would lend more credibility and health expertise to their training:

“I don’t have a health background so that aspect is given to those with health background to do...the aspect that we bring on board is to let them understand the peculiar nature of disabled people and the fact that they need to be extra careful, and they need to be able to give them the necessary support that they need.” – Trainer 1, Male, DPO

Similarly, many participants from other organisations noted the importance of disabled people leading the training to lend their lived experience and provide some credibility to the content.

Secondly, for organisations that did not have the capacity to do important practical learning (i.e., patient simulations, role play, etc.), they felt it was necessary to have a more collaborative approach. By partnering with health institutions, they felt they could provide better exposure to disabled people and solidify the learning from classroom-based teaching, but this was hard to coordinate without formal partnerships and funding.

Finally, several participants noted that one of the expectations of attending the training was that the health workers would share their learnings with those who had not attended. This created an informal community of practice to share learnings about disability, but several participants noted it would be good to have formalized this. Some trainings had included some trainees who had been through a similar training a few years before. These facilitators noted that this had not only enabled them to solidify their skills, but also showed that health workers could help to train their peers:

“Those who were trained first became coaches, or let me say facilitators, in the second training. They were now remembering some of the things and teaching those who are just new...they will just come demonstrate and roleplay whatever they learned previously. If there is anything to add, then [the training leaders] show.” – Trainer 12, Male, Municipal Public Health Nurse

Using a train-the-trainer approach could facilitate more regularity and reach of training for health workers. However, what is most salient is that neither DPOs nor other training organisations (NGOs, academic institutions, government, etc.) said they could adequately implement training without the other, showing the need to collaborate to facilitate health worker training.

8.5.2.3 HEALTH WORKERS WANT DISABILITY IN THEIR CURRICULA

Finally, many health workers suggested that the training was effective, but said that their experience in training made them realise that disability needed to be included more regularly in their curricula. Many saw this as important to not only reach this population, but also to ensure that training reaches all health workers rather than relying on a few, who might not be available when needed:

“Every stakeholder involved in health service delivery should have knowledge [on disability] so that at least if the health worker is not there, the volunteer can take charge. What will build a healthy community instead of just picking a smaller figure in case that person you have trained one person is not there, otherwise, what happens? The disabled person goes back to the same situation he or she was in.” – Trainee 5, Female, Community Health Nurse

While there was overall agreement that there should be some curriculum integration, there were different ideas of what would facilitate the best learning. For example, some interview participants thought that one course on disability during the training would be sufficient, while others thought there should be different levels, evaluated for each year of training. Interestingly, other interview participants, like the following trainer, thought disability should be central to all training and content, including SRH training:

“Let them know about the intricacies, you know what [contraceptive] methods they can use what not they cannot use and a little bit about the challenges that might come with that, so that we will be able to give them proper counselling. For instance, somebody will prefer to use a condom, but she doesn’t have dexterity, so she cannot do it alone, but the partner could do that so that you will want to know whether your partner will be willing to play that role you know for you...if we are able to integrate it, into the curriculum like this, then at every point in the curriculum, we look at what will be applicable to people with disability, then we deal with it so that it becomes like we are not doing anything peculiar – it is just part of the normal things that we do.” – Trainer 14, Male, Academic Physician

The suggestion to integrate specific impairments as part of talking about medical contra-indications presents a new lens with which to integrate and normalise talking about disability into the curriculum. These reflections show the various approaches to disability inclusion in health worker education, but overall highlight the need for more systematic integration into the curriculum.

8.5.3 THEORY OF CHANGE MODEL

Trainers and trainees said they were pleased with the approach used to deliver health worker training and frequently elaborated on how the methods used were intended to develop (trainers) or did develop (trainees) effective skills. Using deductive and inductive methods, I then developed a theory of change model (Table 8.2) to explore what methods and aspects of training appeared to support acceptable and effective training. The model shows the different elements of training that were included in each interview participant’s description of training and validated through comparison

Table 8.2: Training Methods Theory of Change

Content + Methods – Training inputs	Rationale	Intended outcome
Review laws and policies	• Establish importance and rights of disabled people. • Set requirement for quality care	• Change behaviour towards disabled people to adhere to laws and deliver rights
Exposure to disabled people	• Some health care workers may have never (knowingly) met a disabled person before outside their clinical role. • Cultural beliefs and stigma • Some trainees may have beliefs that disabled people are ‘cursed’ or that disability is ‘contagious’	• Challenge stigma, attitudes, and beliefs
Role play and simulations	• Build confidence in interactions, empathy and understanding. • Practice “bad” and “good interactions in a safe space, with feedback for improvement	• Greater empathy • Better interactions
Videos and case studies	• Demonstrate tangible barriers and scenarios for intervention	• Greater understanding
Practical skills (i.e., lifts, sighted guiding, etc.)	• Not covered in most health worker training • Provide support in an empowering way, not making assumptions about need for support	• More supportive interactions
Sign language and communication skills	• Develop tools to communicate with patients. • Provide greater privacy to disabled people	• Better communication • More privacy
Lived experience lectures	• Enhance understanding of disability and barriers to health care • Understand the role of health workers in good-quality health care	• Better understanding of disability and disabled people
Manuals and resources	• Support learning outside the classroom • Help learn how to approach similar situations on the go. • Reinforce appropriate language	• Continuous learning on disability
Community of Practice	• Build connections between facilities. • Share learnings of ‘what works and positive impact stories	• Refresh skills on disability • Adopt a ‘train-the-trainer’ approach

with key methods identified in the systematic review (Chapter 3). The second column highlights why the rationale should be effective in developing health workers skills, largely developed through interview participants' perspectives on why they enjoyed certain aspects of training, as well as reflections from the systematic review papers (Chapter 3), and other reflections on why this might work. Finally, the third column shows the trainers intended outcome and competency for health workers by element. These results highlight that each component of training has a particular role in building health worker competencies for disability.

8.6 DISCUSSION

These findings show that there are several aspects of existing disability training in Ghana from which other institutions and countries can learn. This chapter discusses the various perspectives on current training, including the challenges, improvements, and methods, that may help lever change for training participants. It is the first study to examine trainers and trainees' perspectives on disability training for health workers in Ghana. There is a dearth of evidence examining how existing training can inform improvements in disability training for health workers, aside from the description of trainings themselves, making it difficult to compare these findings with other literature. However, these findings have implications for how training is implemented, incentives for attending training, and informing design of future training interventions and research.

Overall, these results suggest more attention to disability may be needed in the curriculum. The interviews with trainers suggest that existing training in Ghana is mainly delivered through ad-hoc initiatives, rather than concerted, systematic, and/or government-led efforts. This was one of the surprising findings of this study, as Ghana has committed to training health workers in its disability laws, as discussed in Chapter 2, yet there seems to be a gap in implementation. While disability training for health workers is not the only gap in implanting disability laws, improving integration of these trainings was seen by interview participants as an important step towards full implementation of the law. Several trainers expressed frustration at the sporadic and unequal efforts because of the lack of government leadership in funding disability training within health worker

curricula and attaching various policy levers to facilitate its implementation. However, the suggestion to move towards curriculum integration diverges from what other countries have done to implement health worker training systematically. For example, in the UK, the government has enacted a mandatory program (The Oliver MacGowan Mandatory Training on Learning Disabilities and Autism) for all health and social care staff to take as part of CPD requirements.¹³⁰ Similarly, Australia has released a national roadmap for people with intellectual disabilities, which will include developing a required curriculum on intellectual disability for health workers,²³⁶ building on evidence that there has not been sufficient inclusion in curricula to date.²³⁷ While many participants in this study said that training was important, some suggested that forcing people to do extra training would not yield effective uptake of the skills learned. Instead, integrating it into the curriculum as a lens (like adolescent health or gender) could be more acceptable. This could also help with the sustainability of funding and greater coordination—two substantial barriers to full implementation of the training. Therefore, Ghana and other countries may want to consider these approaches for upskilling health workers, rather than the ad-hoc or mandatory disability-specific CPD courses.

Moreover, interview participants highlighted that more policy levers, such as sign language incentives or CPD credits might also facilitate better training, but it is important to note that this may be more appropriate for the current system of ad-hoc training. For instance, CPD credits might be best to incentivise current health workers with no background on disability training to be trained on disability, but that might not be an appropriate incentive once disability is integrated into the curriculum for all health workers. Therefore, more understanding of the impacts of integrating disability into the curriculum will be needed, and any plans for integration should be coupled with appropriate evaluation plans.

Finally, the theory of change model and perspectives on training presented in this chapter largely echo the literature surrounding disability competencies in the US^{80,83} and India.²³⁸ That is, many of the suggested methods and curriculum integration would be captured through developing a core set of competencies to which curricula adhered. While there are some benefits to developing these competencies at a country-level, such an approach would replicate the unsystematic nature of

training at a macro-level, with few similarities between countries. In an era where health workers are more mobile than ever,²³⁹ there is also benefit in developing global standards to ensure similar competencies between all health workers.

8.6.1 STRENGTHS AND LIMITATIONS

While most other studies have described the immediate impact of training, this study is the first to document trainers and trainees' views about the successful aspects of training and areas for improvement. Some studies have tried to appraise training programmes, but it is predominantly through scoping reviews, rather than in-depth interviews with those who have delivered or taken part in training.^{240,241} By interviewing trainers from a variety of trainings, backgrounds, and geographic locations, I was able to access diverse perspectives on training initiatives across Ghana.

However, since the study was only conducted in Ghana, the findings may not be applicable to every context, particularly where the clinical education system differs. While I tried to attract a diverse sample, most health workers interviewed for this study had taken part in the same training and those who had not moved out of the region, which may limit the broader applicability of these findings. To understand the full perspectives on training, it may have been useful to interview some of the non-attendees, as well as observe the training to understand the training fully compared to trainers and trainees accounts. Finally, while the study sought to understand the important components of a disability training on SRH, most individuals commented only on the disability aspect of the training, rather than both components hampering my ability to comment specifically on disability and SRH training.

8.7 CONCLUSION

These findings show that there are several aspects of existing disability training in Ghana relevant to improve future disability training. First, there are several barriers to implementing training, mostly related to the insufficiency of existing training through the lack of formality, costs and sustainable funding, evaluation, and poor sign language implementation. Potential improvements interview participants suggested included: incentives, strong collaboration and coordination, and better

curricula integration can help facilitate better disability training for health workers. In addition, using a combination of teaching methods that have a clear link to the goals of the training will support better training in the future. Ultimately, these results highlight the need to take action to adapt and implement disability training interventions that learn from these barriers, facilitators, and theory of change. By integrating disability training into curricula, health workers will have more opportunities to improve their skills and familiarity with disability.

9 THE IMPACT OF DISABILITY TRAINING FOR HEALTH WORKERS

9.1 CHAPTER PURPOSE

This chapter expands on Chapter 8 by characterising the impact of disability training for health workers, as described by those involved in health worker training. Since existing literature (Chapter 3) often omits these detailed accounts, this helps further contextualise the success of disability training (Chapter 8) and consolidate recommendations for future training initiatives.

9.2 INTRODUCTION

Health workers and trainers described several ways in which training had a substantial impact on their attitudes and actions towards disabled people. Chapter 3 discussed the literature showing the impact of health worker training on attitudes towards disabled people,^{180,242,243} but few qualitative studies have explored health workers' perceptions about the perceived impact of the training. One of the key themes emerging from the analysis of the interview data is the role of social change and empowerment.

9.3 FINDINGS

9.3.1 AWARENESS RAISING TO ADDRESS STIGMA AND HUMAN RIGHTS

Trainees spoke extensively about how their training helped raise their awareness of disabled people. Trainees also remarked (without prompting) that the training increased their understanding of the barriers disabled people faced in accessing healthcare; that disabled people were 'just like' them; that disabled people have equal human rights; and that anyone could become disabled at any time. Interview participants described changes in their attitudes and behaviour towards disabled people. For example:

“For me it changed a lot because any time I saw [disabled people] sitting outside, I passed by before...Before the training, you go on your way. Me too, I will pass. Now, even if they come sitting outside around the facility, the clinic I ask them: ‘Hi, are you ok? Are you coming to me? What do you need from us?’ just to make them feel free that we are all one.”
– Trainee 7, Female, Midwife Officer

Several interview participants suggested that health workers were unaware of what they could do to provide more appropriate care to disabled people:

“When we were doing home visits, even though the disabled person is part of our home visits, we were not paying serious attention to them. But once we went through the training, we realised that the disabled person even needs more help than the normal people. So, we need to pay more attention to the disabled persons for them to really know why they need to do some of the things they should do to keep themselves ok.” – Trainee 16, Female, Community Health Nurse

The emphasis on the impact of the training in these extracts shows that awareness is an important component of behaviour change for health workers. Interview participants also suggested that health workers need to better understand how their attitudes and actions might reinforce stereotypes or stigma or be harmful in other ways. Several interview participants highlighted that it was especially important to avoid harmful language in their practice:

“Up here they will address them by your condition, like a fool or something, but I have been correcting my colleagues; don’t use the condition to address the person. The person has a name...I was also behaving the same before, but after the training I got to realise that it is not humane to address somebody by a condition or a disability.” – Trainee 9, Female, Midwife

Again, this echoes how training improved understanding and awareness about poor actions and attitudes and suggested that the impact of these learnings may have reached other health workers as well—not just those who participated in the training.

9.3.2 BROADER TRAINING—BEYOND HEALTH WORKERS IS NEEDED

Health workers also highlighted the need to expand disability training to wider society. Discriminatory and negative attitudes were largely due to societal norms towards disabled people. Government officials and other community leaders were singled out as stakeholders who could influence other community members. Some interview participants suggested broader training could

facilitate opportunities to have the training ‘rub off’ on health workers, while others noted the challenges involved:

“It is not easy organizing the people from the community...you have to be patient...you have to go into the community to talk about it because the communities’ perception about disability is a different thing. If you are able to go there, and talk, and capture and clean off that perception, then your health message will sell.” – Trainer 11, Female, Public Health Nurse

Many interview participants also noted that including disability awareness in the primary and secondary school curricula would further help this goal.

9.3.3 TRAINING IS IMPORTANT, BUT A BROADER FOCUS ON ACCESSIBILITY IS NEEDED

Similarly, trainers and trainees recognized the limitations of their training and reported frustration that they were not always able to implement the learning because of barriers for disabled people they could not address. For example, one interview participant said she learned about the barriers disabled people experience with healthcare, including physical access to the facility for wheelchair users. While some examples of training were part of an integrated intervention and provided funding to implement accessibility features, this was largely limited to ramps. One nurse said:

“I can’t use our family planning bed for a disabled person unless I assist the person to climb...it would help if the [accessible] equipment are bought” – Trainee 10, Female, Community Health Nurse

Therefore, trainees and trainers recognised that implementing the learnings from the training was not only inhibited by the lack of accessible facilities, but also that the training could not address all barriers to health for disabled people. Other interview participants said that accessibility was one of the next major aspects to address after training, since inaccessibility is a pervasive challenge:

“Ghana Health Service is working with the National Council of Persons with Disabilities to ensure promotion of health for persons with disabilities, but I will say that the key thing for us is to look at the accessibility because that is the only gap that divides the persons with disabilities from non-persons with disabilities - accessibility.” – Trainer 16, Female, Government Official

These extracts demonstrate how interview participants recognised that training was not enough, and more work around accessibility and awareness remains necessary. However, some trainers also reported that the health workers had been successful in making these structural changes after their training:

“When they visit the communities, they realize that there are issues of accessibility within the community. They try to talk to opinion leaders in the community so that they can develop interventions, environmental accessibility, and all that.” – Trainer 10, Male, Academic

This shows that the training may help to have health workers as a vehicle for the structural change needed at the community level to improve access to health facilities for disabled people.

9.3.4 HEALTHCARE WORKERS CAN BE EMPOWERED TO CHALLENGE SOCIAL NORMS

Finally, the interview accounts suggested that training might empower health workers to challenge social norms and act as advocates for disabled people. Raising awareness of the barriers disabled people face when accessing healthcare has resulted in increased awareness of accessibility among health workers. However, interview participants suggested this was not the only domain where the training could help healthcare workers to act as leaders on the rights of disabled people in their communities. One of the trainers recounted the following story:

“Right after training, [a health worker] was posted to a community, where she noticed that there were some disabled children in the house. They were supposed to be sent to school, but they had been kept in the house, hidden more or less by their parents because they don’t want the community to see them. When she got to hear this, she visited the parents and then spoke to them about the potentials some of these hidden children could have, if they were to send them to school. So, some of the health workers are able to convince these parents to bring the kids out and send them to special schools so that they can also receive education.”
– Trainer 10, Male, Academic

Another health worker spoke about how he had changed his own practice after the training:

“I kept it on myself as a task to kind of enlighten their immediate communities. Sometimes I go for home visits and when I encounter such a client, the first point of contact is persons who are in charge of such a client. I brief them as to what I know is the right way to take care of disabled people.” – Trainee 12, Male, Community Health Nurse

These examples highlight how the training might give health workers the confidence to act and advocate for the rights of disabled people in their communities.

9.4 DISCUSSION

Health worker training about disability may make a difference to raise awareness, challenging attitudes, and reducing stigma, as well as empowering training participants to be ‘disability champions’ within their communities. These findings align with the systematic review presented in Chapter 3 which highlighted the effects of disability training in improving health workers’ attitudes and awareness around the barriers for disabled people. However, this qualitative interview study adds a broader stakeholder perspective and provides trainee’s perspectives and accounts of how they changed attitudes and behaviour.

These results help demonstrate the self-reported changes in self-efficacy and behaviour health workers experience after receiving training in disability. This is an important finding, as these changed attitudes, awareness, and advocacy are a positive impact of training. However, the trainees highlight that disability-inclusion cannot be achieved with disability training alone, but there must also be shifts in the structural constraints that inhibit full inclusion of disabled people within health systems. These results should spur further action in-line with the social model of disability, as it emphasises the need to address these structural constraints in addition to attitudes and awareness. Therefore, efforts to pair training with other disability-inclusive health interventions, such as accessibility audits for health facilities is needed.²²

Moreover, interview participants suggested that there could be benefits to implementing the training in all educational settings. This could support a broader shift in societal attitudes towards disabled people, and perhaps be a tool to empower future health workers. Since environmental factors, such as attitudes and awareness, have significant impacts on individuals’ ability to seek care (as discussed in the Levesque Framework in Chapter 1),⁶⁶ this type of broader training could support disabled people’s connection to and use of health services. Given findings from Chapters 5 and 6 showed no

differences in where disabled people seek care for common childhood illnesses or maternal care compared to non-disabled people, these findings also reinforce the idea that a broader training is needed to reach all cadres of health workers and society at large. Other studies have shown that there are positive impacts on community attitudes when there is community-focused training on disability and SRH,²⁴⁴ reinforcing these findings that training needs to also include other community members.

However, training is not a ‘silver bullet’ to enacting societal change. Even where there is broader awareness and recognition of disabled peoples’ rights and efforts to improve accessibility, there is not necessarily better health access or care. For example, in the US, there have been various efforts to include disability in the general education curriculum²⁴⁵ and health centres must conform to the Americans with Disabilities Act standards, but this does not appear to have challenged a pervasive, systemic ableism in the health system.^{67,68,246} Therefore, the participants comments demonstrate training is necessary, but not sufficient to improve disability-inclusion in health systems. Interview participants’ comments emphasised how training should be implemented in concert with other system-level reforms to improve disability-inclusion. This is critical, as health workers desire to change after training could fade, if they continue to face the systemic barriers (i.e., inaccessible facilities) that hamper them from fully implementing their disability training.

9.4.1 STRENGTHS AND LIMITATIONS

This chapter provides novel insights into how people report the impact of their training after it has taken place. It provides further insight into how and why health worker ‘disability training’ may challenge attitudes and stigma against disabled people. However, this study also has several limitations. First, as a small qualitative study in one setting, this study may not be fully representative of the impact of other trainings on disability. Second, trainers may have had a vested interest in promoting the expansion of funded training, as it would be financially beneficial for their work. Since most trainees thought there needed to be more training, this was unlikely a large source of bias, but may have impacted some answers. Finally, the interviews include the health workers accounts of their attitudes and behaviours, but this may not fully align with their actual behaviour in practice. Further research should seek to elucidate the impact of training on disabled peoples’

experiences of healthcare, including how disabled people rate their care before and after health worker training.

9.5 CONCLUSIONS

Overall, this chapter offers new perspectives on how health workers perceive they have changed since undergoing training on disability. It suggests that health workers report changing on an individual level (i.e., in their actions), as well as understanding the system-level changes that would precipitate further inclusion of disabled people. It proposes that health workers may be empowered to promote disability and include disabled people within their community—a particularly important role when there are pervasive negative societal attitudes towards disabled people. While not an intended outcome of training, this evidence that training can precipitate societal change makes it a powerful tool for improving access to healthcare for disabled people. However, there is still substantial work that needs to be done in order to improve disability training for health workers. Ultimately, this was a pilot study that reached only a small percentage of all health workers in Ghana. For many, this was their first-time having disability training, even though evidence from Chapter 2 suggests there are legal requirements to have been trained at some point in their education and the findings from Chapters 5 and 6 suggest broader training is needed. Given the reported efficacy of the training and desire for more found in Chapters 8 and 9, it is clear that the current state of training is poor and more frequent and widespread training is needed to achieve better health for disabled people.

10 DISCUSSION AND CONCLUSION

Ultimately, health workers are humans. The strain on health systems globally during the COVID-19 pandemic has challenged the health workforce in numerous ways. Health workers are experiencing high workloads and levels of burnout, resulting in poor health workforce retention in health systems across the world.^{247,248} These complicated factors make it difficult to broach adding further training to health workers' workloads. However, intervention is necessary to deliver the right to health as the body of evidence around poor treatment of disabled people by health workers grows.^{67,68}

Health workers have substantial power in a patient-provider relationship. When health workers are dismissive, disrespectful, or abusive, they not only immediately harm the patient, but may also impact their future decision to seek care.⁶⁶ Therefore, putting patient-centred interactions at the forefront of care is a key component of improving health systems. Understanding how to train health workers about disability better may help facilitate this goal.

The question is: how do you change people's attitudes? If health workers enter the health sector to care for people who are sick, why do disabled people experience poor treatment? What works to change these pervasive attitudes, particularly in sub-Saharan Africa, where there are little documented about existing training interventions? There are several findings from this thesis that touch on these topics, as well as reinforce that these questions should guide future research.

10.1 SUMMARY OF FINDINGS

This thesis sought to inform how health worker training on disability could be improved, particularly in sub-Saharan Africa. Throughout the thesis, I used an array of methods to answer this question and its three main objectives: 1) to characterise existing interventions, 2) to recommend which health cadres should be prioritized for training based on demand for care and 3) to understand key stakeholders' perspectives on current training initiatives.

10.1.1 OBJECTIVE 1: TO CHARACTERISE EXISTING INTERVENTIONS

For the first objective, I looked at legal, policy, and academic literature to understand existing mandates and interventions to train health workers about disability. The legal and policy review (Chapter 2) found that the laws from the 13 countries examined could be grouped into three stages. Three countries had no laws or policies at all, three had documents from before 2000 and UN CRPD ratification, and the remaining seven had some clause related to UN CRPD language that recommended or required disability training for health workers as part of their laws and policies. Where countries also had national disability strategies or policies, these often elucidated more details on how these laws were enacted or enforced, but based on the laws, the evidence that there was sufficient integration into curricula and health worker licensing was weak.

The systematic review (Chapter 3) found a plethora of interventions to train health workers on disability. While the heterogeneity across outcomes, evaluation tools, study designs, and long-term follow-up hampered our ability to conduct a meta-analysis on the effects of each intervention method, there was some evidence that there are effective interventions to improve health workers' attitudes, awareness, competency, knowledge, confidence, and self-efficacy. It was clear, however, that these training programmes are highly localised, unequally distributed across continents, and unsystematically structured.

10.1.2 OBJECTIVE 2: TO RECOMMEND WHICH HEALTH WORKERS SHOULD BE PRIORITIZED FOR TRAINING

To recommend which health workers should be prioritized for training, I investigated care seeking behaviour of caregivers of disabled children and recently pregnant women to understand if there was a difference in the health workers, they saw for their care compared to non-disabled children and women. Using UNICEF-supported Multiple indicator Cluster Survey (Chapter 4), I looked at data collected between 2017 and 2021 from 10 sub-Saharan African countries for children, and 13 countries for women. For disabled children (Chapter 5), data from 51,901 children showed that disabled children had higher prevalence of ARI, diarrhoea, and fever, but there were no differences in whether caregivers sought care for disabled children compared to non-disabled children for all three illnesses. Caregivers of disabled children had higher odds of seeking care from a trained

health worker for ARI and fever and from non-health professional for ARI than from an unspecified health facility worker compared to caregivers of non-disabled children. However, this association was not seen for diarrhoea. The overall small absolute differences suggest closing gaps in illnesses and access to treatment may be possible but did not show there was a way to use these data to prioritize training for certain health workers based on the demand for care.

For disabled women (Chapter 6), I examined antenatal care access, as well as maternal care providers for antenatal care, skilled birth attendance, post-natal care, and post-partum care. While the sample was small and underpowered, it suggested there were no differences in seeking care or the type of care provider for disabled women compared to non-disabled women. There was some evidence that disabled women were more likely to have a doctor as a skilled birth attendant than non-disabled women (aOR = 1.52, 95% C.I. 0.99 to 2.33), though this may not necessarily be in-line with their desired birth plans.

Overall, this shows that there are not substantial differences in where disabled people seek health care from for regular child and maternal healthcare. It is not possible, therefore, with these data, to identify which healthcare worker cadres should be prioritized for training. Future research could specifically examine where disabled people seek care and their motivations for picking the type of care they seek, as this could inform training initiatives. These variables were not available in the dataset, an inevitable limitation of secondary data analysis.

10.1.3 OBJECTIVE 3: TO UNDERSTAND KEY STAKEHOLDERS' PERSPECTIVES OF CURRENT TRAINING INITIATIVES

Finally, to understand what key stakeholders think about training they have participated in, I conducted fieldwork in Ghana, where there have been various interventions to train health workers about disability and sexual and reproductive health. I interviewed 33 people who had been trainers or trainees in various disability trainings. An analysis of these interviews showed that trainers and trainees alike reported enjoying their training, though they expressed the desire for more training as well as several areas where there could be changes or improvements. Trainers emphasized the

challenges with current approaches to training—being informally organised, unsustainably funded, and unsystematically reaching health workers. Trainees also reported that training helped them to provide better care for patients and some said that they had raised awareness amongst their colleagues and communities about disabled people’s rights. Since only two trainees from each health facility in the district were selected for training, the organisation of the training was seen as a special opportunity to learn, and, therefore, many participants expressed they felt particularly empowered to and responsible for sharing their learnings with colleagues and community members. Both trainers and trainees suggested that future training should be more integrated into any health worker training curricula and there should be more opportunities to practice relevant skills, including sign language. However, both groups also noted that training is only part of improving health for disabled people, and that broader training for other key stakeholders (i.e., community leaders, government officials, in primary schools, etc.) is needed to change societal attitudes towards disabled people. Overall, the three objectives showed little has been done to advance health worker training over the last decade. The interventions (Chapter 3) are similar to previous systematic reviews⁸⁴—piecemeal and varied in frequency, content, health worker trained, and geography—despite legal requirements to institute training (Chapter 2). Therefore, these findings that point to greater training for all health workers (Chapters 5 and 6) and that training is both acceptable and effective (Chapter 8 and 9) show that health worker training on disability is important, but needs to be further scaled to improve health worker attitudes towards disabled people.

10.2 STRENGTHS AND LIMITATIONS

While each study has a section on its strengths and limitations, this section examines the strengths and limitations of the thesis as a whole. This thesis has added to the literature on disability training for health workers by contributing knowledge about how training can be developed and strengthened. I used an array of methods to examine the current state of health worker training as well as possible ways to improve future health worker training. Using a combination of systematic review and document review methods provides a high degree of certainty that the thesis represents

the main literature and laws pertaining to disability training to date. A further strength is the scale and scope of data used. Having access to high-quality data from the MICS in 13 countries in sub-Saharan Africa meant I was able to include data from nearly 62,000 people—including nearly 7,000 disabled people—across the African continent. This scale of data makes the work in this thesis one of the largest studies on care seeking behaviours of disabled people in sub-Saharan Africa. Additionally, the qualitative study generated rich data for analysis. Since few studies have examined health workers' perspectives on disability training, this also provides novel evidence on how to improve disability training. Therefore, the scope and size of the data included in this thesis, and the ability to focus on relevant sub-groups, is a key strength.

This thesis also has limitations. First, this thesis sought to understand and improve health worker training in 'sub-Saharan Africa', but only includes quantitative data from 13 countries and only one country, Ghana, in-depth qualitative interviews. The complexity and richness of each country's distinct political, cultural, social, and health environments are, therefore, not represented in this work. This lack of nuance is particularly important with regards to health systems, as that is a substantial modifying factor that could not be accounted for in this work. For instance, some governments may have introduced specific programmes for disabled people (i.e., home visits, transportation subsidies, etc.) to support their inclusion in the health system, but since this data were not available to adjust for in the quantitative analyses, the lack of nuance around differences in health systems is a limitation of this thesis.

Secondly, the quantitative analysis in this thesis relies on secondary data and was hampered by some of the design of the MICS surveys. Namely, the sample—particularly the work on disabled women—was underpowered for country-specific analyses for all variables. Using the Washington-Group Short Set for adults is a “gold standard” measure of disability, but its narrow definition in only six categories means that it likely underestimates the true prevalence of disability.²²³ Further, the MICS interview manual does not allow for proxy respondents, likely meaning that those with communication impairments or D/deaf and hard of hearing individuals are also undercounted in these surveys.¹⁶⁷ Using a cross-sectional survey such as the MICS rather than an original survey

meant I did not have sufficient data to help elucidate the complex relationships that can lead to differences in care-seeking and some of important covariates and outcomes were not included in the survey, such as quality of care or health outcomes. For example, people may choose to see certain types of health workers because existing training programmes mean this type of health worker already provides high-quality care, or the provider selected may just be the most convenient and affordable option at the time. Because it is impossible to examine why particular health workers were chosen as the care providers, this was a limitation of the data.

Similarly, as the qualitative study was conducted some months after people had attended their training course, it did mean I was not present for the training and my understanding of the training is only based on interview participants' descriptions rather than my own observations. People described their perspectives on their training in the interviews and gave accounts of positive changes in the care they (or others) had offered since attending, but it is a feature of the study design that no independent verification of these accounts was feasible.

10.3 RECOMMENDATIONS

This thesis systematically identified the vastness of existing interventions to train health workers on disability as well as possible new directions for future health worker training. Three main recommendations have developed from this work: 1) adopt a common framework for training health workers on disability; 2) integrate disability training into curricula and licensing requirements to reach all health workers; and 3) evaluate training to develop a more robust evidence base.

10.3.1 RECOMMENDATION 1: ADOPT A COMMON FRAMEWORK

The findings from the systematic review (Chapter 3) suggest a better framework is needed to standardize and improve health worker training, which the findings from this thesis will help inform. To summarise the learning for developing future disability training (Table 10.1) illustrates the core components of training, as described by trainers and trainees (Chapters 8 and 9). These four components: 1) laws and policies, 2) disability awareness, 3) inclusive interactions and

communications, and 4) fundamental practical skills were emphasized as the teaching topics trainees described these topics as key to their learning. The second and third columns of Table **10.1** describe the goal of the module and the beneficial methods, as reported by the trainers and trainees. The fourth column shows the intended outcomes, which I developed deductively from the goals and methods, as well as the interview content. The final column shows the corresponding professional competency that each component seeks to address, drawing on the existing recommendations for competency-based clinical education on disability,^{79,80,83} as well as the systematic review and the qualitative study. Cross-cutting throughout these phases is long-term learning and evaluation of methods, which are intended to fill the gap of lack of evaluation and long-term learning raised in Chapters 2 and 3. Several suggestions from the qualitative study (including adopting a ‘train-the-trainer’ approach) as well as the findings from Chapters 5 and 6 that indicate there may be no particular cadre that need to be prioritized for training. Instead, training might be best integrated into the curriculum at all levels and for all cadres. The framework is therefore applicable to all types of health professionals’ clinical education.

Table 10.1: Core components of health worker training

Core components	Goal of module	Methods	Intended outcome	Corresponding competencies
Learning Components				
Laws and policies	- Establish importance and rights of disabled people. - Set minimum requirement for quality care for policies and laws	- Lectures - Videos and case studies	Change behaviour towards disabled people to adhere to laws and deliver rights	- Knowledge - Awareness - Attitudes
Disability awareness	- Many people have never met a disabled person before. - Cultural beliefs and stigma - See disabled people as ‘cursed’ or that disability is ‘contagious’. - Enhance understanding of disability and barriers to health care - Understand the role of health workers in good-quality health care	- Lived experience lectures. - Videos and case studies - Question and Answer sessions	Challenge stigma, attitudes, and beliefs	
Inclusive interactions and communication	- Build confidence in interactions, empathy and understanding. - Practice “bad” and “good interactions in a safe space, with feedback for improvement - Develop tools to communicate with patients. - Provide greater privacy to disabled people	- Role play and simulations - Videos and case studies - Clinical placements	- Greater empathy - Better interactions	- Skills - Communication
Fundamental practical skills (i.e., lifts, sighted guiding, etc.)	- Not covered in most health worker training - Provide support in an empowering way, not making assumptions about need for support	- Lived experience experts. - Role play and simulation	More supportive interactions	
Operational Components				
Facilitate widespread, long-term learning	- Support learning outside the classroom - Help learn how to approach similar situations on the go. - Reinforce appropriate language. - Build connections between facilities. - Share learnings of ‘what works and positive impact stories	- Manuals - Resources - Leaflets - Community of practice	- Continuous learning on disability - Refresh skills on disability - Adopt a ‘train-the-trainer’ approach to reach a wide array of health workers	Long-term efficacy
Evaluation	Understand ‘what works to train health workers	- Pre-intervention test - Post-intervention test - Long-term follow up	Build evidence-based disability training	

This summary may help guide the future research that is needed to understand what is most effective in training health workers on disability. The current, fragmented approach to health worker training on disability means that it is difficult to compare health worker training programmes and applications to advance the common goal. Instead, adopting a modular, principles- based and competency-based approach that is applicable across geographies and settings will help further learning about what works best. For example, one of the remaining gaps in the literature is a standardized training evaluation tool that could be used across settings and projects. Using the six overarching principles listed in Table 10.1 as the basis for a tool could help develop a standardized approach to training and improve the comparability of evidence across settings. Developing this tool and evaluating future training with it, can help refine the methods and content to truly understand ‘what works’ in training health workers on disability.

10.3.2 RECOMMENDATION 2: FULL CURRICULUM INTEGRATION

The question of how to integrate disability into existing curricula has been a common theme throughout this thesis. While the systematic review (Chapter 3) found limited evidence of integration into existing curricula, the legal and policy review (Chapter 2) found that most countries had a legal mandate to include disability training for health workers as a required part of the curricula. Similarly, the quantitative studies (Chapters 5 and 6) show that since there are no differences in where disabled people seek care, it is important to reach all health workers with training. Health workers and trainers interviewed in the qualitative study (Chapters 8 and 9) also suggested that integrating disability more fully into the curriculum would be an appropriate and desired future direction for health worker training. Therefore, one of the recommendations of this thesis is that health worker training on disability should be in all health workers’ curricula. Countries should work towards developing a nationally standardized curricula with the components listed in Table 10.1 for all health workers or, with content tailored to specific cadres. However, to be effective in scaling up disability training, health educational institutions and licensing boards need to consider how they would include the topic of disability within continuing professional development activities as well as successfully implementing and monitoring these expansion activities. Professional licensing bodies could add

disability competencies as part of the licensing requirements. This regulatory change would force training schools to incorporate disability into their curricula, while also ensuring those already in practice are reached through continuing professional development programmes developed by the licensing bodies. While the implementation of this regulatory shift would require careful coordination between health professional schools and licensing bodies, this recommendation extends laws and policies that recommend or require training on disability to implementing training in a required, standardized way for all health workers. Ultimately, including disability training seamlessly in the curriculum will better equip health workers with the tools they need to feel confident in their ability to treat disabled people in their practices.

10.3.3 RECOMMENDATION 3: EVALUATE TRAINING TO DEVELOP A MORE ROBUST

EVIDENCE BASE

Aside from the qualitative study, this thesis primarily relied on secondary data to understand and improve health worker training. However, more research that focuses on evaluating and comparing training methods would further develop the recommendations and distil the methods and approaches that are most effective in training health workers on disability. Future research should centre around two main areas: 1) understanding health workers' perspectives on how to improve training and 2) understanding disabled people's experience of care before and after training. First, while there are some studies on health workers' perspectives of training, there needs to be further research assessing the training needs of health workers regarding disability, as well as understanding how they would improve training they received. Chapter 8 provided some insights from the case of Ghana, and this was one of the first studies to present this type of evidence. Therefore, to improve training further, there needs to be greater understanding of health workers' perceived training needs and input on improvements.

Second, evaluations of existing training programmes have centred on those health workers who were trained. Future research could shift to centring the people most impacted by the training—disabled people. Any evaluations of a health worker training intervention should measure disabled peoples' use of health services and quality rating to assess how the training has impacted their experiences in

healthcare. Indeed, randomised controlled trials to understand the impact of health worker training interventions on these utilisation and quality metrics may advance our understanding of how-to best train health workers in ways this study was unable to. Therefore, more research in these specific areas could further advance the field of disability training for health workers.

10.3.4 RECOMMENDATION 4: PREPARE HEALTH SYSTEMS TO TRAIN HEALTH WORKERS ON DISABILITY

Training health workers on disability has various implications for the health system, but there are also opportunities to leverage various health systems components to improve the state of disability training. First, as noted in Chapters 8 and 9, training health workers about disability requires financial resources to execute, particularly since the current health workforce would need to have some training. Costs for increasing training will be predominantly associated with continuing professional development programmes versus incorporating disability into existing curricula, so these CPD costs could be covered by professional registration fees or allocated as a line item in annual training budgets. Further research to understand if there are cost savings by having training (i.e., by reduced health care utilisation because of disabled people seek care earlier) may also produce economic incentives at the health-systems level to conduct training. Therefore, earmarking a specific amount of funding to upskill all health workers with disability training is required to ensure the health system can fund the training.

Another important implication for the health system is health worker retention and cultivating a skilled workforce. While the intention of training is to ensure health workers are adequately skilled to provide care for a particular patient group they may already interact with—and evidence shows are likely to make up a substantial portion of patients⁶¹—the additional burden of training should not be underestimated. Therefore, health systems must strike a balance between sufficient and burdensome training. As such, several participants in the qualitative studies suggested training every year or two years in order to maintain adequate level of skill to provide care for this population. However, if training is also integrated into health worker curricula, there is a possibility that this could be less frequent. Finally, as health systems continue to struggle with recruitment and retention

of health workers, particularly in rural areas²⁴⁹ like the setting discussed in this thesis, it is also important to consider how health workers recruit and support disabled health workers as a mechanism to support disabled people in seeking health care. For instance, recruiting a deaf community health worker in a local community may be better for the health system (i.e., more cost-effective and permanent) than training another health worker in sign language, who may move villages in a few months or years, thereby requiring another health worker to be trained or recruited. Similarly, increasing the number of disabled health workers may support training overall, as it would further demystify disability for health workers and possibly reduce the need for frequent training. However, more research is needed to understand if this could also improve disability training and health systems for disabled people.

10.4 FURTHER ACTIONS TO IMPROVE DISABILITY TRAINING

This thesis has shown there has been little progress in the last decade with regards to disability training for health workers. Prior research has highlighted that there are various interventions to train health workers about disability, yet these are diverse interventions across content, design, follow-up, geography, and stage of training,⁸⁴ as highlighted in the updated systematic review (Chapter 3). The other findings of this thesis highlight how critical it is to train all health workers, both from a legal perspective, as well as the child and adult case studies showing higher prevalence of illness in children, but similar care seeking behaviour in disabled children and adults compared to non-disabled children and adults. Indeed, health workers in Ghana repeatedly expressed the desire to have more training and provided evidence that the training had broader societal implications than just the health system.

Health worker training on disability is a recognised component of achieving health equity for disabled people and was recently listed by WHO as one of the top 40 actions to take to close the life expectancy gap.¹⁰⁴ Yet, nearly a year after this call to action, there has been little evidence of action, with most governments and other stakeholders not announcing any action plans or programmes to train health workers on disability. This thesis presents a clear rationale for improving and

implementing further disability training for health workers, as it is not only needed, but legally required in many settings in sub-Saharan Africa. Therefore, governments need to take urgent action to address this skills gap for health workers and improve health care for disabled people. This should include adding disability to the curricula of health worker training schools, increasing disability focused CPD courses, recruiting disabled health workers, and improving monitoring and evaluation of disability training. Continued inaction will only further entrench disability-based inequities in health systems and widen the 10-20 year difference in life expectancy for disabled people already observed in many low- and middle-income countries.²²

10.5 CONCLUSION

Training on disability is an important tool to challenge negative attitudes that health workers may have about disabled people.⁷⁴ However, the unsystematic nature of training currently leaves healthcare workers with different competencies dependent on their geography, educational background, and level of seniority. Instead, health educational institutions and licensing boards should work towards standardizing requirements for health worker training on disability, such as listing it as a licensing requirement to ensure everyone has some form of training as part of the health workforce. This approach, rather than legal solutions, provides a tangible and enforceable way to integrate disability training into health worker curricula.

This thesis has provided evidence on the key gaps in health worker training, the need for coverage of all health worker cadres, and the need for more systemic approaches to health worker training. As health systems continue to recover and be re-imagined in the post-pandemic era, there is renewed focus on how to upskill, task-shift, and retain health workers who are leaving the field in ever-increasing numbers.²⁴⁷ Empowering them with the appropriate tools to deliver high-quality care to disabled people—who have higher rates of health utilisation, worse health outcomes, and higher mortality rates—is an important component of building disability-inclusive health systems.

Ultimately, health worker training on disability is just one component of building inclusive health systems. However, it is essential, since even the most accessible, affordable, and accommodating

health facility will fail to deliver high-quality care without skilled, disability-confident, and respectful staff. Therefore, disability training for health workers is an essential to empower health workers treat all patients. Disability training is an essential component of disability-inclusive health systems that must be rapidly upscaled to meet disabled peoples' right to health.

11 APPENDICES

APPENDIX 1: LAWS AND POLICIES EXTRACTION TABLE

Country and Law/Policy Name	Language	Date	Requirement	Cost	Time	Competencies	Staging	Methods	Impairment Type	Cadres	Benefits	Objectives	Monitoring and Evaluation
Chad - Law No. 007/PR/2007 Bearing Protection for Disabled Persons	French	2007	-	-	-	-	-	-	-	-	-	-	-
DRC - Code de la Personne - Chapitre III sur les Handicapes Infirmes et Prodiges	French	1973	-	-	-	-	-	-	-	-	-	-	-
The Gambia - Persons with Disabilities Bill	English	2020	Mandatory	-	-	-	Health training institutions' curricula, CPD	-	-	All health and rehabilitation personnel	-	-	-
The Gambia - Integrated National Disability Policy	English	2009 - 2018	Recommended	-	-	-	-	-	-	-	-	-	-
Ghana - Persons with Disability Act, 2006 (Act 715)	English	2006	Mandatory	--	-	-	Education programmes	-	-	-	-	-	-
Lesotho - National Disability Mainstreaming Plan	English	2019	Recommended	-	-	Sign language skills	-	-	Intellectual disabilities and d/Deaf and hard of hearing	Nurses, Doctors, HTC counsellors	-	Provide sign language skills to health providers including nurses, doctors, HTC counsellors	Plan included

Lesotho - National Disability and Rehabilitation Policy	English	2011	Recommended	-	-	-	-	-	-	-	-	-	-
Madagascar - Loi sur les personnes handicapées	French	1998	-	-	-	-	-	-	-	-	-	-	-
Malawi - CRPD Initial and Second State Party Reports	English	2016	-	-	-	-	-	-	-	-	-	-	-
Malawi - Disability Act	English	2012	Mandatory	-	-	-	-	-	-	-	-	-	-
Malawi - National Disability Mainstreaming Strategy and Implementation Plan	English	2018 - 2023	Recommended	Free (with 50 million MK budget)	-	Sign language, causes of disability, early intervention, assessment, and referral services	Pre-service, CPD	-	Albinism	Physio, orthopaedics, dermatologists and ophthalmologists, HTC service providers	-	3 new curricula for health personnel; 41 physios trained; 100 rehabilitation technicians trained;	Plan included
Malawi - National Policy on Equalisation of Opportunities for People with Disabilities	English	2006	Recommended	-	-	-	-	-	-	Trained medial and other rehabilitation personnel	-	-	Plan included
Sierra Leone - The Persons with Disability Act	English	2011	-	Contribute expenses to institutions that train carers of PWDs	-	-	-	-	-	-	-	-	-
Togo - Loi Togolaise Relative a La Protection	French	2011	Recommended	-	-	-	-	-	-	-	-	-	-

Sociale des Personnes Handicapees														
Zimbabwe - Disabled Persons Act	English	1992	-	-	-	-	-	-	-	-	-	-	-	-

APPENDIX 2: SAMPLE SEARCH STRATEGY

1
disabled person/
2
(disab* adj3 (people or person* or adult* or children)).mp. [mp=title, abstract, heading word, drug trade name, original title, device
manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
3
(impairment* adj3 (people or person* or adult* or children)).mp. [mp=title, abstract, heading word, drug trade name, original title,
device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
4
(disorder* adj3 (people or person* or adult* or children)).mp. [mp=title, abstract, heading word, drug trade name, original title, device
manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
5
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manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
6
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manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
7
wheelchair user/
8
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manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
9
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manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
10
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11
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device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
12
(learning adj (disab* or impairment* or disorder*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device
manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
13
(hearing adj (disab* or impairment* or disorder*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device
manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
14
(sensory adj (disab* or impairment* or disorder*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device
manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
15
(cognitive adj (disab* or impairment* or disorder*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device
manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
16
(communication adj (disab* or impairment* or disorder*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device
manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
17
(speech adj (disab* or impairment* or disorder*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device
manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
18
language disability/
19
hearing impairment/
20
blindness/
21
(mental adj (illness* or impairment*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug
manufacturer, device trade name, keyword, floating subheading word, candidate term word]
22
autism/
23
((person* or people) adj3 special need*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer,
drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
24
((person* or people) adj with functional diversity).mp. [mp=title, abstract, heading word, drug trade name, original title, device
manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
25
1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
26
medical education/
27

((medical or health or nursing or dental or physiotherapy or physical therapy or healthcare professional or continuing professional) adj
 (school or education or curriculum or training)).mp. [mp=title, abstract, heading word, drug trade name, original title, device
 manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
 28
 clinical competence/
 29
 (disab* adj (curriculum or education or content or training)).mp. [mp=title, abstract, heading word, drug trade name, original title,
 device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
 30
 in service training/
 31
 expert patient.mp.
 32
 clinical encounter.mp.
 33
 accessibility training.mp.
 34
 clinical placement.mp.
 35
 refresher course/
 36
 pre-clerkship.mp.
 37
 clerkship.mp.
 38
 patient encounter.mp.
 39
 med ed.mp.
 40
 residency education/
 41
 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40
 42
 health practitioner/ or paramedical personnel/
 43
 general practitioner/ or physician/
 44
 clinician/
 45
 ((physical medicine and rehabilitation) adj (specialist* or doctor*)).mp. [mp=title, abstract, heading word, drug trade name, original
 title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
 46
 resident/
 47
 preclinical student.mp.
 48
 medical student/
 49
 clinical student*.mp.
 50
 residency education/
 51
 nurse/
 52
 nursing student/
 53
 student nurse*.mp.
 54
 (nurs* adj (assistant* or aide*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug
 manufacturer, device trade name, keyword, floating subheading word, candidate term word]
 55
 midwife/ or nurse midwife/
 56
 dentist/
 57
 (dental adj (student* or assistant*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug
 manufacturer, device trade name, keyword, floating subheading word, candidate term word]
 58
 dental hygienist/
 59
 (health adj (worker* or assistant* or promoter* or surveyor* or volunteer* or auxillar*)).mp. [mp=title, abstract, heading word, drug
 trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate
 term word]
 60
 volunt* health worker*.mp.

61
lady health worker.mp.

62
lay health worker.mp. or lay health worker/

63
village health worker.mp.

64
community health worker.mp. or health auxiliary/

65
community health agent.mp.

66
traditional birth attendant/

67
health care personnel/

68
health promoter.mp.

69
(allied health adj (professional* or student*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

70
personal care attendant*.mp.

71
care staff.mp.

72
physiotherapist*.mp.

73
(occupational therap* or occupational therapy student*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

74
(dietician* or nutritionist*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

75
((speech or language) adj therapist*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

76
audiologist/

77
psychologist/

78
psychiatrist/

79
social worker*.mp.

80
community pharmacist/ or clinical pharmacist/ or pharmacist/ or hospital pharmacist/

81
physical therapist*.mp.

82
42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81

83
25 and 41 and 82

APPENDIX 3: EXTRACTION SHEET

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
PRE-QUALIFICATION											
Thew et al. 2012 ⁴⁵	University of Rochester School of Medicine and Dentistry, USA	First-year medical students (n=99)	Hard of hearing and D/deaf people	Lectures about deaf people and their experiences in health care and simulations of being deaf in different health settings to learn communication strategies. Deaf volunteers and lead a debrief.	x	x			x		knowledge, competence
Gilmore et al. 2019 ¹⁹	Queen's University Belfast, UK	Second year medical students (n=59)	Hard of hearing and D/deaf people	29 second-year students participated in a deaf awareness and sign-language module were compared to 30 controls to examine the course's impact on attitudes and knowledge of deafness. Previous participants were also contacted and evaluated to assess long-term impact.	x						knowledge, attitudes
Smith et al. 2016 ⁴⁶	School of Nursing at Kingston University and St George's, University of London, UK	First year nursing students (n =114)	People with intellectual disabilities (ID)	45-minute session developed and led by people with intellectual disabilities (with input from school lecturers) about their experiences accessing and receiving health and social care.		x					Knowledge, attitudes, confidence, comfort, communication skills
Iannuzzi et al. 2019 ²⁷	University of Massachusetts Medical School's (UMMS) Graduate School of Nursing, USA	Rising third year Doctor of Nurse Practice Family Nurse Practitioner Program students (n=16)	Autism Spectrum Disorder (ASD)	Groups that were exposed to content at different points in the course: Lectures on ASD and common comorbidities given by developmental disability nurses; online modules on epidemiology, medical and diagnosis issues for ASD; and participation in Operation House Call, a parent- and self-advocate program to match health students with transition-aged youth.	x	x	x	x		x	self-efficacy, knowledge, attitudes
Lapinski et al. 2015 ⁴⁷	Kirksville College of Osteopathic Medicine, USA	Osteopathic medical students (n=33)	Hard of hearing and D/deaf people	A four-hour workshop on ASL that included a presentation on deaf culture, key vocabulary (alphabet, numbers, medical words, etc.) and etiquette, stories from the Deaf community facilitators, and an overview of providing health care to deaf patients.	x	x					confidence, competence

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
Holzinger et al. 2020 ⁴⁸	Medical University of Vienna, Austria	Fourth-year dental students (n=154)	Patients with paediatric, geriatric, psychiatric, and neurological disorders	Five 2-hour seminars (lecture and small group case studies) on managing dental needs of patients led by a dentist and specialist in the patient population and a practical course in the community.	x		x	x		x	emotional reactions, acceptance, comfort, attitudes
Saunders and Knight, 2017 ⁴⁹	City University London, UK	Post-grad and undergraduate nursing students (n=146)	People with intellectual disabilities	A three-hour, multi-media 'simulation of simulations' on caring for patients with intellectual disabilities. The intervention also includes group discussions and a workbook.	x		x		x		competence, confidence
Santoro et al. 2019 ⁵⁰	Stanford University, USA	Medical students in paediatric clerkship (n=24)	Intellectual, language, or motor disabilities	A RCT evaluating an intervention that includes lectures, bedside teaching, and five clinical learning scenarios compared to a lecture-only control. Conducted during core paediatrics rotations.	x		x			x	knowledge, attitudes
Symons et al. 2014 ³⁹	State University of New York at Buffalo and Syracuse Medical Schools, USA	Medical students (n=244)	All disability types	A new medical school curriculum that combines lectures, small group and structured encounters with people with disabilities and their families, clinical experiences, workshops, and elective options over four years to improve disability training.	x	x	x	x	x	x	knowledge, attitudes
Perusini et al. 2016 ⁵¹	Faculty of Dentistry, University of Toronto, Canada	Senior dental students (n=92)	People with disabilities (PWDs)	Senior dental students participated in a mandatory clinic placement for people with disabilities.				x		x	attitudes, comfort
Castro et al. 2018 ⁵²	Federal University of Triângulo Mineiro, Brazil	Undergraduate health professional students (n=12)	People with disabilities	Undergraduate health students (medicine, nursing, nutrition, occupational therapy, physiotherapy, and psychology) participated in a 30-hr course that focused on the concepts and policies related to disability and clinical practice. These topics were taught through lectures, movies, case studies, role-play, debates, and discussions.	x	x	x		x	x	competence
Burrola-Mendez et al. 2018 ⁵³	University of Pittsburgh, USA	Graduate rehab. Sciences students (n=6)	Wheelchair users	An 8-module online training course followed by three-day in-person training for low-bandwidth areas that increases service provision for wheelchair users.	x	x		x			knowledge, competence

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
Salama and Al-Balkhi 2020 ²³	College of Dentistry, King Saud University, Saudi Arabia	Dental students (n=150)	People with disabilities	A 30-minute DVD presentation on providing oral care for people with disabilities.	x						knowledge, competence
Mohebbi et al. 2014 ⁵⁴	Tehran University of Medical Sciences, Iran	Senior dental students (n=70)	People with disabilities	The intervention group received training on providing care for disabled patients through group discussions, lectures, and hands-on clinical fluoride varnish/screening for autistic children.	x			x		x	knowledge, attitudes
Bailey et al. 2021 ²¹	Ferris State University College of Pharmacy, USA	First and second-year pharmacy students (n=39)	Hard of hearing and D/deaf people	A four-class, optional, co-curricular course was offered to pharmacy students, focusing on deaf culture, communication, and ASL. Included time to interact with a deaf physician over Skype and with deaf/HOH individuals from the community.	x	x					confidence, communication
Watmough et al. 2014 ³²	University of Liverpool, UK	Third year medical students (n=42)	People with disabilities	A 7-week community placement for third year medical students, including six full-day, small-group sessions, a 5-day GP placement where students clerk with at least two patients with disabilities, communications skills development, and visits to community disability centres	x			x		x	knowledge, comfort
Ahmad et al. 2020 ⁵⁵	Faculty of Dentistry, Universiti Teknologi MARA, Malaysia	Undergraduate dental students (n=165)	Children with visual impairments	Dental students (years 1-5) received a lecture on management of individuals with visual impairments followed by a participating in a clinic where each dental student was assigned to manage of a child with visual impairment at a special education school as part of a dedicated module.	x			x			knowledge, competence, behaviour, attitudes, learning
Crane et al. 2020 ⁵⁶	Ohio State University Wexner Medical Centre, USA	Third-year medical students (n=169)	People with disabilities (mobility, sensory, cognitive)	Medical students participated in a patient encounter with a PwD where they were asked to complete a brief social and medical history.						x	confidence, competence, and comfort
Tai et al. 2018 ⁵⁷	University of Melbourne, Australia	Final year graduate audiology students (n=15)	Hard of hearing and D/deaf people	Students had a clinical encounter filmed and re-played during a clinical communication education session to see their perspectives on their clinical communication skills.						x	communication

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
Ozkan et al. 2020 ⁵⁸	Faculty of Health Sciences, State University in Turkey	Third-year nursing students (n=70)	People with intellectual disabilities	Students participated in a clinical practice for three weeks (2.5 days per week) in 12 different fields- one of them being in a special education school. The experimental group went to a clinic that served special education schools and were exposed to case studies, nursing care examples, and videos care for people with disabilities.	x		x	x			knowledge, competence, attitudes
Sinai et al. 2013 ⁵⁹	University College London, UK	Undergraduate medical students (n=387)	People with intellectual disabilities	A 14-week course taught undergraduate medical students about training patients with intellectual disabilities. As part of the block, participants did a three-week specialist placement on learning disability services.	x		x	x			knowledge, attitudes
Abdi and Metcalf 2020 ²⁵	Cardiff University, UK	Fourth-year undergraduate medical students (n=110)	People with intellectual disabilities	Medical students participated in a mandatory communication skills session that included case studies and simulated patients. This was run by the Speech Language Therapy team three times during the academic year.	x		x		x		confidence, attitudes
Shields et al. 2013 ⁶⁰	Department of Physiotherapy, La Trobe University, Australia	First- and second-year physiotherapy students (n=17)	People with Down syndrome	Students participated in a 10-week, twice weekly community placement at a gymnasium for adolescents with Down syndrome. There, participants were expected to enact a progressive resistance training program.		x		x			communication, comfort, knowledge
Hensel et al. 2015 ³³	University-affiliated wilderness children's camp, USA	Junior-level BSN students (n=9)	Children with intellectual impairments or wheelchair users	Nursing students went to one of two weekend-long fall camps for children with disabilities aged 8-18.				x			knowledge, comfort, attitudes
Watkins and Colgate 2016 ⁶¹	Cardiff University, UK	Medical students (n=45)	People with intellectual disabilities	A self-advocacy agency, Cardiff People First, ran a one-hour video and ice breaker activity. Subsequently, students assessed a simulated patient played by an actor with an intellectual disability. Students then participated in a focus group discussion.	x	x			x		knowledge, attitudes
Forsgren et al. 2017 ⁶²	University of Gothenburg, Sweden	Fourth-year medical students (n=69)	People with acquired communication disorders	All students participated in a 45-minute mandatory lecture on acquired communication disorders. 36 students then participated in a 2.5-hour long workshop with a simulated patient to practice communication skills, and 15 were video recorded during the simulation pre- and post-workshop.	x		x		x		knowledge, attitudes, communication

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
McIntosh et al. 2018 ⁶³	Ball State University School of Nursing, USA	Senior nursing students (n=84)	Autism Spectrum Disorder	Students were exposed to Autism through lectures, case studies, a documentary video, and description of the simulation prior to the study, which was an encounter with a standardized patient. In the encounter, a 14-year-old boy with a fractured wrist was admitted to the emergency department. Students were expected to assess the patient and associated behavioural and emotional symptoms.	x		x		x		knowledge, competence
Woodard et al. 2012 ⁶⁴	University of South Florida Health, Morsani College of Medicine (USF), USA	Primary care clerkship for third-year med. students (n=245)	People with physical, sensory, or intellectual disabilities	Students participated in a 12-week Primary Care and Special Populations clerkship that included a special 6-week module on disability, half-day classroom sessions, online modules, and community site visits twice a week. Classroom sessions included simulations, case studies, and communication and exam technique advice from individuals with disabilities.	x	x	x	x	x	x	knowledge, competence, comfort
Jones et al. 2015 ⁶⁵	Queen's University, Canada	Medicine (n=100), nursing (n=93), clinical psychology (n=6), and rehabilitation students (n=133) (total n=332)	People with intellectual disabilities	Students participated in a three-part course that consisted of an e-learning and case models pre-requisite prior to a day-long course that consisted of group lectures, multidisciplinary experiential learning, and inter-professional team-based learning.	x	x	x				knowledge, competence, attitudes
Beverly and Wooster 2018 ⁶⁶	University of South Alabama, USA	Allied health graduate students(n=9)	Autism Spectrum Disorder	A one-credit online course and day-long conference included lectures, panel discussions, group problem solving, and parent perspectives. Content was focused on inter-professional education and diagnosis and co-morbidities of ASD.	x		x				knowledge, competence, attitudes
Coret et al. 2018 ⁶⁷	Michael G. Degroote School of Medicine, McMaster University, Canada	First-year medical students (n=27)	Intellectual/developmental disabilities (IDD)	Control and intervention groups participated in a baseline introductory video about healthcare and communication skills. After the video, the intervention group were shown videos of individuals and families of individuals with IDD who spoke about their lives, challenges, and perspectives on health care and participated in a reflective activity. Controls were only given a post-intro video quiz. Both groups participated in four clinical encounters and their skills were assessed by a final-year student.	x					x	comfort, confidence, and competence

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
Jain et al. 2013 ⁶⁸	Department of Family Medicine, Lehigh Valley Health Network, USA	Third- and fourth-year medical students (n=44)	Wheelchair users	Two patients with disabilities were trained to teach medical students about disability. In an hour-long session, they described their daily routines and experiences interacting with health care for medical students, followed by Q and A. Students who participated in the session were asked questions about awareness, sensitivity, and competency.	x	x					comfort, knowledge, competency, communication
Karl et al. 2013 ⁶⁹	University at Buffalo School of Medicine and Biomedical Sciences, USA	Third-year medical students (n=144)	People with disabilities (mostly people with developmental disabilities)	Third-year medical students participating in a family medicine clerkship program engaged in a day-long clinical experience at a family practice serving people with disabilities. Students observed and assisted the staff and then were asked to write a reflection. Students had previously done lectures, small group encounters of people with disabilities and their families, and other workshops.						x	communication, comfort, attitudes, knowledge
Thomas et al. 2014 ⁷⁰	University College London, UK	4th year undergraduate medical students (n=47)	People with intellectual disabilities	All participants had attended a 3-hour lecture on ID, session by a speech and language therapist, group work, watching a communication DVD, and basic Makaton training (a simplified British Sign Language). The second session involved students rotating through four stations in groups of four to work with simulated patients with ID.	x				x		competence, comfort, communication
Saldert et al. 2016 ³⁶	University of Gothenburg, Sweden	Medical students (n=59, 33 only lecture, 26 lecture & workshop)	People with speech language disorders	Students attended a 45 min mandatory lecture on different forms of speech disorders. A subset of students attended a mandatory 2.5-hour mixed format workshop two weeks later, led by speech language pathologists, involving role play, a lecture on communication strategies, and discussions.	x		x		x		knowledge, confidence, competence, attitudes
Baylor et al. 2019 ⁷¹	University of Washington, USA	Second-year medical students (n=224)	People with communication disorders	Students received the FRAME training, which looks at five key areas of communication skills, including familiarizing patient communication preferences, reducing rate, assisting patients, mixing methods, and respecting autonomy. Students participated in a 20-minute module on key characteristics of communications disorders, a 2-hour in-person session and practice strategies and simulated patients with aphasia and dysarthria.	x				x		knowledge, self-efficacy, communication, confidence

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
Lynch et al. 2019 ²⁶	Medical School in Ireland	Undergraduate, graduate entry, and international medical students in second or third year(n=320)	People with disabilities	Students taking a mandatory 12 week 'Understanding Disability' module in their course. This involved weekly lectures, applied anatomy laboratory sessions, a day visit to a national rehabilitation hospital, practice taking patient history in rehabilitation programs, and case studies.	x	x	x	x		x	competence, attitude
Garavatti et al. 2018 ⁴⁰	University of Central Florida, USA	2nd year medical student (n=20), final year Doctor of Physical Therapy Students (n=20)	People with disabilities	Medical and physical therapy students in the intervention group went through an interprofessional education (IPE) clinical experience that included an encounter with a disabled patient. 20 students attended a 3.5-hour IPE clinical session, focused on knowledge and interacting with individuals with disabilities through an orientation, performing a neurological examination, and group discussion. The control group (n=20) did not attend the IPE clinical session.	x					x	knowledge, attitudes, competence
Saunders and Berridge 2015 ⁷²	City University London, UK	Undergraduate and post-graduate adult, child, and mental health nurses (n=182)	People with intellectual disabilities	Nursing students participated in a 3-hour session on education around people with intellectual disabilities. This involved 'Shareville', a virtual simulation/software allowing for navigation of real-life scenarios of individuals with disabilities. Group discussions occurred prior to and after Shareville utilization.	x				x		knowledge, confidence
Sheepway et al. 2014 ³⁵	Faculty of health sciences, Australia	Third year undergraduate speech-language pathology students (n=73)	People with communication impairments	Third year speech language pathology students participated in three clinical placements to develop clinical competency over 12 months. The intervention sought to examine the impact of the sequence of placements, setting, and intensity of placements.				x		x	competence
Steedman et al. 2012 ²⁴	Queen's University, Canada	Second year medical students (n=25)	People with visual impairments	Students were split into two groups and watched either a multimedia learning tools (MMLTs) and read a textbook excerpt, covering different topics (Acute visual loss vs cataracts), followed by the other method.	x						knowledge
Dyer et al. 2014 ⁷³	East Midlands, UK	First and second year nursing students (n=138)	People with disabilities	Students watched a 30 minute 'Sexual Respect' DVD to educate on the types of sexual problems individuals with disabilities face, tips on initiating the conversation about sex with patients as well as self-help and peer support	x	x					knowledge, confidence, attitudes, competence

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
				groups that patients can be directed to. Clinicians and people with disabilities are featured in the video.							
Provident and Colmer 2013 ⁷⁴	Camp Kon-o-Kwee/Spencer in Pennsylvania, USA	Level I fieldwork Occupational therapy students (n=37)	Children with muscular dystrophy and related muscle diseases	Students participated in a weeklong summer camp for campers who have muscular dystrophy or related muscle diseases. Students interviewed families on medical care, shadowed nurses, and assisted with daily routines, transfers, and other counsellor duties, as necessary.				x			knowledge, confidence, comfort
Adib-Hajbaghery and Rezaei-Shahsavari 2015 ⁷⁵	Kashan University of Medical Sciences, Iran	Final year nursing students (n=71)	Hard of hearing and D/deaf people	Nursing students participated in two clinical simulations with D/deaf and hard of hearing patients to improve knowledge and performance and confidence in supporting hearing impaired individuals.					x		knowledge, competence
VandeWaa et al. 2019 ³⁴	University of South Alabama, USA	Graduate-level audiology (n=24), undergraduate nursing (n=53), graduate-level speech language pathology (n=24) students (total n=101)	Speech or D/deaf and hard of hearing people	Students completed online training one week prior to a simulation, which used enhanced interprofessional education (Sim-IPE). During the simulation, students worked in groups of 3 (one from each field) and completed 4 scenarios related to medication side effects with simulated patients. The emphasis was on teamwork of the group with emphasis on effective patient communication.	x				x		knowledge, competence
Tate et al. 2020 ⁷⁶	The Ohio State University College of Nursing, USA	Second-year nursing students (n=161)	People with communication impairments	Nursing students took part in the StudentSPEACS program which involved a 1 hr. online training component to improve communications skills, followed by a 1.5 hr. in class lecture on assessing communication abilities and strategies, and then a 1.5hr clinical simulation.	x				x		attitudes, competency

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
Theoret et al. 2020 ⁷⁷	Rutgers University, USA	Medical students (n=56, 19 members and 37 non-members)	people with intellectual and physical disabilities	Students that are members of the Involvement with Disability Education and Advancement (IDEA) partnered with a local middle/high school for students with intellectual and physical disabilities. Students conducted health related workshops (including sexual education) in the classroom and did arts, crafts, and exercise programs to increase independence, confidence, and self-efficacy.				x			confidence
Watters et al. 2015 ⁷⁸	New York University College of Dentistry, USA	Fourth year dental students (n=364)	people with disabilities	Students participated in instruction before each clinic session for an hour and a half and were assigned articles and case studies. Students participated in a 4–6-week rotation (half days) in the special needs clinic in groups of seven to nine students. Students took turns providing care and serving as dental assistants to practice skills, improve comfort, and self-efficacy of students.	x		x	x	x		competency, confidence, self-efficacy, attitudes
Vento-Wilson et al. 2015 ⁷⁹	Large Urban University in Southern California, USA	Nursing students (n=103)	People with communication impairments	Principal investigator conducted a 1 hr. course to train student nurses on Augmentative and Alternative communication strategies (AAC) to improve communication with patients who have severe communication deficits (SCDs).	x						knowledge, confidence, competence
Kirshblum et al. 2020 ⁸⁰	Rutgers Medical School, USA	First-year medical students (n=355)	People with physical disabilities	The training on caring for people with physical disabilities was part of the two-year Health Equity and Social Justice curriculum. The program discussed prevalence, issues with accessible health care and health status, skills to improve care, and perspectives of people with physical disabilities. The course included a lecture, video vignette discussion (2nd year only), and patient panel to illustrate disparities.	x	x					knowledge, comfort
IN-SERVICE TRAINING											
Read and Rushton 2013 ⁸¹	University Hospital of North Staffordshire, UK	Nurses and other allied health professionals (n=157)	People with intellectual disabilities	A year-long intervention included a series of 8 workshops and a toolkit. The workshops were led by clinicians and people with ID to teach about admission, assessment, discharge planning, and values and attitudes regarding ID. The toolkit included a resource directory, assessment tool, DVD, posters, communication book, cue cards, and	x	x	x				knowledge, competence, attitudes

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
				leaflets about good practices to support people with intellectual disabilities.							
Major et al. 2013 ⁸²	33 academic programs across the United States	Pediatric and medicine-pediatric residents (n=114)	Autism spectrum disorder	A trial piloting 7 case-based modules on 1) early warning signs, 2) Screening, 3) Communication, 4) Diagnosis, 3) Early Intervention and Education, 6) Treatment, and 7) Anticipatory Guidance at 33 different sites across the US. Each site offered one of the 7 modules.	x		x				knowledge, communication, confidence, competence
Tuffrey-Wijne et al. 2017 ⁸³	Residential homes for people with intellectual disabilities, UK	Staff in residential/supported living services (n=114)	People with intellectual disabilities	Three-day course consisting of World Café sessions (w/case studies), presentations, feedback from people with intellectual disabilities, and a teaching expert on discussing death and dying.	x	x	x				competence, confidence, communication
Chiang et al. 2013 ³¹	Two public hospitals in Taiwan	Licensed nursing staff (n=62)	People with disabilities	Nurses watched multi-media interactive DVD to improve knowledge and assessment skills. Controls were assigned conventional classroom education on disability assessment.	x		x				knowledge, competence
Toro et al. 2017 ⁸⁴	University of Pittsburgh, USA	61 total participants including clinicians (n=20), manual wheelchair users (n=20), and power wheelchair users (n=21)	Wheelchair users	A wheelchair maintenance training program was developed to improve knowledge in both clinicians and wheelchair users. The clinicians training was a one-day program, and the user training was a two-day program that provided information, simulations, and hands-on experience for wheelchair maintenance.	x				x	x	knowledge, competence
Keisling et al. 2017 ³⁷	Boling Centre for Developmental Disabilities, University of Tennessee Health Science Center, USA	Medicine and Medicine/Paediatric s Residents (n=203)	People with developmental disabilities	Residents participated in a 1) home visit, 2) interview with an agency director/advocate and a parent who has a child with special health care needs (discuss affect children chronic illness history), and 3) Grand Rounds presentation to better understand the health care needs of this population. Residents undergo this training ('Project DOCC, Delivery of Chronic Care) during the Developmental-Behavioral Pediatrics rotation.	x			x		x	knowledge, empathy, collaboration
Bogetz et al. 2015 ⁸⁵	Stanford University, USA	Paediatric residents (n=48)	Children with special health care needs (CSHCN)	Residents participated in the Special Care Optimization for Patients and Education (SCOPE) program over four or more months. The program consists of home visits, monthly communication, and participation in a case-based discussion. In addition, residents had to go through a				x			self-efficacy, attitudes

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
Casson et al. 2019 ⁸⁶	Queen's University, Canada	Family medicine residents (n=100)	People with intellectual and developmental disabilities	toolkit, which included how to review a patient's goals, a contact tree for care issues, plan of care, and home visit summary resources. The program includes clinical encounters with patients with intellectual and developmental disabilities to improve core competencies of caring for patients with intellectual and developmental disabilities. Residents were asked to share their field notes and reflect on clinical encounters.						x	competence, confidence, communication
CONTINUING PROFESSIONAL DEVELOPMENT											
McGonigle et al 2014 ⁸⁷	Pennsylvania, USA	Emergency department staff and emergency service providers (n=110)	Autism spectrum disorders	Participants attended of three structured sessions for emergency medical services and emergency department staff to improve confidence, knowledge, and awareness of patients with ASD. All sessions included a DVD, case studies, and manual.	x		x				knowledge, comfort
Doyle and Bennett 2014 ⁸⁸	Pacific Northwest, USA	Occupational therapists (n=19)	People with physical disabilities	An 8-hour workshop for occupational therapists to improve upper-limb post-stroke sensory impairments.	x						knowledge, attitudes, competence
Dunleavy et al. 2018 ⁸⁹	Two settings: a central urban region and a southern, more rural part, Rwanda	Physiotherapists (n=69)	People with disabilities	Six courses were developed to build clinical skills, improve decision making and evaluation, and treatment techniques for various orthopaedic, neurologic, paediatric, and respiratory conditions, as well as leadership and advocacy. These were offered to physiotherapists in over multiple weekends in the central urban region and a southern, more rural part.	x		x		x	x	quality, competence
Mazurek et al. 2020 ²⁹	Various medical clinics across the USA	Primary care providers (n=16)	Autism spectrum disorders	Primary care providers attended 12 weekly one-hour video-conference sessions taught by interdisciplinary experts to improve knowledge and care for people with ASD.	x	x	x			x	knowledge, self-efficacy, competence
Mazurek et al. 2020 ⁹⁰	10 academic medical centres in the USA and Canada	Primary care providers who provide care to children and to an	Autism spectrum disorder	Over 6 months, 10 academic medical centres participated in a randomized control trial of 12 two-hour long training from interdisciplinary Autism experts through didactic	x		x				competence, knowledge, self-efficacy, barriers to care

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
		underserved population (n=117)		presentations, PCP-generated case presentations, and group discussions.							
Locke et al. 2019 ⁹¹	University of Antananarivo, Madagascar	Doctors in rehabilitation medicine diploma program (n=8) and physiotherapists (n=10)	People with physical disabilities	A 400-hour rehabilitation medicine program was developed in collaboration with the University of Leeds and offered in three sections: general principles of rehabilitation, neurological condition rehabilitation, and musculoskeletal condition rehabilitation. Participants were recruited from different national and regional hospitals to participate in the program.	x						knowledge, improved care
Edinger et al. 2019 ⁹²	Rutgers University, USA	First responders (n=33)	People with developmental disabilities	A one-hour online workshop was held to improve disaster and critical care responders (knowledge and self-efficacy for working with people with developmental disabilities. The intervention included an overview of developmental disabilities, training on communication, and identification and interaction techniques.	x						knowledge, self-efficacy,
Auberry et al. 2019 ⁹³	Indiana University School of Nursing, USA	Volunteer direct support professionals(n=12)	People with intellectual and developmental disabilities	Volunteers participated in sessions on medication administration for people with intellectual and developmental disabilities. The session was facilitated by a doctoral-trained and bachelor-trained registered nurse (RN) certified in developmental disability nursing covered various medication practice instructions through didactic lectures and simulations.	x				x		knowledge, confidence
Olowoyeye et al. 2019 ⁹⁴	Ifo Local Government Area, Ogun State, Nigeria	Maternal and child health care workers (MCHWs) (n=65)	Children with visual impairments	MCHWs participated in a pre-test and focus group discussion on leading causes, identification, management, and prevention of childhood blindness. Participants then participated in a lecture and practical session on eye diseases and asked to log any referrals following the intervention. After 3 months, the participants did a post-test questionnaire.	x					x	knowledge
Cameron et al. 2017 ⁹⁵	Metropolitan Hospital in Australia	Heath professionals (n=52)	People with Aphasia	The intervention programme consisted of a 1-h lecture that discussed strategies for communicating effectively with people with aphasia (PWA). This lecture was provided by a speech language pathologist member of the research team. This was immediately followed by a 15–	x				x		confidence, knowledge

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
				20-minute practical conversation with a PWA to facilitate application of the discussed strategies and approaches.							
Mac Giolla Phadraig et al. 2015 ⁴³	Residential care homes in Dublin, Ireland	key care staff of residential home (n=22), people with ID (n=155)	People with intellectual disabilities	22 trainees from intervention group attended a multi-tiered oral health educational program on the oral health and oral hygiene of people with intellectual disabilities. Trainees were expected to train peers. A control group lived in centres where staff received no training.	x			x			knowledge, attitude, self-efficacy
Dagnan et al. 2018 ²²	An English Improving Access to Psychological Therapies (IAPT) service, UK	Therapists (n=68)	People with intellectual disabilities	Therapists working in an Improving Access to Psychological Therapies Service participated in a one- or two-day workshop on supporting people with intellectual. The workshop was divided into 8 sessions, including introduction to intellectual disability, stigma, assessment, adaptation of therapeutic techniques, approaches, and local services/resources.	x						confidence, self-efficacy, attitude
Catteau et al. 2013 ⁹⁶	Dental practices across France	Dentists (n=26)	People with disabilities	A 10-module online curriculum 'Autonomy and Oral Health' (30-50h of coursework) covered dental health for persons with disabilities, ranging from lack of autonomy to special care dentistry. Dentists also conducted an oral health promotion course for people with disabilities at institutions for children and adults.	x			x		x	knowledge, self-efficacy
Clark et al. 2019 ³⁸	University of Rwanda	Physical Therapists (n=66)	Children with physical disabilities	Physical therapists, to improve paediatric clinical decision making, were taught for a total of 48 hours over the course of 4 weekends. Teaching involved classroom lectures, small group case studies, laboratory skills practice, and clinical visits to participants place of work.	x		x		x	x	knowledge, confidence, competence
Quinn and Smolinski 2018 ⁹⁷	National Association of School Nurses annual conference, USA	School nurses (n=248)	People with intellectual disabilities	School nurses participated in three-hour educational sessions that focused on increasing their knowledge related to pain and pain assessment for students with intellectual disabilities.	x						knowledge, competence

Citation	Place	Sample	Impairment	Intervention Details	Lecture & Didactic	PwD as Teacher	Case study	Placement	Simulation	Clinical Encounter	Outcomes Measured
Phlypo et al. 2018 ⁹⁸	Ghent University and a local residential facility in Belgium	Residential facility caregivers (n=99, control =42, intervention=37)	People with intellectual disabilities	Students initiated an oral health promotion project for people with intellectual disabilities and their caregivers living in a residential care home. Facility caregivers were randomized and those in the intervention group received a booklet including chapters on oral hygiene, nutrition, visiting the dentist and practical tips on providing health care for people with disabilities and an information session for residents and caregivers.	x						knowledge, attitudes, self-efficacy
Sanchez et al. 2017 ⁹⁹	Federally Qualified Health Care Centre in Nogales, Arizona, USA	Female community health-care workers (n=12), 4 of which participated in facilitator training	Hard of hearing and D/deaf people	CHWs attended two-hour focus groups and a 3-hour workshop that included didactic methods and simulation. CHWs who participated in the workshop held community screenings and some participated in an additional 8 sessions over 6 weeks to become facilitators. The goal was to improve screening, understanding, referrals and effective communication.	x		x	x	x		knowledge, confidence, competence
Mac Giolla Phadraig et al. 2012 ⁴⁴	Community-based residential care homes in Dublin, Ireland	Residential care home staff (n=219)	People with intellectual disabilities	22 trainees from intervention group attended a day long training session provided by a team of oral health trainers (lectures, group based practical sessions, role play, group feedback). Trainees were given training packs to go back to care home and train peers. The control group received no training. The goal was to see if training can improve the Knowledge, Attitudes, Self-efficacy, and Reported Behaviour (KBAS) of the intellectual disability staff.	x			x	x		knowledge, competence, attitudes
Pasco et al. 2014 ⁴²	Cities across Romania (Bucharest, Cluj, Iasi, Timisoara)	Professional training programme (n=1075) online course (n=613, GPs and psychiatrists)	Autism spectrum disorder	Three-stage training program to increase knowledge of ASD and share best practices (two 3-day courses, six 6-day courses, and 30h of supervised practice). Two online courses for GPs and Psychiatrists on improving diagnosis and treatment were also offered, among other initiatives as part of a nationwide project to improve awareness and social inclusion of people with ASD.	x			x		x	knowledge, competence
Figueiras et al. 2014 ¹⁰⁰	18 Municipal Health Units in Belém, Pará, Brazil	Health professionals in primary care (n=221)	Cerebral palsy, autism, and preterm new-borns	A course including lectures, discussion, videos, readings, and practical assessments related to assessing developmental disabilities. Participants were followed up 1-3 years later to see the impact on their practice.	x		x			x	knowledge, competence

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APPENDIX 4: MICS CHILDREN UNDER FIVE QUESTIONNAIRE - CHILD FUNCTIONING MODULE

UCF1. Check UB2: Child's age?	AGE 0 OR 1 1 AGE 2, 3 OR 4 2	1 ⇒ End
UCF2. I would like to ask you some questions about difficulties (name) may have. Does (name) wear glasses?	YES 1 NO 2	
UCF3. Does (name) use a hearing aid?	YES 1 NO 2	
UCF4. Does (name) use any equipment or receive assistance for walking?	YES 1 NO 2	
UCF5. In the following questions, I will ask you to answer by selecting one of four possible answers. For each question, would you say that (name) has: 1) no difficulty, 2) some difficulty, 3) a lot of difficulty, or 4) that (he/she) cannot at all. <i>Repeat the categories during the individual questions whenever the respondent does not use an answer category:</i> Remember the four possible answers: Would you say that (name) has: 1) no difficulty, 2) some difficulty, 3) a lot of difficulty, or 4) that (he/she) cannot at all?		
UCF6. Check UCF2: Child wears glasses?	YES, UCF2=1 1 NO, UCF2=2 2	1 ⇒ UCF7A 2 ⇒ UCF7B
UCF7A. When wearing (his/her) glasses, does (name) have difficulty seeing? UCF7B. Does (name) have difficulty seeing?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT SEE AT ALL 4	
UCF8. Check UCF3: Child uses a hearing aid?	YES, UCF3=1 1 NO, UCF3=2 2	1 ⇒ UCF9A 2 ⇒ UCF9B
UCF9A. When using (his/her) hearing aid(s), does (name) have difficulty hearing sounds like peoples' voices or music? UCF9B. Does (name) have difficulty hearing sounds like peoples' voices or music?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT HEAR AT ALL 4	
UCF10. Check UCF4: Child uses equipment or receives assistance for walking?	YES, UCF4=1 1 NO, UCF4=2 2	1 ⇒ UCF11 2 ⇒ UCF13
UCF11. Without (his/her) equipment or assistance, does (name) have difficulty walking?	SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT WALK AT ALL 4	
UCF12. With (his/her) equipment or assistance, does (name) have difficulty walking?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT WALK AT ALL 4	1 ⇒ UCF14 2 ⇒ UCF14 3 ⇒ UCF14 4 ⇒ UCF14
UCF13. Compared with children of the same age, does (name) have difficulty walking?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT WALK AT ALL 4	

UCF14. Compared with children of the same age, does (name) have difficulty picking up small objects with (his/her) hand?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT PICK UP AT ALL 4	
UCF15. Does (name) have difficulty understanding you?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT UNDERSTAND AT ALL 4	
UCF16. When (name) speaks, do you have difficulty understanding (him/her)?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT BE UNDERSTOOD AT ALL 4	
UCF17. Compared with children of the same age, does (name) have difficulty learning things?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT LEARN THINGS AT ALL 4	
UCF18. Compared with children of the same age, does (name) have difficulty playing?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT PLAY AT ALL 4	
UCF19. The next question has five different options for answers. I am going to read these to you after the question. Compared with children of the same age, how much does (name) kick, bite or hit other children or adults? Would you say: not at all, less, the same, more or a lot more?	NOT AT ALL 1 LESS 2 THE SAME 3 MORE 4 A LOT MORE 5	

APPENDIX 5: MICS WOMEN’S QUESTIONNAIRE - ADULT FUNCTIONING MODULE

AF1. Check WB4: Age of respondent?	AGE 15-17 YEARS..... 1 AGE 18-49 YEARS..... 2	1⇒End
AF2. Do you use glasses or contact lenses? <i>Include the use of glasses for reading.</i>	YES..... 1 NO..... 2	
AF3. Do you use a hearing aid?	YES..... 1 NO..... 2	
AF4. I will now ask you about difficulties you may have doing a number of different activities. For each activity there are four possible answers. You may say that you have 1) no difficulty, 2) some difficulty, 3) a lot of difficulty or 4) that you cannot do the activity at all. <i>Repeat the categories during the individual questions whenever the respondent does not use an answer category:</i> Remember, the four possible answers are: 1) no difficulty, 2) some difficulty, 3) a lot of difficulty, or 4) that you cannot do the activity at all.		
AF5. Check AF2: Respondent uses glasses or contact lenses?	YES, AF2=1..... 1 NO, AF2=2..... 2	1⇒AF6A 2⇒AF6B
AF6A. When using your glasses or contact lenses, do you have difficulty seeing? AF6B. Do you have difficulty seeing?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT SEE AT ALL..... 4	
AF7. Check AF3: Respondent uses a hearing aid?	YES, AF3=1..... 1 NO, AF3=2..... 2	1⇒AF8A 2⇒AF8B
AF8A. When using your hearing aid(s), do you have difficulty hearing? AF8B. Do you have difficulty hearing?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT HEAR AT ALL..... 4	
AF9. Do you have difficulty walking or climbing steps?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT WALK/ CLIMB STEPS AT ALL 4	
AF10. Do you have difficulty remembering or concentrating?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT REMEMBER/ CONCENTRATE AT ALL 4	
AF11. Do you have difficulty with self-care, such as washing all over or dressing?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3 CANNOT CARE FOR SELF AT ALL 4	
AF12. Using your usual language, do you have difficulty communicating, for example understanding or being understood?	NO DIFFICULTY 1 SOME DIFFICULTY 2 A LOT OF DIFFICULTY 3	

APPENDIX 6: MULTI-LEVEL MODEL FOR ARI, DIARRHOEA AND FEVER CARE PROVIDER ACCORDING TO CHILD'S
DISABILITY STATUS BY COUNTRY, 2017-2020

ARI Provider												
Country	Unadjusted OR						Adjusted OR (age, sex, wealth)					
	N	Unspecified health facility worker	N	trained health worker OR	N	non-health professional OR	N	Unspecified health facility worker	N	trained health worker OR	N	non-health professional OR
CAR	9	1.00	4	0.52	13	1.35	9	1.00	4	0.52	13	1.40
Chad	14	1.00	9	2.14	12	2.08	14	1.00	9	1.98	12	2.01
DRC	8	1.00	3	0.63	6	1.22	8	1.00	3	0.54	6	1.05
Gambia	12	1.00	1	1.33	0	8.00	12	1.00	1	1.16	0	4.70
Ghana	21	1.00	0	0.00	4	4.83	21	1.00	0	0.00	4	4.78
Lesotho	4	1.00	0	0.00	0	0.00	4	1.00	0	0.00	0	0.00
Madagascar	8	1.00	2	0.22	6	1.60	8	1.00	2	0.23	6	1.74
Malawi	27	1.00	6	1.78	3	1.59	27	1.00	6	1.68	3	1.50
Sierra Leone	23	1.00	2	1.74	3	1.24	23	1.00	2	1.72	3	1.23
Togo	2	1.00	4	0.00	7	6.00	2	1.00	4	0.00	7	9.14

Appendix 6 (continued)

Diarrhoea Provider												
Country	Unadjusted OR						Adjusted OR (age, sex, wealth)					
	N	Unspecified health facility worker	N	trained health worker OR	N	non-health professional OR	N	Unspecified health facility worker	N	trained health worker OR	N	non-health professional OR
CAR	21	1.00	3	0.16	14	1.13	21	1.00	3	0.68	14	1.19
Chad	35	1.00	11	1.23	35	8.57	35	1.00	11	1.15	35	0.81
DRC	15	1.00	4	2.24	12	1.78	15	1.00	4	2.20	12	1.76
Gambia	26	1.00	2	1.11	0	0.00	26	1.00	2	1.26	0	0.00
Ghana	31	1.00	0	0.00	1	0.61	31	1.00	0	0.00	1	0.57
Lesotho	3	1.00	0	0.00	0	0.00	3	1.00	0	0.00	0	0.00
Madagascar	5	1.00	0	0.00	4	3.18	5	1.00	0	0.00	4	3.43
Malawi	32	1.00	7	1.75	7	1.59	32	1.00	7	1.71	7	1.54
Sierra Leone	24	1.00	0	0.31	2	0.65	24	1.00	0	0.33	2	0.56
Togo	6	0.77	2	0.91	8	1.00	6	0.78	2	1.12	8	1.00

Appendix 6 (continued)

Fever Provider												
Country	Unadjusted OR						Adjusted OR (age, sex, wealth)					
	N	Unspecified health facility worker	N	trained health worker OR	N	non-health professional OR	N	Unspecified health facility worker	N	trained health worker OR	N	non-health professional OR
CAR	27	1.00	9	1.34	28	1.69	27	1.00	9	1.33	28	1.69
Chad	36	1.00	13	1.60	30	1.32	36	1.00	13	1.78	30	1.41
DRC	44	1.00	8	1.46	14	0.67	44	1.00	8	1.57	14	0.57
Gambia	32	1.00	2	0.62	1	1.58	32	1.00	2	0.59	1	0.88
Ghana	61	1.00	2	0.28	4	1.11	61	1.00	2	0.28	4	1.08
Lesotho	8	1.00	0	0.00	0	0.00	8	1.00	0	0.00	0	0.00
Madagascar	15	1.00	5	0.70	7	0.78	15	1.00	5	0.63	7	0.66
Malawi	70	1.00	12	2.52	4	0.40	70	1.00	12	2.43	4	0.38
Sierra Leone	57	1.00	4	1.29	8	1.08	57	1.00	4	1.31	8	1.09
Togo	14	0.77	8	3.78	9	1.47	14	0.78	8	5.00	9	1.66

APPENDIX 7: CHAPTER 5 SENSITIVITY ANALYSIS

	OR	Lower C.I.	Upper C.I.
ARI			
No imputation	1.34	1.17	1.53
Missing included in exposed	1.32	1.16	1.5
Missing included in unexposed	1.32	1.16	1.5
ARI Care			
No imputation	0.9	0.69	1.18
Missing included in exposed	0.89	0.69	1.16
Missing included in unexposed	0.89	0.69	1.16
Diarrhoea			
No imputation	1.3	1.14	1.47
Missing included in exposed	1.29	1.15	1.46
Missing included in unexposed	1.29	1.15	1.46
Diarrhoea Care			
No imputation	1.07	0.85	1.36
Missing included in exposed	1.11	0.88	1.4
Missing included in unexposed	1.11	0.88	1.4
Fever			
No imputation	1.21	1.08	1.33
Missing included in exposed	1.2	1.07	1.33
Missing included in unexposed	1.2	1.07	1.33
Fever Care			
No imputation	1.06	0.87	1.29
Missing included in exposed	1.06	0.88	1.28
Missing included in unexposed	1.06	0.88	1.28

APPENDIX 8: CHAPTER 6 SENSITIVITY ANALYSIS

	Healthcare provider											
	Doctor			Community health provider			No-one/relative					
	OR	Lower CI	Upper CI	OR	Lower CI	Upper CI	OR	Lower CI	Upper CI	OR	Lower CI	Upper CI
ANC Coverage				-	-	-	-	-	-	-	-	-
No imputation	0.64	0.39	1.05	-	-	-	-	-	-	-	-	-
Missing included in exposed	0.64	0.39	1.05	-	-	-	-	-	-	-	-	-
Missing included in unexposed	0.64	0.39	1.05	-	-	-	-	-	-	-	-	-
ANC Provider												
No imputation	-	-	-	1.23	0.82	1.88	0.57	0.07	4.71	-	-	-
Missing included in exposed	-	-	-	1.23	0.87	1.75	0.51	0.39	6.64	-	-	-
Missing included in unexposed	-	-	-	1.23	0.87	1.75	0.51	0.39	6.64	-	-	-
Skilled Birth Attendant												
No imputation	-	-	-	1.40	0.93	2.11	0.86	0.51	1.45	0.9	0.53	1.53
Missing included in exposed	-	-	-	1.44	1.03	2.01	0.76	0.49	1.18	0.97	0.6	1.57
Missing included in unexposed	-	-	-	1.44	1.03	2.01	0.76	0.49	1.18	0.97	0.6	1.57
PNC on baby												
No imputation	-	-	-	0.99	0.44	2.2	0.88	0.32	2.46	0.8	0.32	3.26
Missing included in exposed	-	-	-	1.05	0.57	1.94	0.69	0.29	1.66	0.64	0.19	2.09
Missing included in unexposed	-	-	-	1.05	0.57	1.94	0.69	0.29	1.66	0.64	0.19	2.09
PNC on mother												
No imputation	-	-	-	0.82	0.29	2.34	1.58	0.57	4.35	0.35	0.84	1.48
Missing included in exposed	-	-	-	0.85	0.38	8.01	1.55	0.68	3.54	0.47	0.13	1.71
Missing included in unexposed	-	-	-	0.85	0.38	8.01	1.55	0.68	3.54	0.47	0.13	1.71

APPENDIX 9: OXTREC ETHICS APPROVAL LETTER

Oxford Tropical Research Ethics Committee

University of Oxford
Research Services, Research Governance, Ethics & Assurance
Boundary Brook House, Churchill Drive, Oxford OX3 7GB
Tel. +44 (0)1865 (2)82106
E-mail: oxtrecrec@admin.ox.ac.uk



Ms Sara Rotenberg
Radcliffe Observatory Quarter
Woodstock Road
Oxford
OX2 6GG

6 July 2022

Dear Ms Rotenberg

Full Title of Study: Improving disability training for health workers: a qualitative study of stakeholder perspectives

OXTREC Reference: 534-22

Thank you for your email of 06/07/2022 and for your updated documents.

I am pleased to confirm that approval has now been granted for this study. This is valid for the planned duration of the study as detailed in the application and is subject to receiving local ethical approval (if this approval has not yet been received).

The documents approved for this study are as follows:

Documents:	Version:	Date:
Minimal risk form		
PIS	2.0	6July22
Consent form	2.0	6July22
Topic Guide	3.0	9May22

Any subsequent changes to the application must be submitted to the Committee as an Amendment. This should include a letter to give the reasons for the proposed modifications and all revised documents with changes tracked.

Please ensure that you submit a completed Annual Report form on every anniversary of this approval and a final End of Study Report. The relevant forms can be found on the [Oxtrec website](https://researchsupport.admin.ox.ac.uk/governance/ethics).

Finally, please note the following **important information**:

Data safety—all studies

It is the responsibility of the PI to ensure that all data collected during the course of the study is stored

Tel: +44 (0)1865 (2)82106
Email: oxtrecrec@admin.ox.ac.uk Web: <https://researchsupport.admin.ox.ac.uk/governance/ethics>

and transferred safely and securely. Further guidance and advice are available from the [Research Data Team](#).

Only studies that will involve storing human tissue samples in Oxford

If you are planning to import the samples into England, you will need to make arrangements before the samples are transferred to store them under the governance of a Human Tissue Authority (HTA) licence. It is a legal requirement that any tissue or fluid made up of or containing human cells to be used for the purpose of research is stored on premises licensed by the HTA unless covered by an exemption. OxTREC approval is not a recognised exemption. Further information may be found on the University's [human tissue governance web pages](#).

Yours sincerely

DocuSigned by:

AB82F4C4C5154C5...

Ronja Bahadori
Research Support Manager, RGEA

for
Research Ethics Manager, OxTREC

APPENDIX 10: GHANA HEALTH SERVICE ETHICS APPROVAL LETTER

Ghana Health Service Ethics Review Committee

*In case of reply the
number and date of this
Letter should be quoted.*

*My Ref.: ERC-
Your Ref. No.*



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Email: ethics.research@ghs.gov.gh
December, 2022

Dr. John K. Ganle
School of Public Health
University of Ghana
Accra

GHS-ERC Review Comments

Protocol ID NO: GHS-ERC 005/12/22

Protocol Title: “Improving Health Worker Training on Disability and Sexual and Reproductive Health: A Qualitative Study of Stakeholder Perspectives”

Dear Dr. John K. Ganle,

Please find the review comments of the protocol titled: “**Improving Health Worker Training on Disability and Sexual and Reproductive Health: A Qualitative Study of Stakeholder Perspectives**” that was submitted to the ERC secretariat for review.

We wish to inform you that the above-mentioned protocol underwent full general meeting review, and that approval has been granted for implementation of the study.

Your approval letter is being processed and you will be notified when it is ready for collection.

We wish you a successful project implementation.

Accept our congratulations.

Administrator, Ghana Health Service Ethics Review Committee
Name: Nana Abena Apatu
For: Chairperson

APPENDIX 11: INTERVIEW GUIDE –TRAINEES

Part 1: Background Demographics

Date and Place of interview	
Gender	☐ Male ☐ Female
What type of health facility do you work in?	☐ Regional/district Hospital ☐ Health centre/clinic ☐ Health post
What is your role at the [insert health facility]?	☐ Doctor ☐ Nurse ☐ Midwife ☐ Other (specify):.....
Do you have any previous experiences with disability, such as a family member or personal connection?	☐ Family ☐ Personal ☐ Professional ☐ Other (specify).....
How many trainings do you remember having on disability from your medical training, CPD, or other training?	
When was your most recent training on SRH and disability?	

Part 2: Previous Disability Trainings

In this interview, we would like to hear about your experiences of undertaking disability training and how it could be improved. I would also like to hear your ideas for how to improve training for the future. The interview will last approximately 40 minutes, but we can take breaks as needed and we can skip over any questions you would prefer not to answer.

- Please tell me a little bit about the training you were involved in.
 - *Potential probing questions:*
 - In which disability training were you involved?
 - In what context was the training delivered (i.e., medical school, CPD, etc.)?
 - What topics did the disability training cover?
 - Who taught the disability training?
 - Which organisations was it run by?
 - What was the frequency/length of the training?
- What did you think of the disability training you described?
- How helpful have you found the training?
- What do you think was the most important thing you took away from the training?
- Was there anything particularly challenging about the training?
- How would you change it?

- Have you attended any other trainings on marginalized groups (i.e., gender, HIV, etc.)?
 - *Potential probing questions:*
 - Which one was most effective?
 - What made the training effective?
 - Are there any strategies/ways you learned that would be helpful in disability trainings?
 - Was there any content that related to disability in these trainings?

Part 3: Vision for improving disability training.

- *For health providers:* what (if anything) have you used from trainings in your medical practice?
 - Looking back, are there any areas that you think would have been useful to cover?
 - *Potential probing questions:*
 - Why is that?
 - Why do you think that wasn't covered?
 - Is there anything that was not included that would help you be a better clinician for patients with disabilities?
- Have you found any of the areas covered in the training difficult to actually use in practice?
 - Can you give me an example?
 - Is this a shortcoming of training or something else?
- What areas do you think disability training should include?
- If you were designing the training, what sort of format would you use?
 - Are there specific topics/formats your cadre of health workers would benefit from?
- In your view, how often should healthcare staff undertake disability training? Why?

Closing: Is there anything else important that I should have asked you/anything you wanted to tell me about that we haven't got to?

APPENDIX 12: INTERVIEW GUIDE – TRAINERS

Part 1: Background Characteristics

Date and Place of interview (write-in)	
Gender	☐ Male ☐ Female
What type of organisation do you work for?	☐ University/medical school ☐ NGO ☐ Government
What is your role at the [organisation] (write in)?	
Do you have any previous experiences with disability?	☐ Family ☐ Personal ☐ Professional ☐ Other (specify):.....
How many trainings have you conducted?	
When was your most recent training on SRH and disability?	

Part 2: Previous Disability Trainings – asked to all participants.

In this interview, we would like to hear about your experiences of undertaking disability training and how it could be improved. I would also like to hear your ideas for how to improve training for the future. The interview will last approximately 40 minutes, but we can take breaks as needed and we can skip over any questions you would prefer not to answer.

- Please tell me a little bit about the training you were involved in.
 - *Potential probing questions:*
 - In which disability training were you involved?
 - In what context was the training delivered (i.e., medical school, CPD, etc.)?
 - What topics did the disability training cover?
 - Who taught the disability training?
 - Which organisations was it run by?
 - What was the frequency/length of the training?
- What did you think of the disability training you described?
- How helpful have you found the training?
- What do you think was the most important thing you took away from the training?
- Was there anything particularly challenging about the training?
- How would you change it?
- Have you attended any other trainings on marginalized groups (i.e., gender, HIV, etc.)?
 - *Potential probing questions:*
 - Which one was most effective?
 - What made the training effective?

- Are there any strategies/ways you learned that would be helpful in disability trainings?
- Was there any content that related to disability in these trainings?

Part 3: Vision for improving disability training - Questions for trainers (i.e., disabled person, professor, etc.) and NGOs/implementing partners.

- How did you get involved in health worker training on disability?
What do you think are the most important aspects the training should include?
 - *Potential probing questions:*
 - Why those?
 - What do think is the best way of delivering disability training? (Face to face, virtual, small groups, personal experiences, etc.)
- What are some of the challenges to delivering disability training?
 - *Potential probing questions:*
 - Is there any resistance to implementing training?
 - What are some of the barriers (probe with costs, government support, lack of space in curriculum, etc.)?
 - *Potential probing questions:*
 - What are the highlights from participant feedback, if collected?
 - Are there things health professionals' say they enjoyed?
 - What makes you think the people enjoy [aspect of training]?
- How do you find health professionals' reactions to the training?
 - Do you collect feedback on training or do any monitoring and evaluation?
- Are there things you'd hope training would look like/include but aren't possible? If so, why not?
 - Are there specific topics/formats certain cadres of health workers would benefit from?
- In your view, how often should healthcare staff undertake disability training? Why?

Closing: How about, is there anything else important that I should have asked you/anything you wanted to tell me about that we haven't got to?

APPENDIX 13: PARTICIPANT INFORMATION SHEET

Participant Information Sheet (Literate Participants)

Study Title

Improving disability training for health workers: a qualitative study of stakeholder perspectives

Introduction

I would like to invite you to take part in a research study exploring stakeholders' experiences of disability training for health workers. Joining the study is entirely up to you. Before you decide, you need to understand why the research is being done and what it would involve. I will go through this information sheet with you, and answer any questions you may have. Ask questions if anything you read is not clear or you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not to take part.

What is the purpose of the study?

The University of Oxford and School of Public Health (University of Ghana) are conducting this research to learn about how we can improve training on disability for health workers. We are asking participants who have been involved in any disability trainings for health workers as participants, facilitators, or course leaders to participate.

Why have I been asked to participate?

You have been invited to participate because you have experience of disability training in some capacity (participant, facilitator, course leader, etc.).

What is involved for me?

You will be asked to participate in a 30 to 60 minute interview about your experiences taking part in disability training for health workers. Questions will be about your experiences leading or participating the training, what you thought of it, and how these types of trainings could be improved in the future.

What will happen to my data?

Research data (i.e., data that is collected as part of the study) will be used by researchers at both University of Oxford and University of Ghana to understand how to improve training on disability for health workers. The data will not be retained or used for future studies. Personal data (i.e., research from which participants can be identified such as name, gender, position, etc.) will be minimized as much as possible and only available to the lead researcher.

Are there any risks in taking part?

We do not anticipate any physical adverse effects and no major psychological distress from participating in the interviews. Participants will also be able to take breaks if required and/or withdraw consent from participation.

What are the benefits of taking part?

Potential benefits include the opportunity to contribute towards research to assist with improving health worker training through a set of global recommendations.

Do I have to take part?

Participation is entirely voluntary, and participants can ask questions or withdraw from the study at any point in time.

Has the study been reviewed by an ethics committee?

This is to Certify that this Study's Inform Consent

Form Has Been Approved by GHS-ERC for the

Period: 20/12/2022 to 19/12/2023

Sign: [Signature] Date: 27/01/2023

Name: Zelma Alley

GHS-ERC Administrator

Yes, this study has been reviewed and accepted by the University of Oxford's Oxford Tropical Research Ethics Committee (OxTREC) (Ref: 534-22) and Ghana Health Service Ethics Review Committee

What if I have any questions or want to raise a concern?

Participants are free and welcome to ask questions or raise concerns on any aspects of the research that they do not understand or need further clarification. If any participant has concerns about any aspect of this project, please speak to Dr. John K Ganle of the School of Public Health, University of Ghana on telephone (0249957505) or email (jganle@ug.edu.gh) or Sara Rotenberg (sara.rotenberg@phc.ox.ac.uk or +44 7549 183858). For questions regarding the ethical aspects of this research or questions about your rights as a research participant, you may also contact Madam Nana Abena Apatu, the Administrator of the Ghana Health Service Ethics Review Committee, on 0503539896.

How will my data be protected?

The University of Oxford is responsible for ensuring the safe and proper use of any personal information you provide, solely for research purposes.

This is to Certify that this Study's Inform Consent
Form Has Been Approved by GHS-ERC for this
Period. 20/12/2022 to 19/12/2023
Sign. *[Signature]* Date 21/01/2023
Name. Zelma Alstey
GHS-ERC Administrator

APPENDIX 14: QUALITATIVE STUDY CONSENT FORM

CONSENT FORM (Literate Participants)

Study Title

Improving health worker training on disability and sexual and reproductive health: a qualitative study of stakeholder perspectives

PARTICIPANT'S STATEMENT

I have had the nature and purpose of the research explained to me. I believe that I understand what is being proposed and what will be required of me if I take part in this study.

I have been informed about what the data collected in this study will be used for, to whom it may be disclosed, and how long it will be retained.

I understand that my personal involvement and my particular data will remain strictly confidential. Only researchers involved in the investigation will have access.

I have had the opportunity to discuss the details and ask questions about the research, and any question I have asked have been answered to my satisfaction.

I understand that my participation is entirely voluntary and that I may withdraw from this study at any time without giving a reason and that this will be without any detriment to me.

I understand that I will be given copies of the participants' information and signed or thumb-printed consent form for my personal record.

I understand that the interview will be audio-recorded and pictures may be taken. To this arrangement, I hereby 1) Agree; 2) Disagree.

I understand that any audio recordings, pictures or any information obtained from me through my participation will be kept confidential and used solely for the purposes of the research.

I agree to the arrangements described in the information sheet as far as they relate to my participation and hereby voluntarily consent to participate as a subject in the study.

Name of Participant.....

Participants' Signature OR Thumb Print Date:

INVESTIGATOR'S STATEMENT

I certify that the participant has been given ample time to read and learn about the study. All questions and clarifications raised by the participant have been addressed.

Researcher's name..... Signature

Date.....

This is to Certify that this Study's Inform Consent
Form Has Been Approved by GHS-ERC for the
Period 20/12/2022 to 19/12/2023
Sign. SA Date 27/10/2023
Name Zelma Adesey
GHS-ERC Administrator

12 REFERENCES

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