What does a disability-inclusive pandemic response mean for Liberia and how can it lead to genuine systemic change?

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Declaration

I, Ellie Frances Cole, confirm that the work presented in my thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

People with disabilities globally have been disproportionately affected by the COVID-19 pandemic (FCDO, 2020; UN, 2020), but there has been little research on how people with disabilities in low-income countries have been affected by the response to the pandemic, and how this compares with other emergency health responses. My research aimed to understand in-depth how people with disabilities in Liberia experienced the COVID-19 response, and how this compares with their experience of the Ebola response. This is a unique opportunity to analyse systemic ways in which people with disabilities face exclusion from emergency health responses and public health programmes, putting them at greater risk.

Epidemic responses are also an opportunity to reveal broader structural inequalities. People with disabilities faced significant exclusion during the Ebola response in Liberia (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021) and my research sought to understand whether and how this was different in the COVID-19 response.

My research has two main questions:

- How have people with disabilities in Liberia experienced recent epidemic responses and public health measures and to what extent have they been included?
- What approaches can enable people with disabilities to participate in and lead inclusive systemic change?

My project gathered in-depth qualitative data on disability in Liberia, building upon previous research[1]. My research has three main strands: a photovoice project with people with disabilities and caregivers and service providers; key informant interviews with actors involved in the COVID-19 and Ebola epidemic responses; and life-history interviews with people with disabilities in urban and rural settings.

Data were analysed using reflexive thematic analysis (Braun and Clarke, 2006, 2012) using theoretical frameworks on structural violence (Galtung, 1969; Farmer, 2004) and social justice (Fraser, 1997, 2009). Results formed a multidimensional understanding of the impact of epidemic response and recovery on people with disabilities. I examined

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[1] Dr Maria Kett, PI; ES/L005719/1; Kett, Cole and Carew, 2017

inequalities experienced by people with disabilities during public health crises, exploring issues including participation, trust, and poverty (Austin et al, 2021; Kett et al, 2021) to understand how people with disabilities can achieve meaningful inclusion in epidemic responses.

Findings challenge normative assumptions around humanitarian responses to show that systemic exclusions and material deprivations experienced by people with disabilities during times of health crises exacerbate existing systems of exclusion and pervasive ableism, rendering people with disabilities ‘invisible’ to epidemic responses. Results also showed that rurality was a driver of structural violence experienced by people with disabilities, which increased between the Ebola and COVID-19 outbreaks. However, findings also contested assumptions around people with disabilities as passive recipients of aid, revealing a confidence among people with disabilities to actively ‘combat’ COVID-19 due to their learning from the Ebola outbreak.

This research makes a timely contribution by centring the experiences of people with disabilities during two public health emergencies in an extremely resource-constrained context. These findings have relevance beyond Liberia, and the empirical data can offer lessons for other low-income settings on how disability can be meaningfully included in humanitarian preparedness, planning and emergency response and recovery. The research also has global relevance, where insights can inform more inclusive emergency planning and implementation at international levels. By highlighting the systemic gaps encountered by people with disabilities in emergency responses, this work underscores the urgent need to embed disability inclusion as a core principle and not as an afterthought in crisis response frameworks everywhere. Given the increasing frequency and complexity of global health crises, this research is well-placed to have impact within academia and in global health, development and advocacy arenas.

Impact statement

This research project has collected empirical evidence on how people with disabilities in Liberia navigated two major health crises: Ebola and COVID-19. Given the increasing frequency and complexity of global health crises, this research is timely, and its insights have the potential for real impact within academia and in global health, development and advocacy arenas.

Within academia, this project offers an interdisciplinary contribution to the literature examining health crises and disability through the lens of structural violence and social justice. Uniquely, this research enables comparisons between two significant disease outbreaks and can provide insight into how structural violence is (re)produced during health emergencies. Findings challenge normative assumptions around humanitarian responses to show that systemic exclusions and material deprivations experienced by people with disabilities during times of health crises exacerbate existing systems of exclusion and ableism.

Research findings have already been presented at:

- Development Studies Association conference (June 2024, London);
- Central European University conference (April 2024, Vienna);
- DisabilityMatters seminar series at the University of Sheffield (December 2023, Sheffield);
- guest lectures for UCL's iBSc Global Health programme (March 2022 and February 2023, London); and
- League of European Research Universities doctoral summer school (July 2024, Heidelberg).

Future impact activities will include an upcoming book chapter on disability and infectious disease, which will draw on my research as case studies, as well as a series of peer-reviewed articles addressing both empirical findings and my methodological approach. Further opportunities to present findings will include guest lectures, seminars and conferences within UCL and beyond.

Beyond academia, results were first presented in Liberia at a multi-stakeholder 'findings sharing meeting' in Monrovia. The meeting was attended by the disability community, government representatives, UN agencies, Red Cross, as well as local and international NGOs, civil society, and importantly the research participants themselves. This took a collaborative approach to co-producing recommendations, ensuring that they were contextually appropriate and which promoted ownership.

A research summary brochure was also produced and disseminated at the meeting. It is now being used by Liberia's National Union of Organisations of the Disabled as an advocacy and awareness-raising tool. This brochure has also been shared with disability-focused researchers at UCL and other London universities.

This research makes a timely contribution by centring the experiences of people with disabilities during two public health emergencies in an extremely resource-constrained context. These findings have relevance beyond Liberia, and the empirical data can offer lessons for other low-income settings on how disability can be meaningfully included in humanitarian preparedness, planning and emergency response and recovery. The research also has global relevance, where insights can inform more inclusive emergency planning and implementation at international levels. By highlighting the systemic gaps encountered by people with disabilities in emergency responses, this work underscores the urgent need to embed disability inclusion as a core principle and not as an afterthought in crisis response frameworks everywhere.

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And finally, Zazu the cat – my best friend in Liberia and who looked after me while I was poorly. I miss you terribly.

Contents

Figures

Abbreviations

ACPA	Accra Comprehensive Peace Agreement
ACS	American Colonization Society
ACT-A	Access to COVID-19 Tools Accelerator
AIFO	Associazione Italiana Amici di Raoul Follereau
BPHS	Basic package of health services
BRI	Belt and Road Initiative
CDF	County Development Fund
CHO	Chief Health Officer
COVAX	COVID-19 Vaccines Global Access
COVID-19	SARS-CoV-2
DDRR	Disarmament, demobilisation, rehabilitation and reintegration
DLA	Disability Living Allowance
DRC	Democratic Republic of the Congo
ECOMOG	Economic Community of West African States Monitoring Group
ECOWAS	Economic Community of West African States
ESRP	Economic Stabilization and Recovery Plan
ETU	Ebola treatment unit
FGM	Female genital mutilation
HIES	Household Income and Expenditure Survey
HIPC	Heavily Indebted Poor Countries
HRDTF	Human Rights and Disability Task Force
HRPD	Human Rights Protection Division

ICF	International Classification of Functioning, Disability and Health
IDSR	Integrated diseases surveillance and response
IGNU	Interim Government of National Unity
IMS	Incident Management System
INCHR	Independent National Commission on Human Rights
INPFL	Independent National Patriotic Front of Liberia
KII	Key informant interview
LRCS	Liberian Red Cross Society
LURD	Liberians United for Reconciliation and Democracy
MODEL	Movement for Democracy in Liberia
MOHSW	Ministry of Health and Social Welfare
MS	Multiple sclerosis
MSF	Médecins sans Frontières [Doctors without Borders]
NAP	National Action Plan for the Inclusion of People with Disabilities
NPFL	National Patriotic Front of Liberia
NUOD	National Union of Organizations of the Disabled
OIC	Officer in Charge
OPD	Organisation of people with disabilities
PHEIC	Public Health Emergency of International Concern
PPE	Personal protective equipment
PRC	People’s Redemption Council
PRS	Poverty Reduction Strategy
RUF	Revolutionary United Front

SDGs	Sustainable Development Goals
SLI	Sign language interpreter
TRC	Truth and Reconciliation Commission
ULIMO	United Liberation Movement
UNCRPD	UN Convention on the Rights of Persons with Disabilities
UNDP	United Nations Development Programme
UNMIL	UN Mission in Liberia
WFP	World Food Programme
WHO	World Health Organization

Chapter one: introductions

1.1. Introduction

This thesis examines the experiences of people with disabilities during public health emergencies in Liberia, with a particular focus on their experience of the responses to the Ebola and COVID-19 outbreaks in 2014-15 and 2020-2022, respectively. This opening chapter comprises three parts. First, it introduces the Republic of Liberia, providing demographic, geographic, political, and socioeconomic contexts. Second, it outlines the research project itself, including the rationale, aims, and research questions. Finally, it presents the structure of the thesis, summarising the content and purpose of each chapter.

1.2. Country information

The Republic of Liberia is a small low-income country in West Africa with a population of around five million people (LISGIS, 2023). Liberia is an extremely youthful country. 60% of people are under 25, with a median age of just 18.8 years (UNDESA, 2024). Almost a quarter of citizens reside in and around the capital, Monrovia. Liberia covers approximately 43,000 square miles and has 320 miles of coastline. The country is divided into 15 counties (**Figure 1**) and shares borders with Guinea and Sierra Leone to the north and northwest, Côte d'Ivoire to the east, and the Atlantic Ocean to the south. It has a tropical climate with a prolonged and heavy rainy season that typically lasts from May to October, which severely affects mobility, infrastructure, and agricultural productivity.

Liberia is home to 16 distinct ethnic groups, with the Kpelle being the largest. More than 20 languages are spoken across the country, although English is the official language and widely used in government and education. Religion plays a central role in Liberian life. According to the 2008 census, 85.6% of the population identify as Christian, 12.2% as Muslim, and the remainder follow primary 'traditional' or other belief systems (LISGIS, 2008). These identities are not mutually exclusive, and many Liberians simultaneously practise Christianity or Islam alongside traditional animist beliefs (Ellis, 2007).

Figure 1 map of Liberia counties

Environmental and infrastructural factors play a significant role in Liberia. The road network is limited and often in severe disrepair, meaning that some places can be impassable during the rainy season, particularly in rural and remote areas. Access to clean water, electricity, and health services is inconsistent, with rural populations facing the most significant challenges (Republic of Liberia, 2020b). This neglect of rural and remote areas has been a consistent feature of Liberia's governance since its founding. This also includes the neglect of health delivery and has led to people with disabilities having difficulty accessing health services, or being completely unable to (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021). This also has direct implications for effective disease surveillance and timely outbreak response.

1.2.1. Political history

Liberia was founded in 1822 by predominantly formerly enslaved people from the United States of America, who were supported by the American Colonization Society (see chapter two; Ciment, 2014). These settlers, who became known as Americo-Liberians, brought with them Western customs, social norms, and governance structures, which they imposed on the indigenous populations, often violently. While

Liberia was never colonised by European imperial powers[2], it was shaped by a form of quasi-colonialism – politically independent, yet heavily influenced by US interests and dependent on foreign capital and aid (Moran, 2008). Liberia declared its independence from the American Colonization Society in 1847, making it the oldest republic on the African continent (Ciment, 2014). However, this independence masked deeply entrenched inequalities, with power and privilege concentrated in the hands of the Americo-Liberian elite for much of the country's history.

Liberia's complex and unequal foundations contributed to a series of long-standing social, political, and economic tensions. These culminated in two protracted civil wars spanning 1989-1997 and 1999-2003. The consequences of these conflicts remain evident today (Farmer, 2020). An estimated 250,000 people were killed, and nearly two million were displaced internally or sought refuge in neighbouring countries and beyond (Crawley and Fynn Bruey, 2022). The wars devastated the nation's infrastructure, decimated institutions, and left a health system already fragile from decades of neglect in near-collapse (World Bank, 2018). In addition to widespread physical destruction, the wars left behind complex legacies of trauma, mistrust, and displacement. These historical wounds have significant implications for public service delivery and emergency response, particularly for communities that have long been the most marginalised, including people with disabilities. As this thesis explores, Liberia's past plays a central role in understanding how systemic exclusion has persisted – and how it might be challenged.

1.2.2. Economy/development

Liberia is extremely rich in natural resources such as rubber, iron ore, timber, and (famously) diamonds. Yet despite this, Liberia remains one of the poorest countries in the world, ranking 177 out of 189 countries on the Human Development Index (UNDP, 2023). Poverty is extremely pervasive, with more than half the population living below the poverty line, the majority of whom live in extreme poverty (less than $2.15 per day;

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[2] Liberia is one of only two countries to not have been colonised in the 'scramble for Africa', which saw 90% of the continent claimed by just seven imperial nations between the late nineteenth century and 1912 (Pakenham, 1999). The other country is Ethiopia.

LISGIS, 2017). Because the country is so poor, there are limited public services, including weak health and education systems.

This paradox of resource wealth and human poverty reflects Liberia's deep-rooted structural issues, shaped by patterns of neocolonial predatory extraction. Historically, the profits from natural resource exploitation have flowed not to the wider population but to a small domestic elite and to foreign investors, rather than being used to strengthen national infrastructure or improve public services (Ciment, 2014; Mitman, 2021). Concession agreements were negotiated in conditions of major power inequities, and revenues have frequently been mismanaged or lost to corruption, reinforcing patterns of underinvestment in essential sectors such as health, education, and social protection (Farmer, 2020). As a result, economic growth has not translated into development gains for most Liberians, perpetuating a cycle of poverty and exclusion that is both structural and global in nature.

Liberia's economic fragility also leaves it highly vulnerable to shocks, including disease outbreaks, commodity price fluctuations, and donor withdrawal. As the COVID-19 pandemic demonstrated, even modest disruptions in trade, mobility, or aid flows can have disproportionate impacts in low-income settings (Narayan *et al.*, 2022). Informal employment dominates the labour market, contributing over 40% of Liberia's GDP (World Economics, 2025). The vast majority of women (94%) and men (74%) work in the informal employment sector (Karra et al. 2023) and so are vulnerable to the same factors which affect the national economy.

1.2.3. Policies/social context

Liberia is a signatory to several international human rights instruments, including the UN Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006) and the Sustainable Development Goals (SDGs; United Nations, 2015). In principle, the ratification of the UNCRPD in 2012 committed the government to ensuring that people with disabilities enjoy the same rights and opportunities as non-disabled citizens. However, the implementation of these commitments remains limited, and people with disabilities continue to be some of the most excluded and marginalised people in Liberia, and are still routinely subjected to stigma and discrimination (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021; Dean *et al.*, 2022). Progress towards the SDGs has been slow (DASU, 2018) and was severely disrupted by the 2014–2015 Ebola outbreak and again by the COVID-19 pandemic (Republic of Liberia, 2020c). Liberia currently ranks 152 out of 167 countries on the Sustainable Development Report Index, only two of the 17 goals are on track to be achieved, and less than one-third of the SDG targets are achieved or on track (Sachs, Lafortune and Fuller, 2024).

Although disability is largely absent from most national development policies, several notable strategies do make substantive reference to disability rights. These include the *Poverty Reduction Strategy* (Republic of Liberia, 2008); the *National Human Rights Action Plan* (Republic of Liberia, 2019b); and the *Agenda for Transformation* (Republic of Liberia, 2013a), which outlines the country's ambition to achieve middle-income status by 2030. However, in practice, implementation of these policies is hindered by limited financial resources, weak institutional coordination, and low political will (UNDP Liberia, 2023). These constraints are exacerbated during times of crisis, when policy attention and funding are diverted to short-term emergency responses. The Ebola and COVID-19 outbreaks further disrupted fragile policy systems, diverting attention away from long-term development goals and deepening existing inequalities.

In practice, the development and implementation of national policies in Liberia are shaped by a complex interplay of political priorities, donor influence, and state capacity. While key documents tend to reflect international rights-based language – including around disability, gender, and inclusion – these commitments frequently remain aspirational rather than actionable. Policies are commonly developed in consultation with international actors and under conditions linked to aid or debt relief (such as with the Poverty Reduction Strategy; Republic of Liberia, 2008). This can result in misalignment with local priorities and implementation realities. As a result, there is often a disconnect between the rhetoric of inclusion and the lived experience of exclusion, particularly for marginalised groups such as people with disabilities.

There are three major disability organisations operating in Liberia (discussed in detail in **chapter two**): NUOD, an umbrella civil society organisation; the National Commission on Disability (NCD), a government statutory body with responsibility to monitor progress towards the UNCRPD; and the Group of 77, a quasi-governmental organisation with the objective of promoting the welfare of people with disabilities in Liberia. All these organisations operate in an extremely challenging environment and are chronically underfunded, which causes tensions as they compete for scarce resources.

1.3. Research rationale

People with disabilities globally have been disproportionately affected by the COVID-19 pandemic (FCDO, 2020; UN, 2020), but there has been limited research on how people with disabilities in low-income countries have been affected by the response to the pandemic, and how this compares with other emergency health responses. My research aims to understand in-depth how people with disabilities in Liberia experienced the COVID-19 response, and how this compares with their experience of Ebola. This is a unique opportunity to analyse systemic ways in which people with disabilities face exclusion from emergency health responses and public health programmes, putting them at greater risk.

This research builds on previous work, particularly the ESRC/DFID-funded study (2014–2017) *Understanding the Political and Institutional Conditions for Effective Poverty Reduction for Persons with Disabilities in Liberia*[3]. That study collected predominantly quantitative data on disability and Ebola as part of a large household survey, but it did not explore the lived experiences of people with disabilities during the outbreak. This study seeks to fill that gap using qualitative methods to examine how people with disabilities in Liberia navigated both the Ebola and COVID-19 responses, and how structural violence shaped their exclusion from public health measures.

Contemporary international power structures have an impact on Liberia. This is not limited to the World Health Organization (WHO), the United Nations (UN) and international non-governmental organisations (INGOs) but also includes regional and global financial institutions such as the World Bank and the African Development Bank, and the domestication of the UNCRPD and the SDGs – all of which impacts on its citizens. It is also the case during epidemics, where there are tensions between what is expected by the global community and what is acceptable to individuals and communities – this was a central issue in the effectiveness of the Ebola response

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[3] PI Professor Maria Kett, reference ES/L005719/1

(Richards, 2016; Abramowitz, 2017). Therefore, understanding how historic and contemporary power structures have shaped epidemic responses – and their impact on people with disabilities – is essential to gaining a deeper insight into the dynamics of the situation.

By examining two different health crises, this research provides a comparative perspective on how inclusion in (or exclusion from) emergency health responses has evolved. It also aims to highlight systemic barriers to participation, shedding light on how crisis responses can be made more inclusive in the future. This research is timely: as global health systems seek to build resilience in the aftermath of the pandemic, lessons from past crises – including Ebola and COVID-19 – can inform more disability-inclusive and effective public health responses in the future. Without an understanding of how people with disabilities experience these crises, responses will continue to reinforce patterns of exclusion and systemic neglect.

1.4. Disability models

The way that disability has been conceptualised has evolved over time and in response to changing social, political, and scientific contexts. These models influence how societies understand impairment and disability, shaping public attitudes, policy and practice, and the power underpinning systems of exclusion or inclusion. These models are not discrete and often overlap, sometimes in contradictory ways.

1.4.1. Charity/tragedy model

Historically, disability was treated as a personal or familial tragedy. In the charity model, disability is conceptualised as individual or family misfortune, with people with disabilities as objects of pity, as passive recipients who are dependent on the charity of others for support or care (Barnes, 2013). This model was reinforced by narratives of moral failure or wrongdoing, punishment or witchcraft. This led to widespread stigma or exclusion, positioning people with disabilities as burdens or aberrations.

1.4.2. Medical model

The rise of ‘modern’ medicine in the eighteenth century led to the emergence of the medical model. Here, disability is regarded as an individual pathology or deficit located in the body or mind, and which requires medical intervention to ‘fix’ the problem

(Shakespeare, 2013). When people with disabilities are unable to achieve the biomedical ‘healthy’ ideal, this is regarded as personal failure on the part of the individual, reinforcing conceptions of deficiency, again positioning them as dependents, this time of medical care, and of having abnormal bodies or minds (Goodley, 2014).

Whilst the development of ‘modern’ medicine led to advancements in health and rehabilitation, the medical model received widespread criticism for being reductive and paternalistic (Shakespeare, 2014). The medicalisation positions ‘disability’ as something inherently negative, and casts people with disabilities as powerless patients, stripping them of agency. The model also places medical professionals as having total authority and cure being the preferred outcome, thereby obscuring the wider social and structural dimensions of disability.

1.4.3.Social model

The social model grew from the global disability rights movement in the 1970s as a response to the charity and medical models. It marked a significant shift from medicalised or ‘tragic’ definitions, which located disability within the individual, to one where disability is conceived as a social creation. Disability in this model is caused by the social and structural barriers encountered by a person with an impairment and the consequent exclusion and social disadvantage they experience (Oliver, 1990).

The social model was transformative and was a powerful force for advocacy for social and political change, such as in struggles for anti-discrimination legislation and policy reform. However, it has not been without its critics. Tom Shakespeare (2014) regarded the social model as having become rigid and as an impediment to any evolution of the disability movement. Other critics argued that the model ignores the often significant impact of an individual’s impairment on their lived experience (Meekosha and Shuttleworth, 2009). The model has also been criticised for failing to account for the intersectional experience of disability (Goodley, 2013).

1.4.4. International Classification of Functioning, Disability and Health (ICF) model

The ICF was developed by WHO and attempted to bring together aspects of both the medical and social models into one multidimensional model (Kostanjsek, 2011). The biopsychosocial model embedded in the ICF understands that the experience of an individual with a 'health condition or disorder' interacts dynamically across three key domains: body functioning and structures, activities, and participation (WHO, 2001). These then are shaped by environmental and personal factors. The ICF also considers the universality of disability, recognising that it is part of the spectrum of the human condition, and not confined to a minority group (Kostanjsek, 2011).

This model has been criticised, however. One such critique is that the ICF overlooks key issues often important to the disability experience such as poverty and exclusion (Grech and Cheng, 2016). The model also has been criticised for being 'global North'-centric and therefore may have less relevance in other settings (Grech and Soldatic, 2016). Further, while the ICF claims for universality, it is not a neutral model as it still assumes a normative 'ideal' from which all bodies 'deviate' (Hammell, 2004; Mitra and Shakespeare, 2019).

1.4.5. Human rights model

The Convention of the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006) was adopted by the UN General Assembly in 2006 and entered into force in 2008. The UNCRPD was the first human rights convention of the 21st century and while it does not enshrine any new rights, it affirms that rights enshrined in other conventions apply equally to people with disabilities.

The human rights-based model that grew out of the UNCRPD places people with disabilities are active rights-holders, not passive recipients of charity. It broadens the focus beyond political and civil liberties to encompass economic, social, and cultural rights, and prioritising autonomy, participation and non-discrimination (Degener, 2014). The human rights model aims to prevent direct and indirect (including structural and institutional) discrimination, and by promotes a 'transformative equality', the human rights model situates social justice as being integral to, and inseparable from, the realisation of human rights (Degener, 2016).

Critics of the model maintain that it is lacks definitional clarity (Sedova, 2024) and that the overlaps with the social model have not been completely resolved (Lawson and Beckett, 2021). In addition, much like the ICF framework, the human rights model has also been criticised for emanating from the ‘global North’ (Meekosha, 2011; Grech, 2015), and its emphasis on individual autonomy and assumption of strong state institutions may not reflect realities faced by people with disabilities in other settings.

Mindful of these critiques, my research employs the human rights model of disability as a foundation as it speaks to my key analysis frameworks: structural violence and social justice.

1.5. Analysis frameworks

Structural violence refers to the ways in which social, political, and economic structures and institutional arrangements systematically harm or disadvantage certain groups of people (Galtung, 1969; Farmer, 2004). The framework provides a lens through which to examine how deep-rooted historic and contemporary structures perpetuate and reproduce suffering and inequality (Farmer, 2009). In the context of disability, structural violence manifests in exclusion from the health and education systems, as well as from decision-making processes, reinforcing stigma and systemic ableism, and exacerbating poverty.

Whereas structural violence focuses on the systems that produce suffering and exclusion, social justice as conceptualised by philosopher Nancy Fraser is concerned with how they can be redressed. This three-pronged model comprises the equitable **redistribution** of resources; **recognition** of groups and individuals as having cultural value and addressing sigma; and **representation** and influence in decision-making (Fraser, 1998, 2000). She further argues that all three of these areas must be achieved for true social justice.

1.6. My research – with this focus on structural violence and social justice – therefore considers disability inclusion as both structural and transformational: structural in that meaningful inclusion necessitates redressing the systems and structures that sustain inequality and curtail life chances; and transformational in that to achieve this, the structures themselves may need to be dismantled and reconfigured with inclusion embedded its core.Research questions

My research had two overarching questions.

- How have people with disabilities in Liberia experienced recent epidemic responses and public health measures, and to what extent have they been included?
- What approaches can enable people with disabilities to participate in and lead inclusive systemic change?

1.7. Thesis structure

This thesis comprises eight chapters. **Chapter one**, the present chapter, provides an overview of Liberia and sets the scene for the research that follows. It briefly introduces the political, historical, social, and economic context in which the study is situated and foregrounds the systemic and structural inequalities that shape the lives of people with disabilities. It also outlines the motivation for the research, the questions it seeks to answer, and the conceptual grounding that informs my approach.

Believing that history profoundly shapes the present, **chapter two** is dedicated to tracing Liberia's complex and often turbulent history. This chapter considers how 'colonial' legacies, state formation, and civil conflict have influenced national identity, citizenship, and access to rights. Liberia marked the bicentennial of its 'settlement' in 2022, and the country has experienced profound upheavals over these two centuries. Understanding this context is essential for interpreting contemporary challenges related to health, governance, and exclusion. The chapter also situates disability within this broader historical trajectory, examining how people with disabilities have been positioned within Liberia's social, political, and institutional development – or, more often, omitted from it.

Chapter three goes on to present a scoping review that synthesises the existing literature on disability and the Ebola and COVID-19 outbreaks in Liberia, Sierra Leone, and Guinea. It examines how the impact of these health emergencies on people with disabilities has been represented, identifying key themes and gaps, and highlighting areas where further research is needed.

Chapter four sets out the study's methodology and methods. It describes the rationale for using qualitative methods – photovoice, life-history interviews, and key informant interviews – and sets out the analytical frameworks of structural violence and social justice that underpin the research. It also discusses how questions of ethics, power, and participation were navigated throughout the research process. This chapter includes reflections on my positionality and the implications of conducting research as a disabled researcher, including the opportunities and challenges this presented.

I then move on to my results chapters. These next two chapters foreground the voices and opinions of the people with disabilities who took part in my research. Using reflexive thematic analysis, **chapter five** explores participants' experiences of the Ebola response, structured around four key themes and accompanying subthemes. **Chapter six** then examines their experience of the COVID-19 response, which is also structured into four themes and incorporates visual and narrative data from a photovoice project.

Chapter seven brings the findings into dialogue with the study's theoretical frameworks, using structural violence and social justice as lenses through which to explore how exclusion is produced and sustained during health emergencies. Finally, **chapter eight** brings together key insights, offers concluding thoughts, reflects on how this research contributes to the literature, and ends with my own reflections on the three-year research journey.

Chapter two: history of Liberia

The previous chapter provided an overview of Liberia, the research project, and the structure of this thesis. This chapter expands on the broad history of the Republic of Liberia introduced earlier, offering a more detailed examination of key historical events and their lasting impact. Understanding Liberia's past is essential to making sense of its present-day political, social, and institutional landscape, particularly in relation to public health and disability inclusion. Situating the research within this context allows for a more meaningful exploration of how past and present health emergencies have disproportionately affected marginalised populations, including people with disabilities.

The chapter is structured around major events in Liberia's history, tracing its turbulent past from the early settlement period through to the devastating civil wars. The aftermath of these wars set the stage for the 2014-2015 West Africa Ebola outbreak, which, in turn, shaped Liberia's experience of the COVID-19 pandemic. The final section explores the major disability organisations active in Liberia, highlighting their roles and contributions in both historical and contemporary contexts.

2.1. Introduction

The history of Liberia is marked by a history of violence, which dates back to the very first days of its settlement (Bøås, 2005; Ciment, 2014). It is also a history of epidemics and infectious diseases (Farmer, 2020). Liberian identity, its land and its peoples have been 'shaped and scarred' by its short yet turbulent history (Bøås, 2005, p. 88), which still reverberates today. Understanding Liberia's history is crucial to understanding the contemporary experience of people with disabilities.

2.2. American Colonization Society

The issue of what to do after enslaved people were manumitted was considered an increasingly pressing issue in the 19th-century United States of America (US; Dunn-Marcos *et al.*, 2005; Moran, 2008). The 1820 census estimated there were over 1.5 million enslaved people living in the US (some 15% of the total population; cited in US Census Bureau, 2021), and if this 'race problem' was not addressed, many were fearful that formerly enslaved people would cause violent uprisings (Kieh, 2012; Ciment, 2014).

In an attempt to solve the ‘race issue’, the American Colonization Society (ACS) was established in Washington DC in December 1816[4] (Moran, 2008). Its mandate was to establish a colony in Africa for the purpose of removing free black people from the US (Ciment, 2014). The ACS had the support of the US government, which provided funding for several voyages, and President Monroe set aside $100,000 (Ciment, 2014). However, by this point, most black people in the US had lived there for multiple generations, and many were strongly opposed to the ACS’ activities, believing it tantamount to forced expulsion or an excuse not to afford them equal rights (Mills, 2014).

2.3. Settlement

The *Elizabeth*, the first ACS sponsored ship, landed on the West Coast of Africa in 1820. The ship carried 88 migrants and three (white) ACS employees and landed at Sherbo Island (in present day Sierra Leone; Dunn-Marcos *et al.*, 2005). The location was marshy and mosquito infested, and a quarter of the initial settlers died[5] (Ciment, 2014). More ships followed despite this inauspicious start, and in December 1821 settlers negotiated the acquisition of Cape Mesurado from indigenous leaders[6]. This colony would go on to become Monrovia, the capital city of Liberia.

Settlers faced severe challenges. These included malaria and other diseases, inhospitable swampy conditions, the protracted rainy season, and frequent battles with indigenous groups. This led to an extremely high mortality rate, and almost half of all early settlers in Monrovia died, the majority either of disease or physical violence (Ciment, 2014; Farmer, 2020). Despite these challenges, between 1822 and 1861 (the start of the American civil war) around 12,000 people arrived in Liberia and a permanent settlement was established.

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[4] The ACS was not formally dissolved until 1964.

[5] The remainder sought refuge in Freetown, Sierra Leone (Ciment, 2014).

[6] The extent to which this negotiation happened ‘under the gun’, rather than through treaty and trade is increasingly questioned by revisionist historians (Ciment, 2014; Hardgrove, 2017).

Liberia declared independence from the ACS on the 26th July 1847, acquiring the name Liberia and becoming Africa's first republic. The first constitution swiftly followed[7]. Modelled on the US Constitution, the declaration of rights states:

> *'We the people of the Republic of Liberia were originally the inhabitants of the United States of North America.... Article 1. all men are born equally free and independent, and have certain natural, inherent and unalienable rights; among which, are the rights of enjoying and defending life and liberty, of acquiring, possessing and protecting property and of pursuing and obtaining safety and happiness (Republic of Liberia, 1847)*

However, the 'all men' referred to in the Liberian constitution did not, in fact, refer to 'all men', but only the 'right men' (and no women). Although the Americo-Liberians (as the settlers became known) represented just 5% of the population (Afolabi, 2017), the 'Americo-Liberian hegemony' dominated. Because the majority of the settlers had been born and lived in the US (even when enslaved people), they were convinced of their supremacy in civilisation, religion and social structure (Dunn-Marcos *et al.*, 2005; Kieh, 2017). Indigenous people did not enjoy the same rights as Americo-Liberians; they were not eligible to vote and would not be granted suffrage for over one hundred years (Pailey, 2016)[8]. This extremely unequal system of privilege and dominion sowed the seeds for conflict from the beginning.

While Liberia was never colonised by an imperial power, the Americo-Liberians were effectively colonisers. From the outset, Americo-Liberians and indigenous peoples had an often violent relationship, particularly when expanding territory into the interior (Dunn-Marcos *et al.*, 2005; Ciment, 2014). Populations were kept in check through indirect rule, which deliberately stoked conflict, creating schisms between ethnic

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[7] The second constitution came into force in 1986 following a referendum in 1984. The first constitution had been suspended in 1980 after the coup d'état. In both iterations, disability is only mentioned once and is in reference to the incapacity of the president/vice-president (Republic of Liberia, 1847, 1986).

[8] Suffrage was extended to indigenous Liberians in 1946, one year after it had been extended to women (Dunn-Marcos *et al.*, 2005).

groups[9]. This ‘divide and rule’ approach to governance, a standard part of the colonisation playbook (Muck, 2020), elevated some groups over others, again laying the groundwork for the civil wars that were to come (Bøås, 2005). The interior also became a key source of revenue. Indigenous people were heavily taxed[10] and when people were unable to pay they were forced to work in indentured servitude in what effectively equated to slavery conditions (Ciment, 2014), an irony considering the ideals upon which the country was founded.

Americo-Liberians, and the predominantly unopposed True Whig Party[11], remained in power for more than a century in what was effectively a one-party *state* (Howard, 2017). Corruption and cronyism were rife, serving only to increase the prosperity of the few Americo elites, and always at the expense of the indigenous peoples. The corrupt and self-serving state provided nothing in the way of healthcare to its citizens (Kieh, 2017). What little health provision that was available was entirely concentrated in Monrovia, and even then only available to the Americo-Liberian population (Farmer, 2020). People in the interior or indigenous people living in the capital had to rely on traditional medicine or no healthcare at all.

2.3.1. Indigenous peoples

Of course, Liberia was not empty before the settlers arrived, and its history did not begin when the first boats arrived in 1820. What became Liberia had been inhabited for at least 700 years before the settlers came (Dunn-Marcos *et al.*, 2005; Gobewole, 2021). The land was already host to 14 main ethnic groups (**Figure 2**; CIA, 2023).

Tribal custom and culture vary substantially between groups (Ellis, 2001). However, communities were often characterised by communal (rather than individual) living based around kinship networks and ‘prestige was based on how much you gave away,

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[9] This indirect rule also created artificial boundaries. What became the ‘Krahn’ ethnic group was made up of small groups who were united only by a common language, not particularly by custom or culture (Bøås, 2005).

[10] Despite being taxpayers, indigenous people were not granted citizenship until the 1940s (Konneh, 1996).

[11] The True Whig Party was the oldest political party in Liberia and was founded in 1869 (Ciment, 2014).

not how much you accumulated' (Dennis and Dennis, 2008, p. 75). Age continues to confer authority, and there is often a strict social hierarchy based on age (Ciment, 2014). Village elders wield a huge amount of power, leading on decision-making and resolving disputes between community members. However, the highest authority was conferred to individuals who interacted with the spiritual world, such as the powerful *Zo* (priests) of the *Poro* or *Sande* society (Ellis, 2001).

Today there are two main 'secret' societies in Liberia, the *Poro* (male) and *Sande* (female) sodalities. *Poro* and *Sande* networks are extremely powerful, and are found across the West Africa (Depo Oyedokun, 2025), transcending ethnic groups and national boundaries (Ellis, 2007). Liberian presidents and civil warlords often presented themselves as powerful *Poro* members, and would wear clothes and amulets associated with society membership (President Tubman declared himself 'Grand *Zo*' and would travel with a witchdoctor; Farmer, 2020).

Figure 2 distribution of ethnic groups in Liberia

As well as being religious societies, the *Poro* and *Sande* also function as educational and civic institutions. Young people spent four years at the 'bush school', learning the skills and responsibilities they would need as an adult. For example boys learn hunting and tribal law and regulations; girls learn how to be good mothers, fishing and useful crafting (Best, 1974; Dennis and Dennis, 2008). *Sande* initiation ceremonies often include female genital mutilation (FGM). UNWOMEN estimates that half of all women in Liberia aged 15-49 have undergone FGM (UNWOMEN, 2021).

2.4. Firestone

From the outset, the US enacted structural violence over Liberia. The US wielded a huge amount of power, involving itself in Liberia's affairs and using the country as a resource for raw materials with little compensation in terms of development (Kieh, 2008). An instructive example of this is the Firestone rubber plantation. Rubber is not indigenous to Liberia. It was introduced by American businessman Harvey Firestone in the 1920s specifically to challenge British dominance in the global rubber trade (Ciment, 2014; Farmer, 2020). With the widespread manufacture of cars and tyres, demand for rubber increased drastically, and the Firestone plantation became the largest in the world, reshaping the Liberian economy.

The notorious 99-year lease was signed in 1926[12], granting Firestone control over one million acres for just 6¢ per acre (Konneh, 1996). His company secured a monopoly on rubber production in Liberia, along with highly favourable export levies (Konneh, 1996; Ciment, 2014). Consequently, the concession from Firestone did little to promote development in Liberia. It took but never gave. The land used for the plantation was not empty, however. The Bassa people were forcibly displaced to make way for rubber cultivation (Mitman, 2021). This kind of mass eviction had been inflicted on indigenous communities repeatedly since the arrival of the first settlers (Ciment, 2014; Gobewole, 2021). However, this marked the first instance of multinational corporate involvement, setting a precedent that would be repeated many times (see **section 2.11)** – and remains to this day (Pailey, 2024).

Unfettered neocolonial capitalism is a cause of disability (Grech, 2011). The mass exploitation of Liberians in Firestone and other extractive industries through forced

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[12] In 2005 the lease was extended for a further 36 years – 16 years beyond the initial lease period (Bavier, 2009).

labour was effectively a form of slavery (Ellis, 2007, p. 46) and which continues to this day (Pailey, 2023). Such exploitation is likely to have caused many disabilities due to dangerous and toxic working conditions (Mitman, 2021), unsanitary living conditions (Konneh, 1996), and lack of any kind of labour rights or health services for workers to deal with injury or disease. Firestone workers underwent medical surveillance and experimental drug testing was routine (Mitman, 2021). For example, Firestone workers were deliberately infected with non-native malaria to investigate their susceptibility to the parasites (Bray, 1958) – direct violence against indigenous bodies. The commodification of people and labour under capitalism breeds ableism, which valorises and makes compulsory 'ablebodiedness' (McRuer, 2006). This means that people with disabilities become inherently de-valued because their impairment is perceived to make them less productive workers (Campbell, 2008; Mladenov, 2016).

Beyond the Firestone rubber plantation, understanding how mechanisms of structural violence set the stage for the 1980 coup and subsequent civil wars requires examining the actions and legacies of Liberia's final two pre-coup presidents: William Tubman and his successor, William Tolbert.

2.5. William Tubman

William Tubman was elected as president in 1944 and remained in the role until his death three decades later. Tubman's presidency has been described as a cult of personality (Bøås, 2005; Ellis, 2007), portraying him as a fatherly figure who was 'powerful, stern, generous' (Ellis, 2007, p. 215). However, he was an autocratic 'father figure', maintaining his authority and influence through a complex web of patronage (Ciment, 2014) and manipulating the constitution so as to extend his rule indefinitely (Frempong, 2000).

Tubman wielded his power skilfully. When his presidency came under pressure he proposed two policies. The first aimed to pacify (by further enriching) the conservative Americo-Liberians elite through an 'open-door policy' which welcomed foreign investors into Liberia for the first time (Kieh, 2012). The second was a 'unification policy' which aimed to garner support from the indigenous population (Frempong, 2000). The policy also enabled Tubman to extend his influence and web of patronage into the interior (Ellis, 2007). Both these policies warrant discussion because they were key stepping stones in the progress towards the extreme violence of war.

2.5.1. Open-door policy

The stated aim of the open-door policy was to stimulate employment and economic growth by attracting foreign investment through lucrative concessions and favourable export duties (Frempong, 2000). The open-door policy, which began in 1944 after Tubman took office, was an immediate resounding success. Launched in 1944 under Tubman, it initially boosted revenues, generating $300 million in a decade and enabled debt servicing (Ciment, 2014). However, this growth was unsustainable. Concessions were negotiated under deeply unequal power relations, benefiting foreign corporations while making Liberia heavily dependent on external investment. They required no improvements to infrastructure, education, or local development, instead enriching international stakeholders and Americo-Liberians while indigenous communities bore the brunt of the land grabs[13] (Frempong, 2000; Kieh, 2012). Ultimately, over 40% of Liberia's territory was handed to extractive industries (Gobewole, 2021). While Liberia saw prosperity in the 1960s, wealth remained concentrated among Americo-Liberian elites (Dennis, 2006); the indigenous workers who sustained the industries reaped little in the way of benefits. While there had been precedent for this in the Firestone concession, the open-door policy made it a free-for-all. Facing growing unrest from the indigenous population, Tubman introduced the 'unification policy' in an attempt to ease tensions.

2.5.2. Unification policy

The unification policy has been described as 'a decidedly failed attempt to construct a nation within a state' (Pailey, 2016, p. 4). Introduced in 1964, it ostensibly aimed to increase indigenous political participation and representation (Ciment, 2014). The policy sought to appease indigenous communities by framing participation as equal to

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[13] Indigenous people would not be given any kind of formal land rights until 2018 (Republic of Liberia, 2018b).

Americo-Liberians[14] (Konneh, 1996). During Liberia's unsustainable economic boom, it led to the expansion of schools, roads, and health clinics, which, while improving infrastructure, also reinforced 'Western cultural supremacy'. Roads facilitated the spread of 'Western medicine', which framed disability as a condition requiring treatment and cure (Grech, 2011). Consequently, as capitalism spread along these same routes, 'productive' and 'functional' bodies became valorised, serving to marginalise and exclude people with disabilities.

'Western education' was also prioritised (Hardgrove, 2017). At the end of World War Two, Liberia had just 200 schools with a total of 2,000 students. By 1968 this had soared to over a thousand schools with around 130,000 students (Best, 1974). While access to education expanded, it was largely missionary-led, promoting the superiority of Christianity and 'Western' values (Dennis and Dennis, 2008). This framed indigenous populations as 'lesser', and needing to be 'civilised' through education and religion.

2.6. William Tolbert

After William Tubman's death in 1971, long-serving vice president William Tolbert took office. Unlike his predecessor, Tolbert faced economic and social crises. a number of which were set in motion by Tubman's policies. The open-door policy, which had driven post-war growth, was unsustainable and left Liberia vulnerable to the open market (Kieh, 2012). The 1970s recessions and oil crises led to a sharp decline in the price of Liberia's key exports, causing severe economic strain (Ciment, 2014). Meanwhile, structural inequalities persisted, with nearly two thirds of the country's wealth controlled by just 4% of the population (Konneh, 1996; Adebajo, 2007).

Tolbert pursued ambitious reforms, including establishing the Group of 77, Liberia's first disability-focused government organisation (see **section 2.17.1**). He also further expanded the road network to all 15 counties, and reduced school tuition, which boosted enrolment in the interior (Dunn-Marcos *et al.*, 2005). However, his reform pace alienated both indigenous communities, who felt that social change was too slow

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[14] However it is telling that the preamble of the constitution remained unchanged until after the overthrow of the Americo-Liberian regime: 'We the people of the Republic of Liberia were originally the inhabitants of the United States of North America…' (Republic of Liberia, 1847, emphasis mine).

(Ciment, 2014) and Americo-Liberians, who feared losing power and status (Dennis, 2006; Ellis, 2007).

In April 1979, Tolbert's proposal to increase rice prices by nearly 50% – intended to boost domestic production and slow rural-urban migration – sparked mass protests (Dennis, 2006). Police opened fire on demonstrators, escalating the Rice Riots, which left over 40 dead and 400 injured (Winfrey, 1979; Hardgrove, 2017). The riots set in motion a chain of events that led to the 1980 coup, abruptly and violently ending Tolbert's presidency – and with it, 133 years of Americo-Liberian rule (Toure, 2002).

2.7. Overthrow

Samuel Kanyon Doe, born around 1951 in Grand Gedeh County, belonged to the Krahn, one of Liberia's smallest ethnic groups. He joined the Armed Forces of Liberia (AFL) in 1969, rising to master-sergeant (Ellis, 2007). On the 12th April 1980, a group of soldiers led by master-sergeant Doe stormed the Executive Mansion in Monrovia to assassinate President Tolbert. Doe declared victory over the radio and was initially celebrated by indigenous Liberians, who saw the end of Americo-Liberian rule as liberation (Dennis, 2006). The streets erupted in looting and celebrations while Americo-Liberians fled in droves[15] (Ellis, 2007; Ciment, 2014).

The euphoria was short-lived. Doe consolidated power through violence, executing 13 members of Tolbert's regime on a beach on the 22nd April 1980[16] and establishing the People's Redemption Council (PRC) with himself as chairman. While the PRC repealed the widely hated 'hut tax'[17], it was reinstated two years later to counter economic struggles (Konneh, 1996). Corruption swiftly engulfed the regime. During Doe's tenure, he and his cronies accumulated more than $300 million (Ellis, 2007) and funnelled development aid into his own private account (Kieh, 2012). He favoured Krahn and

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[15] Including future-president Ellen Johnson-Sirleaf.

[16] In what horrifyingly became known as the 'Beach Party' (Hardgrove, 2017).

[17] The 'hut tax' was enacted in 1910 by then-president Arthur Barclay. This regressive taxation was initially set at $1 per hut and ostensibly aimed to increase government revenue to repay debt and meet state loan servicing obligations (Konneh, 1996). Payment of the 'hut tax' was strictly enforced by the Liberian military (Ciment, 2014), which descended into violent rebellion in 1915 by members of the Kru tribes (Konneh, 1996).

Mandingo groups, promoting them within the PRC and AFL, and marginalising Gio and Mano communities, fuelling tensions that later erupted into war (Annan, 2014).

Facing international pressure to return to democratic rule, in 1985 Doe replaced the constitution (which had been suspended following the coup) and held an election. However, the results of the election were widely regarded as fraudulent (Toure, 2002; Bøås, 2005; Adebajo, 2007; Kieh, 2012). Yet despite rigging the vote, his support base was so weak that he could only secure 50.9% (Ellis, 2007), but US approval legitimised his rule on the premise that even a flawed election was better than none (Kieh, 2012).

Soon after, Thomas Quiwonkpa, a Gio ex-AFL general and former ally, attempted a coup. Having fled in 1983, fearing Doe's paranoia, Quiwonkpa returned to overthrow him but was captured and killed. In retaliation, the Krahn-dominated AFL massacred 3,000 Gio and Mano people in Nimba County (Adebajo, 2007; Afolabi, 2017). This massacre is seen as being a catalyst for Liberia's civil war (Bøås, 2005).

Civil war does not happen in a vacuum and international influences and events must be considered. One of the causes of the civil war has been attributed to 'multidimensional crises of underdevelopment' (Kieh, 2012, p. 180). Another way of describing this could be long-term structural violence perpetrated by (predominantly) the US on Liberia, who viewed extraction as more important than people. This was a 'hopelessly unequal relationship between a major power and a near mini-state' (Toure, 2002, p. 8). Doe initially enjoyed strong US backing for his anti-communist stance[18]. Liberia was seen as a Cold War asset, and the US feared Qaddafi's potentially destabilising influence in the region (Kieh, 2012). As a reward, Liberia received more US aid than any other sub-Saharan country, totalling half a billion dollars (Ellis, 2007; Kieh, 2012). However, following the Cold War, Liberia lost its strategic value, and the US abruptly withdrew support, leaving Doe politically and financially vulnerable.

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[18] Doe was received at the Whitehouse in June 1982, where President Ronald Reagan remarked on the 'special relationship' between the US and Liberia (National Archives, no date).

2.8. Civil wars

2.8.1. First Liberian civil war: 1989-1997

On 24th December 1989, the National Patriotic Front of Liberia (NPFL), led by Charles Taylor, crossed into Liberia from Côte d'Ivoire, aiming to overthrow Samuel Doe. Doe responded by deploying the AFL, targeting the Gio and Mano populations who, enraged by previous massacres, flocked to join the NPFL. The widespread reprisals ignited a seven-year civil war (Dennis, 2006; Bøås and Hatløy, 2008)

Taylor, like Doe before him, exploited ethnic tensions. The NPFL, which started with 100 fighters, grew to 10,000 by the time it reached Monrovia, with child soldiers forming the infamous 'small boy units' (Adebajo, 2007; Ellis, 2007). By mid-1990, the NPFL besieged Monrovia, cutting off water and electricity. A splinter faction, Prince Johnson's Independent National Patriotic Front of Liberia (INPFL), seized key areas. At the same time the Krahn-dominated AFL retaliated against Gio and Mano civilians living in Monrovia, culminating in the St Peter's Lutheran Church massacre on 29th July 1990, where 600 people were killed (Reuters, 1990) making it one of the worst single atrocities committed during the war.

Fearing regional instability[19], the Economic Community of West African States (ECOWAS) deployed a 3,000-member peacekeeping force (ECOMOG[20]), dominated by Nigerian troops (Adebajo, 2007). ECOMOG's official mandate was to enforce a ceasefire and facilitate elections, but its underlying objective was to prevent Taylor from seizing power (Bøås, 2005). On 9th September 1990, the INPFL captured, tortured[21], and executed Doe (Dennis, 2006; Ellis, 2007). However, Taylor's ambitions extended beyond Doe's removal – his goal was complete control, not reform (Hardgrove, 2017).

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[19] ECOWAS was particularly concerned about Libya's involvement in providing finance and training to the NPFL (Williams, 2002).

[20] Economic Community of West African States Monitoring Group

[21] The video is available on YouTube.

By September 1990, 700,000 Liberians had fled, many spending years in refugee camps[22] (Ellis, 2007). People with disabilities, older adults, and others with limited mobility were often left behind, their fates often unknown (Williams, 2002). By this time, casualties had reached between 13,000 and 20,000 (Ellis, 2007).

ECOMOG eventually pushed the NPFL out of Monrovia (Adebajo, 2007). Taylor, however, retained control over 95% of Liberia including its extractive industries, and exports resumed. It is estimated that between 1990 and 1994, illicit diamond sales generated $300 million annually (Ellis, 2007), much of which funded arms purchases for the NPFL.

In March 1991, the war spilled over into Sierra Leone, as the NPFL backed Foday Sankoh's Revolutionary United Front (RUF). The two conflicts remained linked through weapons trafficking and 'blood diamonds'[23] (Ellis, 2007). Meanwhile, ULIMO, a faction of predominantly anti-NPFL exiles, launched an invasion from Guinea in 1992, cutting off Taylor's ties to the RUF. In retaliation, Taylor ordered 'Operation Octopus', a failed attempt to retake Monrovia (Kieh, 2011). ECOMOG went on the offensive, shifting from peacekeeping to 'peace enforcement' (Adebajo, 2007), bombarding NPFL positions with artillery and airstrikes, causing significant civilian casualties. Reports suggest that indiscriminate use of shells, napalm, and cluster bombs led to as many as 6,500 deaths (Ellis, 2007; SCSL, 2008). Humanitarian aid to Greater Liberia was blocked, and MSF relief convoys were attacked, further exacerbating civilian suffering (Ellis, 2007).

After years of failed peace agreements, international pressure and 'war-weariness' (Ciment, 2014) led to the signing of the Abuja II Peace Accords in August 1996. The agreement mandated a nationwide ceasefire, a 'buffer zone' along Liberia's borders, an

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[22] The UN repatriation programme concluded only in 2012, nearly 25 years after the war began (Palmisano and Momodu, 2013)

[23] Blood diamonds (also called conflict diamonds) are mined in conflicts zones and sold by rebel or insurgent forces to fund their ongoing regimes. Liberia served as a conduit for the sale of blood diamonds from Sierra Leone, where they were exchanged for weapons and ammunition to support Sankoh's RUF rebellion (Global Witness, 2006). In 2000 the UN Security Council imposed sanctions on exporting diamonds from Sierra Leone, and the following year it imposed the same sanctions on Liberia (United Nations, 2001).

arms embargo, the formation of an interim Council of State, and democratic elections (Kieh, 2011).

Women's civil society groups played a crucial role in the peace process, exposing atrocities and advocating for gender inclusion (Toure, 2002). Reflecting this influence, Ruth Perry was appointed as Liberia's first female head of state, leading the 1996–1997 interim government (Afolabi, 2017).

2.8.2. Fractious peacetime: 1997-1999

A general election was held just 10 months after the ceasefire. Charles Taylor won the 1997 presidency with 75% of the vote in what was considered to be the freest and fairest election Liberia had ever seen (Bøås, 2005)[24]. However, it is likely that fears that his defeat would trigger further violence played a large part in his overwhelming victory (Bøås, 2005; Ciment, 2014). Like Doe, Taylor's rule was marked by corruption, oppression, and misgovernance (Kieh, 2008). His presidency made little effort to address the root causes of unrest and inequality worsened (and continues to remain a huge issue in Liberia; Pailey and Weah, 2023).

The international community prioritised elections over long-term peacebuilding or reconstruction (Toure, 2002). An incomplete disarmament, demobilisation, rehabilitation and reintegration (DDRR) programme left 33,000 ex-combatants without adequate reintegration support (Kieh, 2009), including an estimated 10,000 disabled fighters (IRIN, 1999). Interestingly (and anecdotally), however, during Charles Taylor's tenure as president, some disabled residents of Monrovia reported to be surprisingly well-treated, regularly receiving food donations such as rice. Some people with disabilities are reminiscent of this time, feeling that they have not been treated as well since[25]. The reasons for this are not clear. However, it is interesting to note that the people who disclosed being recipients of these food donations were not disabled ex-combatants.

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[24] Taylor ran against Ellen Johnson Sirleaf, who would go on to become president in 2005. She only received around 9% of the votes, which may be partially attributable to the perception that she would have been a return to the old Americo-Liberian regime (Bøås, 2005).

[25] Anecdotal evidence from interviews with people with disabilities in Monrovia.

In the face of increasing inequalities that lead to deep undercurrents of rage, the return to civil conflict was inevitable (Kieh, 2009). After two uneasy years of peace, in 1999 the country was plunged back into civil war through the invasion of yet another faction: LURD.

2.8.3. Second Liberian civil war: 1999-2003

On 21st April 1999, Liberians United for Reconciliation and Democracy (LURD), a coalition of dissident groups, invaded Liberia from Guinea. Composed of former ULIMO members, Mandingo soldiers, and disaffected NPFL fighters, LURD exploited UN sanctions[26], which had weakened Taylor's forces (Dennis, 2006; Kieh, 2009). By the following year, they controlled 80% of Liberia.

In early 2003, a second rebel faction, Movement for Democracy in Liberia (MODEL), invaded from Côte d'Ivoire (Dennis, 2006). Composed mainly of former Krahn refugees, it soon joined LURD in besieging Monrovia (Käihkö, 2021). Heavy and indiscriminate shelling devastated the city, killing over 1,000 people and leaving thousands injured or disabled. Atrocities and looting were widespread (Human Rights Watch, 2003).

As Taylor's grip weakened, women's peace movements gained momentum. Led by Leymah Gbowee[27], Women of Liberia Mass Action for Peace staged nonviolent acts of resistance, including mass sit-ins, 'sex strikes,' and direct confrontations with leaders (Gbowee, 2011). Frustrated by stalled talks in Ghana, they blockaded the negotiations, forcing progress (Gbowee, 2011; Kuwonu, 2018). Their efforts helped push forward the Accra Comprehensive Peace Agreement (ACPA), signed on the 18th August 2003, one week after Taylor went into exile in Nigeria[28], formally ending the Second Liberian Civil

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[26] The UN Security Council imposed sanctions on Liberia from 1992 including weapons embargos, trade embargos on diamonds and timber (an important part of the Liberia economy) and travel bans (Toure, 2002). UN sanctions against Liberia were not lifted until May 2006, and the US did not lift its own sanctions until 2015, twelve years after the conflict ended (BBC, 2015).

[27] For her role in helping to end the civil war Gbowee received the Nobel Peace Prize in 2011, co-recipient with Ellen Johnson-Sirleaf and Tawakkol Karman, a Yemeni human rights activist (Nobel, 2023).

[28] Taylor became the first sitting president to be indicted for war crimes by the International Criminal Court for his role in the civil war in neighbouring Sierra Leone. He was arrested on the 29th March 2006 trying to flee from Nigeria to Cameroon (INTERPOL, 2006). Taylor was eventually tried at the Hague and

War (Gbowee, 2009). Over the course of the two wars, over 250,000 people had been killed, with over a million internally displaced and hundreds of thousands seeking refuge in neighbouring countries (TRC, 2009a). Some argue that the failure to take the peacebuilding talks seriously prolonged the second war, leading to thousands more casualties and injuries (Gbowee, 2009).

As mandated by the ACPA, a National Transitional Government of Liberia was established. This included representatives from all the major belligerents in the war as well as civil society. Unfortunately, this did not include representatives from organisations of people with disabilities (OPDs), despite the text of the ACPA specifically listing people with disabilities among 'vulnerable' groups in need of rehabilitation (USIP, 2003).

2.9. Aftermath

Every major faction in Liberia's civil wars had international backing, each with its own agenda – border security, regional stability, or economic gain (Adebajo, 2007). LURD relied on Guinea[29], which in turn had received US military aid (Annan, 2014; Käihkö, 2021). The UK indirectly supported rebels in Sierra Leone, while French weapons to Côte d'Ivoire reached MODEL. This highlights how 'global North' interference (Bøås, 2005) helped sustain violence in Liberia. In addition, Libya, under Qaddafi, had backed the NPFL as it sought to overthrow US-aligned Doe with Taylor to strengthen anti-American influence in Africa (Kieh, 1992; Adebajo, 2007)

The wars caused mass injury, disability, and psychosocial trauma. An estimated 800,000 people were injured (SIDA, 2014), and by 2008, 44% of Liberians were still affected by PTSD (Johnson *et al.*, 2008). Mental health support remains scarce, leaving most conditions untreated. In addition, up to 21,000 child soldiers required demobilisation and reintegration (Annan, 2014). Many had witnessed or committed

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convicted of 11 counts of war crimes and crimes against humanity for his involvement in assisting the RUF. He was sentenced to 50 years in prison, which he is serving at HMP Falkland, County Durham (BBC, 2013).

[29] The leader of LURD, Sekou Conneh, was Guinean President Lasana Conté's son-in-law (Dennis, 2006), also connected by ethnic group and *Poro* society membership (Bøås, 2005).

extreme violence, leading to PTSD, substance abuse, depression, and sexual violence (Borba *et al.*, 2016). The number of disabled children remains unknown but is likely high due to injuries, lack of healthcare, and missed vaccinations. Many of these children have now grown up and continue to live in Monrovia. As adults with disabilities, they are forced to navigate the compounded effects of poverty, inequality, and persistent stigma.

2.10. Building back better?

Conflict fuels disease outbreaks (Sirleaf, 2018). In 2003, Monrovia suffered a severe cholera outbreak, driven by overcrowded and unsanitary conditions among internally displaced people and refugees (CDC, 2003). The August 2003 ceasefire led to a surge in cases as 230,000 displaced citizens returned home, spreading the disease beyond central Monrovia (WHO, 2003). Since then, Liberia's weakened health system has faced repeated outbreaks of Lassa fever, typhoid, and dengue fever (Abramowitz, 2014a).

International donors favoured 'vertical' single-issue programmes over the unglamorous task of health system strengthening (Farmer, 2020). INGOs effectively ran Liberia's healthcare system (Sirleaf, 2018), but when post-war funding was withdrawn, this caused widespread turmoil and led to the closure of vital hospitals and clinics. This 'transition gap' disproportionately affected poor and remote communities (Abramowitz, 2014a).

After the civil war, the international community imposed a neoliberal peacebuilding model, prioritising security over the reconstruction of essential services, including healthcare (Kieh, 2017). Insufficient investment in the health system denied citizens access to care due to severe capacity shortages and further entrenching poverty, as many were forced to rely on out-of-pocket expenses for private treatment (Sirleaf, 2018; Farmer, 2020). Meanwhile, a 'brain drain' saw nine out of ten physicians leave Liberia (Budy, 2015), significantly undermining public healthcare services (Kieh, 2017).

The lack of attention to health-system strengthening, in conjunction with chronic underdevelopment, predatory extraction and the ongoing impacts of colonialism, meant that Liberia was extremely vulnerable to outbreaks of infectious disease (Sirleaf, 2018; Farmer, 2020). In addition, the health system's lack of capacity had devastating consequences. In 2003, the maternal mortality rate stood at more than 805 per 100,000 live births (Macrotrends, 2025), and under-5 mortality was a horrifying 151 per thousand children (WHO, 2024). For people with existing disabilities, who already found accessing health services more difficult than non-disabled people, many faced insurmountable challenges (WHO and World Bank, 2011).

Prior to both the Ebola and COVID-19 outbreaks, less than 10% of the national budget was allocated to health services (9.2% and 9.5% respectively; World Bank, 2023) – significantly less than the 15% benchmark set by the 2001 Abuja Declaration (WHO, 2010). While this allocation is substantially higher than the average for sub-Saharan Africa (5.8% in 2015 and 4.8% in 2019; World Bank, 2020), it is clearly nowhere near sufficient to rebuild a health system that had been destroyed by civil war twice.

UNMIL

In September 2003, a month after the peace agreement, the United Nations Mission in Liberia (UNMIL) was established to monitor the ceasefire, support DDRR, and oversee democratic elections (Davies and Rushton, 2016). Initially having a mandate of only one year, the UN Security Council went on to extend its mandate a total of 16 times, and UNMIL would not, in fact, complete its mission until March 2018. Over its lifetime, over 180,000 peacekeepers were deployed and at its height, more than 15,000 people were stationed simultaneously (UNMIL, 2018a). The mission was to eventually cost the UN $7.5 billion.

The second DDRR process began in September 2003. By the following year, 100,000 ex-combatants had participated, surrendering 24,000 weapons and nearly six million rounds of ammunition (UNMIL, 2023). DDRR also provided training, but a small research project with disabled ex-combatants in Monrovia found that they were largely excluded (Taylor, 2017), and many remained unemployed and reliant on begging. Participants described extreme marginalisation, facing stigma for both their disability and their combat history (no matter which side of the conflict they fought). However, even government veterans did not receive free healthcare, while former rebels were denied any state support at all.

UNMIL was criticised for failing to bring substantive development (Sirleaf, 2018), instead focusing predominantly on security and stability. This may be an unfair criticism to some extent as it was constrained by its mandate, which did not include service delivery or wider recovery activities (Davies and Rushton, 2016). However, one success was its strong support for disability rights, including the Human Rights and Disability Task Force (HRDTF), a coalition of eleven civil society organisations (CSHRAP Liberia, 2018). The HRDTF played a key role in disability advocacy, securing the presidential nomination for the Executive Director of the National Commission on Disability and ensuring disability was recognised as a cross-cutting issue in the Agenda for Transformation[30], the Government of Liberia's five-year development strategy (2013-2018; Republic of Liberia, 2013a).

The HRDTF also led research on disability inclusion, publishing an 'issues paper' (Dennis, Boima and Pay-bayee, 2010). Led by people with disabilities and supported by UNMIL and a UK-based academic[31], primary research comprised interviews with 105 disabled people across Liberia's 15 counties. The research recommendations called for: the full implementation of the CRPD; reducing stigma and discrimination; sign language interpreter training; improving disability representation; and enhancing education for disabled children and youth. This issues paper has been widely used as an advocacy tool by the disability community as a key piece of primary research with people with disabilities in Liberia at the time. Ownership and validity were also strengthened by the fact that it was conducted by people with disabilities themselves.

2.11. The Sirleaf years

In August 2005, Ellen Johnson Sirleaf was elected Liberia's first female president[32]. Her tenure was widely regarded as more democratic than any in Liberia's history, but critics pointed to authoritarian tendencies, particularly during her 2011 re-election campaign[33] (Kieh, 2017). Corruption remained widespread, despite Sirleaf declaring it 'public enemy number one' (Ford, 2018). In her first term alone, more than 20 government

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[30] Personal communication, former UNMIL Human Rights Advisor, 2023.

[31] Primary supervisor Professor Maria Kett.

[32] Former Montserrado senator, UNICEF Goodwill Ambassador, and AC Milan striker George Weah came second. Weah would go on to win the 2017 general election.

[33] The regime forcibly shut down critical media organisations or those that were favourable towards opposition candidates (Kieh, 2017).

officials were accused of corruption (Lee-Jones *et al.*, 2019), and she was criticised for nepotism after appointing three of her sons and other relatives to senior positions (Reuters, 2012).

A Truth and Reconciliation Commission (TRC) was established in 2006, with its findings published three years later (TRC, 2009a, 2009b). It collected 22,000 victim statements, held public hearings where 500 people testified, and identified nearly 100 alleged war criminals (Carter Center, 2009). People with disabilities participated in the TRC, highlighting their unique challenges and vulnerabilities during the war. However, while the report included recommendations for disability inclusion, most were never implemented, so the impact of their participation was minimal. The TRC also called for psychosocial and medical support for war victims, along with reparations – none of which materialised (TRC, 2009b).

The impact of the TRC was limited. Inexperienced prosecutors, combined with Sirleaf's resistance (she dismissed public hearings as 'a charade' after an aide was accused of atrocities) meant that few recommendations were implemented (Gberie, 2008; Aning and Jaye, 2011). Two decades after the war, the TRC remains incomplete, key warlords[34] remain unpunished, and the root causes of violence remain unaddressed (Human Rights Watch, 2022). Like in the 'between-war years', rising inequalities and political tensions risk sowing the seeds for future conflict (Pailey and Weah, 2023).

2.12. The Ebola time[35]

In December 2013, the first case of Ebola was reported in Guéckédou in Guinea. Guéckédou is in an extremely remote region very close to Sierra Leone and Liberia. The same porous border that had once facilitated the movement of weapons, fighters and diamonds now enabled the spread of Ebola (Sirleaf, 2018). The disease soon spread to Conakry[36]; by March 2014 Ebola had spread to Liberia; and it reached Sierra Leone in

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[34] Prince Johnson, leader of the INPFL and killer of Samuel Doe, was elected to the Senate in 2005 and remained a senator until his death in November 2024 (BBC, 2024).

[35] 'Ebola time' is what Liberians call the crisis. See **chapter 5** for a detailed outbreak narrative

[36] capital of Guinea – this was the first time Ebola had ever reached a capital city (Lucey, 2015)

May (Lo *et al.*, 2017). By mid-2014, more than 100 cases were being reported per week (Reid, 2020).

WHO was slow to act, only declaring a Public Health Emergency of International Concern (PHEIC) in August 2014 – eight months after the first case and only after the virus spread beyond West Africa (Horton, 2015). The global community chose not to fully intervene in the outbreak until it was perceived as a direct threat (Abramowitz, 2017). Yet even then WHO lacked coordination, in part due to logistical and financial challenges in the region and in Geneva[37] (Wilkinson and Leach, 2015). In response, the UN created UNMEER in September 2014, its first-ever emergency health mission, but critics dismissed it as too late and reactive (Sirleaf, 2018).

The Sirleaf administration operated under a neoliberal peacebuilding and reconstruction model that prioritised security over public services. This model failed to build institutional capacity and inter-ministerial mechanisms for managing national emergencies, what Farmer (2020) calls the 'austerity virus', which 'shattered and shuttered public institutions' (p.420). Liberia's lack of emergency mechanisms and epidemic protocols delayed the government's response (Kieh, 2017), and the health system was woefully inadequate – in 2010, Liberia had just 90 physicians (WHO, 2021a), the majority of whom would have practiced in Monrovia[38].

Government responses such as lockdowns, quarantine zones, and a bushmeat ban were often contradictory and poorly received (Abramowitz et al., 2017). Policies such as mandatory cremation triggered violent protests, particularly in West Point, an informal settlement in Monrovia (ACAPS, 2015; Hoffman, 2016). The outbreak pushed people into precarity, exacerbating poverty and food insecurity (Elston *et al.*, 2017), disproportionately affecting people with disabilities (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021).

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[37] WHO was labouring under chronic underfunding due to a number of member countries reducing their contributions. This amounted to one billion dollars in 2011, leading to the loss of 300 jobs and WHO's emergency response capacity was badly hit (Boseley, 2014).

[38] There is no information as to how many physicians were in Liberia at the start of the Ebola outbreak, but the number will undoubtably still be critically low

The wide and swift spread of Ebola was widely blamed on weak and fragile health systems with limited surveillance and treatment facilities (Kruk *et al.*, 2015; O'Hare, 2015; WHO, 2015a). However, this overlooks the ongoing impact of colonialism and Western interference (Wilkinson and Leach, 2015; Farmer, 2020). An example, out of the 11 Ebola treatment units (ETUs) constructed by the US military, nine did not house a single Ebola patient during the outbreak (Farmer, 2020), exposing the flaws and presumption of 'Western supremacy' over consultation with communities about the most appropriate placement of the ETUs.

Ebola also caused disabilities. Post-Ebola syndrome became a recognised issue for many survivors, with a constellation of symptoms including musculoskeletal pain, headache and memory problems, and hearing and vision loss that persisted for years after recovery from Ebola (Elston *et al.*, 2017; PREVAIL III, 2019). Long-term psychosocial distress was also understandably widespread (Rabelo *et al.*, 2016; Secor *et al.*, 2020). People with pre-existing disabilities were disproportionately impacted by the Ebola outbreak as the response exacerbated exclusion and pre-existing inequalities (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021), including due to worsening access to general health services.

The 2014–2016 outbreak was the worst Ebola epidemic in recorded history, with 28,652 cases and 11,325 deaths (CDC, 2019). Liberia was disproportionately affected, recording 10,678 cases and 4,810 deaths. The crisis demonstrated not only the biological violence of the disease but also the structural violence of government failure and an international response that, in prioritising Ebola-specific efforts, inadvertently weakened broader healthcare capacity (Sirleaf, 2018; Farmer, 2020).

Post-Ebola recovery and reconstruction was hampered by a lack of funding and implementation. While the donor community was enthusiastic about funding efforts to contain and end the outbreak, there was less enthusiasm in the recovery phase (Republic of Liberia, 2021). As the outbreak waned, Liberia launched the Economic Stabilization and Recovery Plan (ESRP), focused on growth, resilience, and public services (Republic of Liberia, 2015c). However, an $812 million funding shortfall and donor fatigue stalled implementation (Republic of Liberia, 2021). Similarly, the African Development Bank's Post-Ebola Recovery Fund, announced in 2015, was delayed until

2020, with Liberia ultimately withdrawing due to a US funding cut (African Development Bank, 2019; Thomas, 2020).

In 2016, President Sirleaf launched the *Investment Plan for Building a Resilient Health System*, leading to the creation of the National Public Health Institute of Liberia[39] (NPHIL; Republic of Liberia, 2016a). However, funding gaps hampered implementation, which was often slow or patchy (Dreisbach, 2019), and the plan failed to mention people with disabilities. It may not , therefore, adequately address the difficulties that people with disabilities face in accessing the health system (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021), thereby reinforcing and possibly even accentuating the structural inequalities of the health system on people with disabilities, or widening the 'gap' between people with disabilities and non-disabled people (Groce *et al.*, 2016).

2.13. George Weah takes over

In 2017, after two failed attempts, George Manneh Weah was elected president of Liberia. His victory was attributed to 'a populist tidal wave of anti-intellectualism' (Pailey and Siakor, 2018). Former Montserrado senator, UNICEF Goodwill Ambassador, and AC Milan striker, Weah campaigned on economic reform, anti-corruption, and improving education and healthcare.

However, his presidency has echoed William Tolbert's tenure, as Liberia was plagued by economic crises. A global downturn in iron and rubber prices, rising fuel costs, and a spike in rice prices led to protests in Monrovia in December 2022 (Bondo, 2022). Inflation reportedly hit nearly 30% (Lee-Jones *et al.*, 2019), worsening the cost-of-living crisis, which most severely impacted the poorest citizens, including people with disabilities. By 2023, over half a million people – nearly 10% of the population – faced 'acute food insecurity' (CIA, 2023).

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[39] NPHIL is an autonomous government organisation mandated with the task of improving disease surveillance, responding to outbreaks and improving infection prevention and control across the country.

Beyond Ebola's lasting effects, Weah's government has also had to navigate the fallout of the COVID-19 pandemic, further straining Liberia's fragile economy and health system.

2.14. COVID-19[40]

Just five years after Ebola, Liberia faced another public health emergency: COVID-19. The first case was confirmed on 16th March 2020, after a traveller returned from Switzerland. President Weah publicly disclosed his name, accusing him – possibly wrongly – of violating screening protocols (Koinyeneh, 2020). As with Ebola, many infected or suspected individuals went into hiding to avoid stigmatisation and media exposure (Sieh and Dodoo, 2020). The first COVID-19 death was reported on 4th April 2020.

Many of Liberia's COVID-19 restrictions mirrored its Ebola response – stay-at-home orders, school closures, and limits on gatherings (Brown Wilson *et al.*, 2021). However, unlike Ebola, these measures applied nationwide. As with past outbreaks, people with disabilities faced greater risks, with barriers to social distancing, and a lack of accessible information and public health measures (Shakespeare, Ndagire and Seketi, 2021).

Wealthy nations stockpiling vaccines created structural violence. The COVAX[41] initiative, a resource-pooling mechanism led by Gavi, WHO, and CEPI, aimed to ensure equitable vaccine access for low- and middle-income countries, covering up to 20% of populations (Gavi, 2020). However, funding shortfalls and 'vaccine nationalism' – where rich countries secured and stockpiled vaccines through bilateral deals with pharmaceutical companies – delayed distribution (Usher, 2021; Pushkaran, Chattu and Narayanan, 2023).

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[40] See **chapter 6** for a detailed outbreak narrative

[41] COVAX is one of the four pillars of the WHO-led Access to COVID-19 Tools Accelerator (ACT-A). The ACT-A was launched in April 2020 and aimed to support the COVID-19 response and reduce morbidity and mortality through enabling the equitable distribution of vaccines and testing. ACT-A brings together institutions ranging from governments, global health actors and philanthropists to science and business organisations (WHO, 2023c).

Despite these barriers, Liberia outperformed much of the region in vaccine uptake. By August 2023, over 80% of its population had completed the full COVID-19 vaccine protocol, compared to 31% across sub-Saharan Africa (Africa CDC, 2023) – a remarkable achievement given Liberia's financial, logistical, and social challenges. This achievement may be in part due to learning from the country's Ebola experience, including through greater involvement of community infrastructure and mobile vaccine delivery programmes (WHO Africa, 2022a; Ako-Egbe, Seifeldin, Saikat, Wesseh, Bolongei, Ngormbu, George, Ocan and Peter Lasuba, 2023; Clarke, Jeurlink and Amaechi, 2024).

2.15. The run-off and Boakai's first 100+ days

A general election was held in October 2023. The forerunners were sitting president George Weah and former vice-president Joseph Boakai[42] (who had lost the election to Weah in 2017). A runoff election was held the following month[43], which Boakai won by the most razor-thin of margins: 50.9% vs 49.1%. Despite the close result, Weah conceded defeat immediately. The handover of the presidency was peaceful, marking the second peaceful transition of power since the end of the civil wars (Doe and Toweh 2023). President Joseph Boakai was sworn in as president in January 2024.

Unlike every president before him who promised to fight corruption, only for it to run rife under their administration, newly inaugurated President Boakai took early, concrete steps. In February 2024 he suspended 457 government officials over their failure to declare their assets (a requirement of assuming office). However, despite these early steps, civil unrest erupted in December 2024 following protests that alleged government Speaker Fonati Koffa of corruption (Bondo 2024). The unrest culminated in a large fire at the Capitol building[44] on the 18th December (Kollie Garzeawu 2024). Fortunately, no-one was hurt in what was a significant fire. In a surprising turn of events, (former) Speaker Koffa has been charged with arson, along with several co-defendants.

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[42] Weah is from Foya and visits regularly.

[43] A run-off election is held if no candidate gets over 50% in the first round. The run-off is held with the two forerunners of the first election.

[44] The seat of government

At the time of writing, no trial has yet been held and in late September 2025, the Supreme Court issued a temporary halt to proceedings (Tokpah 2025).

2.16. Civil war justice?

President Boakai also attempted to push forward Liberia's long-stalled civil war justice agenda. In April 2024, he signed an executive order to establish a war crimes court to try people accused of committing atrocities during the civil conflict (Reuters 2024). This court was a recommendation of the Truth and Reconciliation Commission (TRC 2009). Boakai was also the first sitting president to formally apologise to war victims (Doe 2025).

In April 2025, Boakai renewed the expiring executive order and approved a budget of $2 million to fund the war crimes court, a marked increase from the previous $380,000 (Stephens 2025a). However, as is often the case, financing became an issue. By August 2025 the Office of War and Economic Crimes Court of Liberia had only received 15% of the promised funds (Stephens 2025b). In the face of the shutdown of USAID in July 2025, it is not clear where the remainder of the money will come from. Prior to the shutdown, US support made up 2.6% of the country's gross national income, money which funded almost half (48%) of the health system's annual budget (Associated Press 2025).

2.17. Disability in Liberia

Liberia signed the UN Convention on the Rights of Persons with Disabilities in 2007 (UNCRPD; United Nations, 2006), and it was formally ratified in 2012[45] (DASU, 2018). The UNCRPD recognises that disability is the result of the interaction between a person with an impairment and wider social and environmental barriers (United Nations, 2006). This is also in line with the WHO International Classification of Functioning, Disability and Health (ICF) framework (WHO, 2001), which conceptualises a 'biopsychosocial' model of disability. The ICF is a multidimensional model whereby an individual's functioning (participation and activities) is influenced by a dynamic interaction of their

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[45] The Government of Liberia in fact ratified the UNCRPD in 2008, but this was not communicated to the UN for several years (DASU, 2018).

health condition, bodily functions and structures, and environmental and personal factors.

Critics argue that the development of the UNCRPD was strongly influenced by ‘global North’ discourses which reflect a legacy of colonial oppression (Meekosha and Soldatic, 2011). The Convention’s emphasis on individualism and independent living may not align with local realities where community-based support structures play a central role. In addition, while the UNCRPD can be a powerful tool in disability advocacy, its implementation in low-income settings often still requires external funding. This reproduces and reinforces the power imbalances between ‘global North’ (‘donor’) and ‘global South’ (‘recipient’) countries.

Despite ratification of the UNCRPD in 2012, disability is often still considered a catastrophe and people with disabilities continue to face ‘cultural stigmatization’ (Republic of Liberia, 2016b). Despite the ratification of the UNCRPD and the adoption of a rights-based model, the general opinion of disability in Liberia remains predominantly pity- or charity-based and medicalised. This is likely due to the lack of provision of any kind of social safety net for people with disabilities living in entrenched poverty.

There remains a widespread belief in Liberia that disability is caused by witchcraft, mystics or curse, or that people with disabilities are themselves witches (TRC, 2009b). There have been recorded ritual attacks against children with disabilities (ACPF, 2022). Specific types of disability, such as leprosy, albinism and intellectual impairment, are most often considered as curses (Collins, 2012). It is believed that people with albinism will bring misfortune as they have supernatural powers (Rao, 2018), and there have been reported cases of ritual murder (CSHRAP Liberia, 2018). There is still stigma attached particularly to intellectual disabilities. Parents of children with intellectual disabilities report having refused to take their child for medical treatment for fear of the community branding them as a witch (US Department of State, 2019).

There are also structural challenges that people with disabilities regularly encounter. People with disabilities are often unable to access systems and services that benefit the wider population (Republic of Liberia, 2018a). They also feel excluded from community meetings and do not have a say in community decision-making (Carew *et* *al.*, 2019). Additionally, while people with disabilities have an equal right to vote, registration and election periods often remain inaccessible due to both physical and procedural issues (CSHRAP Liberia, 2018). Likely because of this, people with disabilities report being politically disenfranchised and less likely to vote in elections (Kett *et al.*, forthcoming). In addition, people with disabilities are also extremely disadvantaged in accessing the justice system (UNDP Liberia, 2023). This is particularly troubling considering that people with disabilities are at greater risk of being victims of crime and subject to human rights abuses (Kett, Cole and Carew, 2017; US Department of State, 2019). Environmental challenges are also extreme. The quality of roads in Liberia is universally poor, there is a lack of building codes to mandate accessibility standards (Republic of Liberia, 2016b), access to transportation is challenging (Republic of Liberia, 2019a), and the protracted rainy season makes mobilisation even more difficult. This has led to people with disabilities having difficulty accessing health services, if even possible (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021).

Recently, the Government of Liberia published a National Action Plan (NAP) for the Inclusion of People with Disabilities (2023-2027; Republic of Liberia, 2023). This is the second NAP that has been implemented in Liberia (the first covered the years 2018-2022) and has been developed in consultation with and ratified by the disability community in Liberia (mainly in Monrovia). The plan identifies various priority areas, such as education or health, with a series of goals, activities and budget allocations attached to each. The NAPs are extremely ambitious, particularly when looking at the price tag – in the 2018 NAP the ‘health’ pillar alone was forecast at more than $2.5 million – a huge financial undertaking for a country with extremely limited resources[46]. Maybe unsurprisingly then, an evaluation of the first NAP found that implementation was stymied by the low-priority given to people with disabilities, and a lack political will or accountability (UNDP Liberia, 2023). Whether this will change in the implementation

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[46] To put this into perspective, the 2018 national budget allocated just $319k and $301k to the Group of 77 and National Commission on Disability respectively (Republic of Liberia, 2018c).

of the new NAP is uncertain but in the face of the continued economic challenges that Liberia is facing, other areas are likely to once again take priority.

There are three major disability organisations in Liberia: two governmental and one civil society. These are the main structures through which people with disabilities can advocate for their rights and to improve their situations. It is worth discussing each of these as they, in theory, play a key role in improving the welfare and achievement of rights of people with disabilities and will be referred to throughout the thesis.

2.17.1. Group of 77

In 1977, President Tolbert established the Group of 77, a quasi-governmental organisation with the aim of promoting the welfare of people with disabilities in Liberia. The official story is that Tolbert was inspired to set up the Group of 77 after attending a G-7 meeting where disability issues were discussed (Republic of Liberia, 2019a). The Group of 77 is legally established as an OPD[47] and currently has branches in thirteen of the 15 counties in Liberia. Its mandate is to support people with disabilities in Liberia through the provision of education and training, housing, and the distribution of food and medication (Republic of Liberia, 2019a). Also, like many organisations in Liberia, a very charity/medicalised approach to disability is still in evidence.

Tolbert was the first president of Liberia who regarded disability as a key issue. An initial initiative of the Group of 77 was the construction of a residential home on Newport Street for unhoused people with disabilities in Monrovia (Republic of Liberia, 2019a). Tolbert gifted 200 acres of land in Todee (a district close to Monrovia) to the Group of 77 for farming (Kwame, 2020). The first school for blind people in Liberia was also set up during his time in office (Dennis, Boima and Pay-bayee, 2010). The Group of 77 also holds ten acres of land in Virginia (a district on the outskirts of Monrovia). While there are plans to build a residential compound on the plot, lack of funding means that this has not been realised.

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[47] While the Group of 77 is described as an OPD, these are usually civil society organisations, run by and for the communities they serve, and not government entities.

Tolbert gave the responsibility for the Group of 77 to his wife, who had oversight of the institution until the 1980 coup. However, when Samuel Doe took power, he charged the responsibility for the Group of 77 to the wife of the Vice-President (Dennis, Boima and Pay-bayee, 2010), abdicating his own wife of the responsibility. To-date, the Group of 77 is still held by the Office of the Vice-President, and by tradition the oversight for the Group of 77 automatically falls to the wife of the Vice-President (DASU, 2018). However, when the Vice-President is female, as is the case at the time of writing, rather than the role falling to her husband, a person is appointed as the Executive Director of the Group of 77. According to the current Constitution, presidential appointments should be from a shortlist of qualified candidates and must receive Senate approval (Republic of Liberia, 1986).

Following the 1980 coup and throughout both civil wars, all activities promoting people with disabilities were abandoned. The Newport Street home became a place of destitution where people with disabilities resorted to begging to survive and were often victims of exploitation (Dennis, Boima and Pay-bayee, 2010). During Ellen Johnson-Sirleaf's stay in power, the home was reclaimed by the government, evicting the residents and repurposing the building as a mainstream school. People with disabilities staged protests in 2018 after the death of one of the former residents who remained unhoused after their eviction[48].

The Group of 77 is chronically underfunded and is heavily reliant on charity from NGOs and donor organisations. The 2020-2021 national budget only allocated $300,000 to the whole organisation, and this is likely to have been reduced due to the ongoing effects of COVID-19 on the Liberian economy. During the COVID-19 epidemic, for example, the Government of the People's Republic of China donated PPE, food, electronics and other items to the Group of 77 for distribution (Nimley, 2021). The activities of the Group of 77 are stymied due to this lack of funding. While it has branches in the majority of counties, the organisation lacks vehicles to monitor programme activities and this significantly limits the ability of the institution to distribute relief items to people with disabilities in

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[48] Personal communication, former Group of 77 employee, September 2023.

the rural areas of Liberia, such as those donated by China[49]. This means that relief continues to be concentrated on the more easily reached people with disabilities in Monrovia, perpetuating inequalities between 'urban' and largely indigenous people who live in hard-to-reach rural areas.

2.17.2. National Commission on Disability

The National Commission on Disability (NCD) Establishment Act was passed in 2005 (Republic of Liberia, 2005)[50]. NCD's mandate as a statutory body is to coordinate and promote disability issues, be responsible for welfare and education of people with disabilities, push for mainstreaming within governmental and national programmes, and monitor progress towards the implementation of the UNCRPD (Republic of Liberia, 2019a).

The text of the Act reads that 'immediately upon passage into law, the commission shall be established and the president shall appoint three persons with disabilities to head the commission' (DASU, 2018). However, as the president did not make these appointments until 2011 after extensive advocacy by the disability community and the HRDTF, NCD was functionally non-operational (DASU, 2018). Even after the appointments were made, the effectiveness of NCD has remained hampered due to an extremely limited budget and limited government priority (SIDA, 2014). NCD has managed to provide some funding for schools and rehabilitation centres (CSHRAP Liberia, 2018). It also has responsibility for reporting progress against the UNCRPD. However, it is somewhat telling that the initial report that was due in 2014 was submitted five years late (Republic of Liberia, 2019a).

2.17.3. National Union of Organizations of the Disabled

In 2009, the National Union of Organizations of the Disabled (NUOD) was formed. NUOD is a pan-disability umbrella organisation with members from OPDs across Liberia. Membership is concentrated in Monrovia, but does include member OPDs from all 15 counties. NUOD was first registered in 1995 during the first civil war as a non-

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[49] Personal communication, former Group of 77 employee, September 2023.

[50] The NCD Act was revised in 2013 but it has not yet been approved by the National Legislature (DASU, 2018).

profit organisation, and its mission is to promote the inclusion of people with disabilities through advocacy and building the capacity of its member organisations (DASU, 2018). NUOD's statute was revised in 2012 to include a coordinator in each county. Their responsibilities include advocacy, attending general assemblies, and are an effort to strengthen the OPD network in the counties (DASU, 2018).

NUOD is heavily reliant on financial support from external actors. The United Nations Development Programme (UNDP) has recently supported NUOD extensively in the National Action Plan development and validation programme (Republic of Liberia, 2023), and AIFO[51] works closely with NUOD to implement programmes and build operational capacity. During the Ebola time, UNDP and AIFO provided food- and non-food items to NUOD for distribution to its member organisations[52].

NUOD is also a member of the Disability Alliance in Liberia. In addition to NUOD, the Alliance has full members of active disability-focused international NGOs, and associate members from Ministries, and official observers being UNDP and the Independent National Commission on Human Rights (INCHR)[53]. The Alliance grew out

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[51] The Associazione Italiana Amici di Raoul Follereau (AIFO) is an Italian NGO that has a particular focus on people with disabilities and people affected by leprosy (AIFO, 2020). AIFO has been operating in Liberia since 1997, and AIFO-Liberia came into being in 2010. AIFO-Liberia works closely with the disability community and OPDs in areas including rehabilitation, advocacy, capacity building, and assistive technology (DASU, 2018). At the time of writing, one of the key projects that AIFO is implementing is the 'disability start up'. This project aims to promote economic empowerment through supplying seed funding for people with disabilities to set up businesses (AIFO-Liberia, 2022).

[52] Interview, NUOD Director, 2023.

[53] INCHR was established in 2005 as one of the provisions in the Accra peace agreement (USIP, 2003). Its mandate is to promote and protect human rights in Liberia. Its original remit was to monitor the implementation of the recommendations from the TRC, many of which did not come to pass (Gberie, 2008). This was in part due to INCHR's being functionally non-operational, lacking investigative and monitoring capacity (ISHR, 2014). UNMIL's Human Rights Division provided technical support to INCHR to increase its operational capacity (Manuel, 2018). INCHR's main focal areas are now the implementation of the National Action Plan on Human Rights, training human rights monitors, and compliance with international human rights instruments (Manuel, 2018). It is an independent commission but is financed by the national budget (Republic of Liberia, 2018c). However, as it is funded

of the UNMIL-supported HRDTF and aims to increase the visibility of people with disabilities and promote actions towards the realisation of the CRPD. For example, in 2017, the Alliance supported NUOD in preparing the CRPD national monitoring report which was presented to OHCHR in Liberia (DASU, 2018).

2.18. Conclusion

This chapter has outlined the key moments in Liberia's history, tracing how its turbulent trajectory – from the first days of its 'settlement' to its civil wars and modern governance – has been shaped by cultural, structural, and direct violence (Galtung, 1969, 1990). The exclusion and oppression of indigenous peoples, entrenched through political, economic, and social inequalities, set the stage for civil conflict, economic instability, and health crises, with consequences that reverberate to this day, including during the Ebola and COVID-19 outbreaks (Kieh, 2008, 2009, 2017).

Liberia's history continues to shape contemporary experiences, with the legacy of neoliberal economic policies, extraction-driven development, and failed peacebuilding further entrenching structural violence. People with disabilities, who often live in precarity, are among the most affected, with limited resilience to changes in the political, economic, and social landscapes (Kett, Cole and Carew, 2017; Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021). The lack of inclusion of people with disabilities in contemporary policymaking and crisis planning – including during Ebola and COVID-19 – means that they often remain overlooked in emergency response and recovery efforts.

The next chapter builds on this historical analysis with a literature review, specifically examining how disability has been included in research on the Ebola and COVID-19 outbreaks. This scoping review will also further highlight existing gaps, underscoring the need for the present study.

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by government, it could be argued that INCHR's continued effectiveness is contingent on sustained political will.

Chapter three: scoping review

The previous chapter provided a historical narrative of Liberia, tracing its trajectory from early settlement through to the COVID-19 pandemic. This overview highlighted key events and structural dynamics, including the enduring consequences of conflict, fragile governance, and recurring public health crises. Situated within this broader historical context, the present chapter turns to the academic literature to explore how health emergencies have impacted people with disabilities in the region.

This chapter reviews and synthesises existing research on disability and the Ebola and COVID-19 outbreaks in the three countries most significantly impacted by the 2013-2015 West Africa Ebola crisis: Liberia, Sierra Leone, and Guinea. Through a scoping review, I examine how these crises have been documented in the literature, identifying key themes, trends, and limitations. In doing so, this chapter not only maps the current state of knowledge but also highlights critical gaps and under-researched areas, offering direction for future research and contextualising the contribution of this thesis.

3.1. Introduction

Scoping reviews are a valuable exploratory method for synthesising heterogeneous literature and identifying gaps in knowledge (Colquhoun *et al.*, 2014; Munn *et al.*, 2018). They are particularly effective for emerging or under-researched topics, as they can accommodate diverse study designs, methodologies, and sources. Following Arksey and O'Malley's (2005) framework on scoping studies, this review does not seek, therefore, to answer a specific research question but instead aims to map existing literature and highlight areas requiring further research.

To enhance rigour and transparency, this study uses the scoping review extension to the widely recognised PRISMA guidelines (Tricco *et al.*, 2018). This structured approach is particularly well-suited to multidisciplinary fields, where synthesising diverse perspectives and data types is essential for developing a comprehensive understanding of the evidence base (Peters *et al.*, 2021).

3.2. Inclusion criteria

The eligibility criteria for this review comprised:

- Peer-reviewed articles
- Published 2014-present (the start of the West Africa Ebola outbreak)
- Primary research
- Focus on Ebola or COVID-19
- Key focus on disability
- Focus on Liberia, Sierra Leone or Guinea (later broadened to include DRC)

Literature not meeting all these criteria was excluded.

Five databases were searched in February 2025 (last search 23 February):

- Scopus
- Web of Science
- JSTOR
- ProQuest
- UCL Explore

3.3. Search strategy

This review used key phrases related to population of interest, outbreak and location to identify papers for inclusion. The syntax was adjusted slightly to fit the search parameters of each database but was a variation of:

> *("person* with disab*" OR "people with disab*" OR "disabled people*" OR "disabled person*") AND (Ebola OR "COVID-19" OR "COVID19" OR coronavirus OR EVD) AND (Liberia OR "Sierra Leone" OR Guinea)*

The review strategy was limited to articles published from 2014, as this was the start of the West Africa Ebola outbreak.

This strategy resulted in few articles for inclusion (see **section 3.5**). To try to address this, the search was widened to include DRC, which, while a very different context, had a recent large Ebola outbreak in Kivu (2018-2020). The same syntax was used on the same databases but included search terms such as "DRC" and "Congo". This search only resulted in one potential additional paper for inclusion.

The search was further broadened to include other infectious disease outbreaks in the three countries affected by the Ebola outbreak. The WHO Disease Outbreak News database[54] was trawled for outbreaks that had occurred over the past 13 years (**Table 1**). The only major outbreaks reported by WHO were cholera in Sierra Leone (2012), diphtheria in Guinea (2023) and a long-term outbreak of Lassa Fever in Liberia (2016-2020). The search was run for a third time for articles focused on disability and these outbreaks. This resulted in no additional papers for inclusion. This finding is in line with the Disability Helpdesk rapid review of the impact of COVID-19 on people with disabilities (Meaney-Davis, Lee and Corby, 2020), which found extremely limited data on any past epidemics bar the Ebola outbreak (where data were still quite limited).

Table 1 outbreaks (2012-2025)

Year	Country	Disease	Cases (deaths)
2012	Sierra Leone	Cholera	22,815 (296)
2013-2015	Guinea[55]	Ebola	28,616 (11,310)
2014-2015	Liberia	Ebola	
2014-2015	Sierra Leone	Ebola	
2016-2020	Liberia	Lassa Fever	168 (70)
2017	Liberia	Meningitidis C	31 (13)
2020	Guinea	Yellow Fever	50 (not reported)
2021	Guinea	Ebola	23 (12)
2021	Guinea	Marburg	1 (1)
2022	Guinea	Lassa Fever	2 (0)
2023	Guinea	Diphtheria	538 (58)
2023	Sierra Leone	Yellow Fever	1 (0)
2024	Guinea	Yellow Fever	3 (0)

Source: WHO disease outbreaks news[56]

3.4. Selection process

All results from the database searches were imported into Zotero (version 7) and were screened on title and abstract. Papers included on abstract were then reviewed full-text

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[54] The review was initially conducted in 2022

[55] The outbreak did not appear in the database until 23 March 2014 (the day after it was confirmed as the Zaire stain of Ebola); by which time there had been 49 reported cases in Guinea and 29 deaths.

[56] https://www.who.int/emergencies/disease-outbreak-news

and the same screening criteria applied. Reference lists of all included articles were scanned for further relevant articles. No automation tools were used, and the results were also independently reviewed by one person, as they formed the basis of this thesis.

3.5. Results

A total of 1,378 results were generated by the database search, of which five articles were included in the final review (**Table 2**). Of these, two focused on Ebola and three on COVID-19. While most papers focused on COVID-19 referred to the Ebola outbreak as a comparison, no study made an in-depth comparison between the two crises. Two studies were focused on Sierra Leone, two on Liberia, and one on the West Africa region. No studies focused specifically on Guinea.

The results of this literature search were heterogeneous and employed a variety of methodologies and research approaches (see **Figure 3**). Two of the five included papers present quantitative research: acquired disability amongst Ebola survivors (Jagadesh *et al.*, 2018); and the impact of COVID-19 lockdowns on young people with disabilities in Sierra Leone and Zambia (Sharpe *et al.*, 2021). One article reported on a mixed-methods research project comparing the impact of Ebola on people with and without disabilities (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021). The final two articles included reported qualitative findings: one of a media analysis of COVID-19 reporting in the West Africa region (Saalim *et al.*, 2021); and one which employed photovoice as participatory research exploring COVID-19 with people with disabilities in Liberia and Bangladesh (Chowdhury *et al.*, 2022). None of the articles described the outcomes of an intervention.

Research that was focused on people with disabilities in the target countries that was conducted around the time of the Ebola outbreak/during COVID-19, but which did not explicitly refer to the impact of outbreaks on participants was also excluded (e.g. Carew *et al.*, 2019; Austin *et al.*, 2021). The one paper emanating from the DRC that appeared to meet the inclusion criteria (focused on disability and COVID-19) had to be excluded due to extreme poor quality (Ibrahim, 2021).

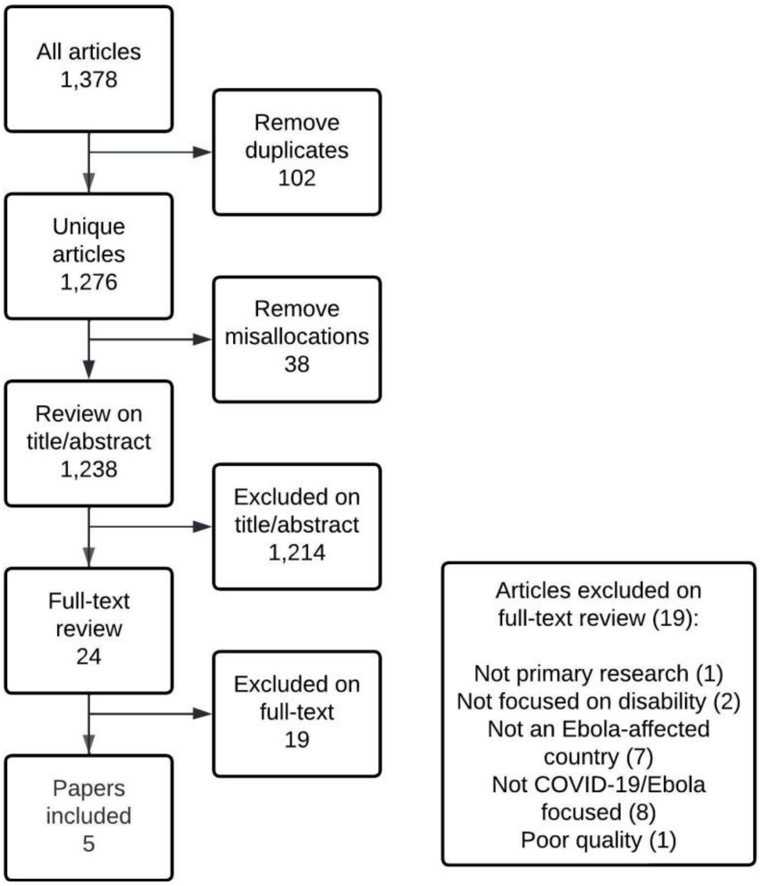

Figure 3 study selection process

Trustworthiness in qualitative research can be used to assess rigour and certainty of evidence. The papers included in this review were assessed against four key criteria to establish trustworthiness: credibility, transferability, confirmability, and dependability (Shenton, 2004). One paper that had initially been included in the review was excluded following this assessment. The paper by Ibrahim (2021) provided very little information on the research, including no information on sampling strategies beyond participants' belonging to a specific population group (disabled cross-border traders). The author reports that a short interview was conducted with people with disabilities; however, this is not available. There is also no information on the analysis methods. There was very little discussion of their findings, and the author did not present any triangulation with other sources to establish credibility. They also did not provide any justification for transferability of findings. However, the research was undertaken in a highly specific context, so transferability would always be limited. The author provided their affiliation but not any information about the project or their involvement, so their neutrality cannot be determined. No metadata are provided, so the study is not replicable, and not dependable. It also appears that the paper may have been published in a predatory journal. Overall, the paper was deemed to be of extremely poor quality and was therefore excluded from this review.

3.5.1. Overview of selected studies

Chowdhury et al. (2022) present results from a two-country photovoice project involving people with disabilities and caregivers in Liberia and Bangladesh. The research was focused on the experiences of people with disabilities and caregivers during COVID-19. This qualitative research had a sample size of 27: 13 in Liberia (nine people with disabilities and four caregivers) and 14 in Bangladesh (seven people with disabilities and seven caregivers).

Kett and colleagues (2021) discuss the impact of Ebola on people with and without disabilities in five counties in Liberia. I was part of this study, and the results form the background to my PhD research. It is a mixed-methods project which included a large household survey (n=2,020) that contained a section on Ebola. This article focuses specifically on the impact of the outbreak on people with disabilities – findings from the full research project have been reported elsewhere (Kett, Cole and Carew, 2017; Carew *et al.*, 2019). The study had 37 outcomes across seven domains (community, access to health, health treatment, information sources, behaviours, attitudes, and wellbeing). These domains were drawn from previous surveys by the authors. Disability was measured through the Washington Group on Disability Statistics extended question set (Washington Group on Disability Statistics, 2020b). Survey respondents were not asked directly whether they had survived Ebola as the authors felt that this would be substantially underreported due to stigma.

Jagadesh et al. (2018) reported on a case-control study examining acquired disability amongst Ebola survivors in Sierra Leone. The total sample size was 27 survivors and 54 close contacts who had not contracted Ebola (two per survivor). This study also used the Washington Group extended questionnaire. The main outcome of interest was the difference in disability scores between people who had survived Ebola and those who had not contracted the disease.

Saalim et al. (2021) performed a qualitative media analysis of 4,388 articles published in six West African countries. The research aimed to explore how ‘threats and consequences’ of COVID-19 for ‘vulnerable populations’ were reported.

Sharpe et al. (2021) used the short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS; Tennant et al., 2007) to assess the mental health and wellbeing of the young people with disabilities in the Northern and North-West provinces in Sierra Leone and several provinces in Zambia. A total of 468 participants were recruited, 228 from Sierra Leone and 240 from Zambia. Additional open-ended questions regarding social distancing, connectedness and challenges around education were also included. This paper does not explicitly set out how participants’ disability was identified but appears to be selecting an impairment from a drop-down list.

3.5.2.Synthesis of results

The impact of epidemics on **health** was reported in four of the five articles. Results from Kett et al. (2021) found that access to healthcare worsened for people with disabilities in Liberia, particularly in areas severely affected by Ebola. Similarly, Chowdhury et al. (2022) reported that during COVID-19, existing barriers to accessing healthcare were exacerbated, and fear of infection led disabled people to avoid formal health services and public transport. Kett and colleagues (2021) highlighted that health workers and community volunteers were overwhelmed during the Ebola outbreak and that treating people with disabilities was not a priority[57]. Accessibility of health messaging was another key issue, as noted by Chowdhury et al. (2022). In Liberia, people with hearing impairments were unable to access crucial COVID-19 information via radio or television for much of the pandemic due to the absence of sign language interpretation.

Saalim and colleagues (2021) report that reduced **health-seeking** behaviour during COVID-19 was more frequently mentioned in news articles in Ebola-affected countries than in countries unaffected by outbreak. They speculate that recollection of the fear of contracting Ebola at health facilities may influence care-seeking during COVID-19

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[57] worryingly none of the health professionals interviewed said that they had received any training on disability or awareness-raising on disability issues (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021)

(Saalim *et al.*, 2021). This finding is supported Kett et al. (2021), who report that people with disabilities in Liberia often did not access formal health systems during the Ebola time due to fear of contracting the virus. Instead they found that disabled households were more likely to seek healthcare from traditional healers or self-treat illness (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021). However, as mentioned, the same study found that during Ebola access to healthcare worsened, meaning that services may not have been available, which would also affect their health-seeking behaviour.

Jagadesh and colleagues (2018) reported a small case-control study assessing disability among a cohort of **Ebola survivors** in Freetown, Sierra Leone. Results from the research showed that survivors of Ebola were significantly more likely than control participants to report limitations in at least one of six functional domains. Mobility was the most commonly reported functional limitation. Survivors were also more likely to report visual limitations compared with the control population.

Four of the five papers included in this review presented findings about the **psychosocial impacts of the outbreaks**. Jagadesh and colleagues (2018) found that Ebola survivors had significantly higher anxiety and depression scores than the control population. Sharpe et al (2021) present findings from a study in Sierra Leone and Zambia. The project focused on the mental health impacts of COVID-19 lockdowns on school-age young people with disabilities. Findings showed that physical and visual impairments, as well as multiple disabilities, were significantly and negatively associated with mental health and wellbeing scores. The sense of social loss and loneliness experienced by co-researchers in Chowdhury et al. (2022) led to negative impacts on participants' mental health and wellbeing. Results from Kett et al. (2021) found that people with disabilities in study locations both affected and unaffected by Ebola reported feeling less happy and having worse lives than before the Ebola time.

Saalim et al. (2021) found that news reports in Liberia feared that COVID-19 would worsen the **educational** outcomes for at-risk children (including children with disabilities). This was echoed in research with young people with disabilities in Sierra Leone, where Sharpe et al. (2021) found that participants were anxious about the long-term impact of COVID-19 restrictions on their education and future work opportunities.

The impact of epidemics on **poverty** was highlighted by four authors. Kett et al. (2021) found that people with disabilities reported being poorer than they had been before Ebola. Qualitative findings showed that people with disabilities were not always able to comply with the stay-at-home epidemic response measures, as they were reliant on begging activities to supplement household income. This put them at increased risk of contracting Ebola. However, despite this, participants also reported being excluded from programmes and activities related to economic and social regeneration post-Ebola (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021), perpetuating structural inequalities. This is concerning because people with disabilities in Chowdhury et al. (2022) reported that even pre-pandemic, they were already experiencing greater poverty than non-disabled people.

Saalim and colleagues (2021) reported that media sources in Liberia primarily attributed heightened **food insecurity** to COVID-19 curfews and lockdowns. The *Liberian Daily Observer* reported that some households had reduced their meals to one per day, and 60% of citizens were facing starvation[58]. Similarly, in Chowdhury et al. (2022), participants experienced heightened food insecurity due to disruption to their livelihoods, and many stated that they relied extensively on family and friends for support. Further, Sharpe et al. (2021) highlighted that income loss, which impacts household food security, negatively affected young people with disabilities' mental wellbeing in Sierra Leone and Zambia.

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[58] It has not been possible to verify this finding in the *Liberian Daily Observer*

Table 2 Results characteristics

Article	Country	Focus	Study type/sampling	Sample size	Themes
Chowdhury et al. (2022) Pandemic portraits: an intersectional analysis of the experiences of people with disabilities and caregivers during COVID-19 in Bangladesh and Liberia	Liberia (and Bangladesh)	COVID-19	Qualitative: photovoice Purposive sampling	Liberia: 9 (and 4 caregivers) Bangladesh: 7 (and 7 caregivers)	Impacts of restrictions Gendered impacts Accessibility
Jagadesh et al. (2018) Disability among Ebola survivors and their close contacts in Sierra Leone: a retrospective case-controlled cohort study	Sierra Leone	Ebola	Case-control (Washington Group questions) Systematic sampling	81 (27 survivors)	Survivors Acquired impairment
Kett et al. (2021) The Ebola crisis and people with disabilities' access to healthcare and government services in Liberia	Liberia	Ebola	Mixed methods: case-control survey (Washington Group questions), focus groups and interviews Random sampling	2,020 survey, 34 KIIs, 22 FGDs	Multidimensional impacts of disability
Saalim et al. (2021) Reported health and social consequences of the COVID-19 pandemic on vulnerable populations	6 West African countries including	COVID-19	Qualitative media analysis: two news websites per	285 media excerpts from 12 publications	Vulnerable populations (including

and implemented solutions in six West African countries: A media content analysis	Guinea, Liberia and Sierra Leone		country searched for references to COVID-19		people with disabilities)
Sharpe et al. (2021) Mental health and wellbeing implications of the COVID-19 quarantine for disabled and disadvantaged children and young people: evidence from a cross-cultural study in Zambia and Sierra Leone	Sierra Leone (and Zambia)	COVID-19	Cross-sectional, cross-cultural SWEMWBS Convenience sampling	468 (228 Sierra Leone; 240 Zambia)	Mental health Disabled children Impact of COVID-19 response

3.6. Discussion

The aim of this review was to assess existing research on disability and recent epidemics in the three countries most severely affected by the West Africa Ebola outbreak. The findings reveal an alarming lack of attention to disability issues. A recent meta-analysis of qualitative research on disability in West Africa (Blasko *et al.*, 2022) found that only 11 of 223 studies were conducted in Liberia, Sierra Leone or Guinea. None of these focused specifically on Ebola or COVID-19 (the majority were in Nigeria or Ghana). This is particularly concerning given the heightened risks faced by people with disabilities during health emergencies, not only as a result of impairment-related factors, but also due to systemic exclusion from both routine healthcare and emergency public health interventions (Pearce *et al.*, 2022).

This lack of research has predictably resulted in substantial gaps in knowledge and policy guidance. However, even within the small number of studies included in this review, several key themes begin to emerge. These themes not only reflect common experiences of exclusion and vulnerability but also point to important areas for further investigation. The remainder of this chapter will discuss these themes in more detail and end by raising some potential limitations to this review.

3.6.1. Health and wellbeing

All of the articles included in this literature review discussed the impact of COVID-19 or Ebola on the health, mental wellbeing, and broader experiences of people with disabilities. Some authors have suggested that COVID-19 constitutes a syndemic (Horton, 2020a; Rod and Hulvej Rod, 2021) – a term used to describe the interaction of multiple diseases under conditions of social inequality (Singer *et al.*, 2017). However, others caution against applying the syndemic framework too broadly. Courtin and Vineis (2021) argue that the co-occurring disease pathways central to syndemic theory are not yet clearly understood in the context of COVID-19. In addition, Mendenhall (2020) asserts that applying the syndemic label to a global pandemic may be reductive, as it risks overlooking the diversity of localised impacts, contexts, and responses.

I argue that COVID-19 and Ebola are not a syndemic, as they occurred sequentially rather than concurrently and consequently lacked direct disease interaction (Singer *et* *al.*, 2017; Singer, Bulled and Ostrach, 2020). In addition, neither outbreak can be conceptualised as forming a syndemic with 'disability' (rather than with specific impairments or causes). Disability results from the interaction between a person with an impairment and wider environmental and attitudinal barriers (WHO, 2001; United Nations, 2006). As a result, the disability experience varies widely depending on context, impairment, individual circumstances, and structural factors.

A recent paper by Dean et al. (2022) argues that a syndemic exists between neglected tropical diseases (NTDs) and mental distress, shaped by the lasting structural violence of the civil wars. According to the authors, disability (as a result of social exclusion and stigma) and multi-morbidities are key pathways through which this syndemic unfolds (Dean *et al.*, 2022), rather than disability itself acting as a synergistic factor. This distinction is crucial: it reinforces the importance of attending to structural and social conditions rather than treating disability as a homogeneous or inherently pathological category.

While the syndemic framing may not fully capture the complexity of disability in the context of COVID-19 and Ebola, the literature does reveal how structural exclusion shaped people's access to care and treatment during both outbreaks. Health services – and the systems in which they are embedded – played a central role in reinforcing or mitigating the vulnerabilities experienced by people with disabilities. The studies included in this review consistently highlighted barriers to accessing routine and emergency healthcare, as well as the broader failures of health systems to accommodate disabled people's needs during times of crisis. The following sections explore how health service provision (or lack thereof) impacted the health and wellbeing of people with disabilities during these epidemics.

Health services

One of the most consistent themes to emerge from the literature is the significant disruption to health services during both the Ebola and COVID-19 outbreaks. These disruptions affected the general population, but the impact was often more severe for people with disabilities, who already face considerable barriers to healthcare in many West African contexts. The combination of system collapse, fear of infection, and structural exclusion likely resulted in both reduced access to care and worsening health outcomes for people with disabilities. This section explores how these dynamics played out across both epidemics, with a particular focus on the disabling consequences of interrupted services.

During the COVID-19 pandemic, Chowdhury and colleagues (2022) reported that people with disabilities often avoided formal health services due to fear of contracting the virus. This mirrors patterns seen during the Ebola outbreak, when individuals turned to informal healers or self-treatment rather than seeking care through ‘official’ channels (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021). These individual behaviours among people with disabilities reflect a broader mistrust in formal health systems, shaped by widespread experiences of discriminatory attitudes from health professionals and persistent inaccessibility of services (Kett *et al.*, forthcoming).

Beyond individual behaviour, structural failures also played a major role. A systematic review of the indirect impacts of the Ebola outbreak found that utilisation of a wide range of health services declined significantly in Liberia (Brolin Ribacke *et al.*, 2016), including malaria prevention programmes. This decline contributed to a surge in malaria cases, with related deaths eventually outstripping those caused directly by Ebola (Heuschen *et al.*, 2021). While the longer-term disabling effects of this increased malaria burden are rarely discussed, they are particularly severe in children, who are at heightened risk of neurodevelopmental complications and cognitive impairment (Boivin *et al.*, 2007). People with disabilities are already at increased risk of contracting malaria and other infectious diseases, owing to poverty, poor living conditions, and systemic barriers to care (WHO and World Bank, 2011; United Nations, 2018).

Disruptions to maternal and child health services were also widely reported during both the Ebola outbreak (Brolin Ribacke *et al.*, 2016; Delamou *et al.*, 2017) and the COVID-19 pandemic (Shapira *et al.*, 2021; Aranda *et al.*, 2022). Such disruptions are likely to have an even greater impact on pregnant people with disabilities, who often face increased barriers to accessing care, especially in rural areas (United Nations, 2018). Interruptions have serious implications for disability for both parent and child, including from complications arising during births without a skilled attendant, as well as a decline in routine childhood immunisations.

The collapse of the health system during Ebola was driven by a convergence of factors – including the deaths of health workers, the legacy of civil war, and the dominance of vertical, siloed Ebola programming (O'Hare, 2015; Richards, 2016; Farmer, 2020). During COVID-19, similar concerns emerged around the reallocation of resources away from other critical and disease prevention services (Heuschen *et al.*, 2021), leading to major disruptions in general healthcare provision (Shapira et al., 2021), both of which would lead to worsening health outcomes for populations already living with structural disadvantage. This highlights the immense challenge of mounting an effective emergency response in contexts where health systems are under-resourced, and where the burden of endemic diseases may far exceed that of the pandemic itself.

Mental health

The COVID-19 pandemic had a profound impact on mental health globally. In the first year of the pandemic alone, the global prevalence of depression and anxiety increased by more than a quarter (WHO, 2022). For people with disabilities, this psychological toll was particularly acute. A growing body of evidence highlights the disproportionate mental health impacts of COVID-19 on people with disabilities, who were more likely to experience heightened stress, isolation, and anxiety (Meaney-Davis, Lee and Corby, 2020; Kubenz and Kiwan, 2021; WHO, 2022).

A scoping review by Mann et al. (2021) found that children and young people with disabilities experienced worsening mood, challenging behaviours, and reduced overall wellbeing as a result of the pandemic. In a related study included in this review, which focused on the implications of COVID-19 quarantines in Sierra Leone and Zambia, Sharpe et al. (2021) reported that 91% of young participants with disabilities required substantial psychological support in response to their experience of the pandemic. The study also identified particular risk factors associated with poor mental wellbeing, including being female, living with a visual impairment, or having multiple disabilities.

Yet the availability of appropriate support services remains extremely limited. In their analysis of Child and Adolescent Mental Health Services (CAMHS) in Sierra Leone, Yoder-Van Den Brink (2019) found that these services were chronically under-resourced and deprioritised following successive crises, including the Ebola outbreak. At the time of writing, only a single specialist outpatient clinic was operating in the country. This lack of infrastructure significantly undermines the ability to respond to the mental health needs of young people with disabilities – both during the COVID-19 pandemic and in its aftermath.

The psychological burden of Ebola was also documented. In this review, Jagadesh and colleagues (2018) found that Ebola survivors reported significantly higher levels of anxiety and fatigue than the general population, a finding echoed by other studies reporting widespread psychological distress among survivors (James *et al.*, 2019; Bah *et al.*, 2020; Secor *et al.*, 2020). James et al. (2022) further observed that post-Ebola symptoms contributed not only to mental health difficulties but also to declining physical functioning, compounding mobility impairments and creating new barriers to daily life. These findings speak to the long-term and intersecting nature of physical and psychological recovery following epidemic exposure – and underscore the need for consistent and accessible psychosocial support.

While the previous sections have focused on the psychological impacts of COVID-19 and Ebola, it is also important to consider the physical consequences of surviving epidemic illness.

Impairment in survivors

In the wake of Ebola, many survivors were left with long-term impairments that significantly altered their lives. These post-Ebola sequelae have received comparatively little attention in research and programming (Chertow, 2019; PREVAIL III, 2019), despite their potential to create new disabling experiences and compound existing exclusion.

The Ebola and COVID-19 outbreaks have each produced lasting impairments among survivors, generating both new cases of disability and compounding existing ones. One paper included in this review examined acquired disability among Ebola survivors in Sierra Leone. Jagadesh et al (2018) found that people who had survived the disease were more likely to experience blurred vision and physical impairments compared to a control group. This finding aligns with broader evidence on post-Ebola sequelae (Clark *et al.*, 2015; Scott *et al.*, 2016; Chertow, 2019), including data from a large longitudinal cohort study in Liberia (PREVAIL III, 2019), which identified vision problems as often causing the greatest burden for survivors.

A smaller study in Sierra Leone reported a range of neurological symptoms among Ebola survivors, including severe migraines (Howlett *et al.*, 2018). The authors also found a correlation between higher levels of physical disability and the presence of co-existing mental health challenges. However, they caution that the study's cross-sectional design and lack of a general population control group prevent any firm conclusions about causality. A systematic review of long-term neurological and physical sequelae of Ebola similarly found inconclusive results, largely due to limited and non-comparable data across the ten studies reviewed (Lötsch *et al.*, 2017).

By contrast, the long-term disabling consequences of COVID-19 – particularly those associated with 'long covid' – have gained much more global attention. It was estimated in 2022 that at least 65 million people worldwide were living with 'long covid' (Davis *et al.*, 2023). In Liberia, nearly half of those who experienced symptomatic COVID-19 continued to report symptoms up to six months after recovery, with 40% stating that these symptoms significantly impacted their daily functioning (Gwaikolo *et al.*, 2024). While it is now widely recognised that people with disabilities or pre-existing health conditions were disproportionately affected by the pandemic (Kubenz and Kiwan, 2021; Pearce *et al.*, 2022), there are still limited data on the long-term impact of 'long covid' within these groups. One exception is a large-scale survey in the United States, which found that people with disabilities were significantly more likely to experience 'long covid' than non-disabled respondents (40.6% vs 18.9% respectively; Hall *et al.*, 2024).

Fear and mistrust

While long-term physical and psychological consequences shaped many people's post-epidemic realities, another crucial – and often underestimated – factor influencing health outcomes was fear. Across both Ebola and COVID-19, fear and mistrust played a central role in shaping how people responded to health information, engaged with services, and made decisions about seeking care. For people with disabilities, these dynamics were compounded by pre-existing experiences of exclusion, stigma, and ableist attitudes. This section explores how fear – both rational and socially constructed

– shaped health-seeking behaviour, and how mistrust of authorities, health workers, and government responses influenced people's actions during both outbreaks.

During Ebola, widespread misinformation and conspiracy theories further eroded public trust. These included beliefs that the virus was a government tool for population control, that it was spread by the military or that it was a myth altogether (Richards, 2016; Abramowitz *et al.*, 2017; Elston *et al.*, 2017; Farmer, 2020). Such narratives had tangible effects, particularly in the initial stages where fear spread like an epidemic: 'rapidly and contagiously' (Shultz *et al.*, 2016, p. 104). People were hesitant to attend Ebola Treatment Units (ETUs) when they showed symptoms out of fear (Yamanis, Nolan and Shepler, 2016), some believing that health workers were harming patients or harvesting body parts (Shultz *et al.*, 2016; Yamanis, Nolan and Shepler, 2016; Farmer, 2020).

Misinformation also played a significant role during the COVID-19 pandemic. Early on, global health authorities warned of an 'infodemic' – an overwhelming surge of mis- and disinformation (Horton, 2020b; United Nations, 2020). In Liberia, this took the familiar misinformation forms as with Ebola. The echoes of Ebola-era mistrust were clear – reinforcing how epidemics unfold not only pathologically but socially and emotionally.

This fear of Ebola in particular has had a lasting effect. In their media analysis, Saalim et al. (2021) speculate that the reason that media narratives in Ebola-affected countries continued to emphasise reduced care-seeking during COVID-19 may have been due to the recalled fear of contracting Ebola. Fear significantly influenced health-seeking behaviours. Kett et al. (2021) found that people with disabilities were less likely to visit formal health services during the Ebola outbreak due to fear of infection. These fears were not unfounded. Limited infection prevention and control mechanisms meant that nosocomial transmission was common, and hospitals were regarded by many as being high-risk environments (Shultz *et al.*, 2016; Farmer, 2020). Similar fears resurfaced during the early stages of the COVID-19 pandemic, with some people again expressing reluctance to attend hospitals (Layton *et al.*, 2021).

Fear and mistrust were also drivers of perceived 'non-compliance' with health measures. The Ebola outbreak saw a widespread collapse in trust, particularly in state and health institutions (Abramowitz *et al.*, 2017; Elston *et al.*, 2017). In Liberia, Blair et al. (2017) found that 'compliance' with health policies was positively associated with trust in government, while knowledge about Ebola itself had little impact. Kett and colleagues (forthcoming) report that people with disabilities in Liberia frequently expressed low levels of trust in government health systems, citing discrimination by health workers, a lack of available medication, and poor quality of care. When possible, participants preferred to seek care through private providers – an approach that further entrenched health inequities due to the burden of out-of-pocket costs.

Together, these findings from this scoping review illustrate how epidemics do more than disrupt immediate health outcomes; they expose and deepen structural inequalities. For people with disabilities, barriers to healthcare during Ebola and COVID-19 were shaped not only by impairment-related factors but also by systemic failures in service provision, widespread discrimination, and deep-seated mistrust. These dynamics were not confined to the health sector alone. As the following section will show, the education system was similarly affected.

3.6.2. Education

Beyond the health system, education is another sector in which people with disabilities experienced intensified exclusion during both the Ebola and COVID-19 outbreaks. School closures, the shift to remote learning, and reduced support services disrupted education for 1.5 billion learners globally during COVID-19 (UNESCO, 2023) – but the impact was particularly severe for children and young people with disabilities (IEI, 2021). These disruptions compounded pre-existing inequalities in access to education, learning outcomes, and retention, with long-term consequences still unfolding. This section explores how public health emergencies affected educational inclusion for disabled learners in West Africa, drawing attention to the structural barriers that persisted – and, in many cases, worsened – during times of crisis.

Even prior to the COVID-19 outbreak, children and young people with disabilities faced significant and often insurmountable challenges in accessing education. It has been estimated that around half of all children with disabilities are out of school globally (Education Commission, 2016). For those who do enrol, many experience lower learning outcomes and are at greater risk of dropping out (United Nations, 2018). These educational disparities are often linked to intersecting barriers, including poverty, inaccessible learning environments, stigma, and a lack of teacher training or appropriate support.

The COVID-19 pandemic profoundly disrupted education worldwide. At the height of school closures, more than a billion children across 151 countries were affected (UNESCO, 2020). In West Africa, these disruptions echoed patterns seen during the Ebola outbreak, where approximately five million children ended up losing nearly a year of schooling (Elston *et al.*, 2017). Concerns about the educational fallout from COVID-19 were widespread. Saalim et al. (2021) reported that news coverage in Liberia frequently expressed fears that the pandemic would worsen educational outcomes, deepen existing inequalities and increase the risk of drop-out for vulnerable learners – particularly children with disabilities. Similarly, Sharpe et al. (2021) found that young people in Sierra Leone felt the restrictions significantly undermined their educational opportunities.

Saalim and colleagues (2021) also emphasise that the impact of school closures extends beyond educational outcomes. Prolonged absences from school increase the risk of exploitation, abuse, and teenage pregnancy (Elston *et al.*, 2017; Chavez Villegas *et al.*, 2021). In both Liberia and Sierra Leone, media reports expressed concerns that due to COVID-19 school closures, young people with disabilities were at increased risk of permanent drop-out due to worsening household circumstances and the inaccessibility of remote learning platforms (Saalim *et al.*, 2021).

For many students with disabilities, remote learning was not a viable alternative. In many countries, data is extremely and prohibitively expensive. In Sierra Leone, young people with disabilities reported that disruptions to education during the COVID-19 pandemic heightened their anxiety (Sharpe *et al.*, 2021). In Liberia, media sources highlighted that poor digital infrastructure and unreliable internet access posed significant barriers to online education, particularly for children living in poverty (Saalim *et al.*, 2021). These challenges were especially acute for students with intellectual disabilities, who often require specialised support and accessible materials that were not incorporated into emergency education responses.

Despite the clear barriers, there remains a striking absence of research on how home-based or remote learning was adapted – if at all – for children and young people with disabilities (Saalim *et al.*, 2021). Very few studies captured the perspectives of learners themselves or examined how inclusion was addressed within national education responses. This lack of information not only reflects a gap in research but signals a broader failure to consider disability within emergency education planning. As with healthcare, the education system's response to the COVID-19 and Ebola outbreaks often reinforced existing inequalities – pushing already marginalised learners further to the margins.

3.6.3. Poverty and food insecurity

Poverty is both a cause and consequence of exclusion for people with disabilities (Banks, Kuper and Polack, 2017), and public health emergencies can exacerbate existing vulnerabilities. Across the literature, the impacts of both Ebola and COVID-19 on poverty were reported to varying degrees, with several studies highlighting how people with disabilities experienced disproportionate financial hardship during and after these crises. This section explores how income loss, food insecurity, and structural poverty shaped disabled people's experiences of epidemic response measures and their ability to comply with public health guidance.

The economic impacts of both Ebola and COVID-19 were significant, particularly for people with disabilities, who were already living in precarious circumstances. Jagadesh and colleagues (2018) found that Ebola survivors with acquired disabilities were more likely to be unemployed due to ongoing health-related challenges than a control group of unaffected community members. During the COVID-19 pandemic, this economic vulnerability was further exacerbated by rising food insecurity. Research found that lockdown measures had deepened the risk of hunger and malnutrition among already marginalised groups, including people with disabilities (Saalim *et al.*, 2021; Sharpe *et al.*, 2021; Chowdhury *et al.*, 2022). Similarly, other authors reported that that restrictions on movement, coupled with inadequate social protection, increased the likelihood of starvation for those who were already excluded from mainstream support systems (Kassa and Grace, 2020; Hearst *et al.*, 2021). Ezirigwe et al. (2021) argue that COVID-19 was not the primary cause of food insecurity but rather it intensified an existing crisis exacerbated by rising food prices and reduced household incomes. For people with disabilities, who often lack stable employment and are underserved by government support, the pandemic exposed and amplified long-standing economic fragilities (United Nations, 2018).

Poverty also shaped people's ability to follow public health guidance. Kett et al. (2021) found that during Ebola many respondents relied on charitable or food donations to survive. As a result, people with disabilities were unable to comply with 'stay at home' orders as they often needed to leave their homes to beg. Similarly, Hearst et al. (2021), in a small study with caregivers of children with disabilities in Zambia, reported that lack of access to soap, hand sanitiser, and personal protective equipment (PPE) created significant barriers to adhering to COVID-19 prevention guidelines. These findings underscore how economic marginalisation directly affects the feasibility of compliance, particularly in communities already excluded from essential services.

It is widely reported that people with disabilities are more likely to live in poverty than non-disabled people (Banks and Polack, 2014; United Nations, 2018). However, this relationship is not uniform. A study on poverty reduction and disability in Liberia conducted in the aftermath of the Ebola outbreak found little material difference in poverty levels between households with and without a disabled member (Carew *et al.*, 2019). The authors suggest that this reflects the depth of poverty across Liberian society, where access to resources and services is extremely limited for all. In such contexts, disability-related disadvantage is layered upon widespread systemic deprivation, making the intersection of poverty and disability even more complex to address.

3.6.4. Participation

Meaningful participation is a cornerstone of rights-based approaches to disability inclusion. The principle that people with disabilities should be actively involved in decisions that affect their lives is embedded in international frameworks such as the UNCRPD (United Nations, 2006). Participation becomes even more vital in times of crisis, when decisions are made rapidly and have far-reaching consequences. Yet despite this, the literature reviewed revealed a stark absence of attention to participation – both in the design and delivery of epidemic responses.

Disability issues were not given priority during the Ebola outbreak (Meaney-Davis, Lee and Corby, 2020). Kett et al. (2021) found that people with disabilities were excluded from the Ebola response due to the lack of targeted health activities. Further findings from the same research project suggested that this exclusion extended beyond emergency contexts – many participants reported feeling marginalised from community life more generally, which limited their ability to participate in decision-making processes (Carew *et al.*, 2019). In such circumstances, the rights and needs of people with disabilities are easily overlooked, with serious implications during crises where resources and attention are already stretched.

This should not have been the same for the COVID-19 response, given the raft of guidance that was published on the inclusion of people with disabilities (COVID-19 Hygiene Hub, 2020; OHCHR, 2020; UN, 2020; WHO, 2020c). One of the central principles promoted by all these guidelines was that people with disabilities and their representative organisations (OPDs) should be consulted in the planning, implementation and evaluation of COVID-19 response actions. Yet despite this, a global monitoring initiative found widespread failures to involve OPDs in COVID-19 response planning (Disability Rights Monitor, 2020). Kubenz and Kiwan (2021) similarly note that, even where inclusion is formally acknowledged, people with disabilities continue to be deprioritised in practice, reinforcing patterns of systematic exclusion.

The near-total absence of participation-focused research in this review suggests a significant gap in both scholarship and practice. This lack of evidence makes it difficult to assess the extent to which people with disabilities were meaningfully engaged in shaping epidemic responses and highlights a critical area for future investigation. The following section discusses some of the limitations of this review and reflects on how these may have shaped its findings.

3.7. Review strengths and limitations

Although I conducted this scoping review alone, this brought several strengths. It ensured consistency and efficiency across all stages of the review process and avoided the variability that can arise in multi-person review teams. My prior experience in disability-inclusive research and contextual knowledge of Liberia further strengthened the interpretive process, allowing for a more in-depth and nuanced exploration of key themes.

On the other hand, there are several potential limitations to this review that should be considered. The first is that only one person conducted the literature searches and reviewed the articles for inclusion. This may have led to some bias in the selection process. However, as mentioned previously, a focused syntax and a strict set of inclusion criteria were applied, both of which were reviewed by two other people, which hopefully limits the potential bias.

Another limitation is the lack of articles focused on Guinea. While no language exclusion was applied to the syntax or databases, only one paper in French came up in the results (focused on DRC), which unfortunately had to be excluded due to its poor quality. The lack of articles may be due in part to Guinea being a francophone country, meaning that potential articles were not available on databases cataloguing predominantly English resources. This may also have limited the number of articles to review from DRC. However, it may also be the case that there is no published research focused on disability in these countries.

The third limitation is that the syntax employed in this review did not include terms specifically related to mental health (“mental health”, “mental illness”, psychosocial, etc.). These were initially part of the search terms used, which resulted in thousands of hits. However, during the initial review of the results, it transpired that every paper was related to the impacts of the epidemics on non-disabled people’s mental health (rather than people who were already experiencing psychosocial disabilities), which is not the aim of this review. It is possible therefore that some papers that were focused on people with pre-existing mental health challenges were unintentionally excluded.

3.8. Conclusion

There is a substantial dearth of evidence on the impacts of Ebola or COVID-19 on disabled populations in West Africa. This points to a worrying lack of focus on disability issues in the region. Consequently, there are predictably many gaps in the literature.

There is a lack of research and data that has a historical lens examining, for example, the impact of colonialism on the experience of the Ebola and COVID-19 crises for people with disabilities in West Africa (Wilkinson and Leach, 2015). There is also little research that considers the heterogeneity of people with disabilities – who will have very different experiences of epidemics depending on their impairment and personal circumstances (Kubenz and Kiwan, 2021).

This review has clearly demonstrated that the intersection of disability and epidemic response remains a critically under-researched area. There is an urgent need for research that centres and foregrounds the voices and experiences of people with disabilities, particularly in West Africa, where structural exclusion continues to shape outcomes during public health emergencies. My research project aims to address at least some of these gaps. The following chapter outlines the methodological approach I adopted to address some of these gaps and to generate new evidence on how people with disabilities navigated the Ebola and COVID-19 crises.

Chapter four: methodology and methods

4.1. Introduction

This chapter outlines the methodologies and methods used in this research project. I begin by presenting my research approach and the academic discourses that underpin it, followed by the theoretical frameworks that informed my research design, data collection, and analysis. I then describe the methods employed during the study, before providing an overview of the six months I spent conducting primary data collection in Liberia between October 2022 and June 2023. Finally, I reflect on my own positionality, including my identity as a disabled researcher, and discuss a particularly challenging moment during fieldwork – a severe case of shingles that resulted in hospitalisation – which influenced many of the themes explored in this thesis.

4.2. Methodology

Because my research is qualitative rather than quantitative, I take an interpretivist stance, grounded in the understanding that people construct meaning and reality through their experiences and interactions. Whereas positivist approaches treat reality as objective, observable and measurable, interpretivist approaches hold that reality is socially constructed, subjective, and shaped by context (Schwartz-Shea and Yanow, 2020). As an epistemological position, interpretivism is concerned with how people gain knowledge, interpret the world, and ascribe meaning to their experiences (Pauwels and Mannay, 2020).

My research methodologies are strongly informed by anthropology, particularly research with a focus on West Africa (for example: Leach, 2015b; Richards, 2016; Abramowitz, 2017; Wilkinson *et al.*, 2017a), as well as theoretical approaches that engage with structural inequalities and social suffering (Scheper-Hughes, 1996; Kleinman, 1997). These perspectives allow for a deep engagement with the lived experience of crisis and exclusion, and how broader systems and histories shape those experiences.

In addition, my research adopts a critical stance, grounded in the belief that understanding power, structural inequality, and social justice is essential to uncovering how privilege is maintained and how exclusion and suffering are produced. My critical research approach seeks to interrogate the structural forces and historical processes that shape knowledge production, including the ways that institutions and systems uphold the marginalisation of particular groups (Kincheloe, 2005; Budd, 2012).

Power – who has it, how it operates, and how it is maintained – is a core concern in critical research. It recognises that inequitable structures and cultural norms are continuously re/produced, legitimising dominant institutions while excluding others (Galtung, 1990). Critical research also works to situate individual experiences within wider historical, geopolitical and domestic-political contexts, analysing the impacts of policy decisions, governance structures, and broader systems (Budd, 2012). This resonates with Paul Farmer's (2004) call for a 'geographically broad and historically deep' perspective (see **section 4.3.1**), which is particularly relevant for research in Liberia. My work considers how both near histories – such as the COVID-19 and Ebola responses – and longer histories – including colonisation, civil war, and patterns of exclusion – shape how people with disabilities experience epidemic responses.

Epidemic responses are an opportunity to reveal broader structural inequalities (Bowleg, 2020; McKinney, McKinney and Swartz, 2021). Critical research seeks to challenge structural processes and institutions that serve to marginalise populations and limit choice (Kincheloe *et al.*, 2018). Johan Galtung's concept of structural violence (1969) is central to my analysis (discussed in **4.3.1**). It offers a lens through which to understand how systemic inequalities rooted in historical, political, and economic structures manifest as embodied suffering, exclusion, and preventable harm. This is particularly relevant in epidemic contexts, where structural violence shapes both exposure to risk and access to care, and where people with disabilities often face intersecting forms of marginalisation.

I also draw on Nancy Fraser's model of social justice (1997; 2009), which emphasises the importance of redistribution, recognition and representation (**Table 4**). Her framework supports an exploration of how people with disabilities in Liberia have been structurally excluded from health systems and public discourse, not only through material deprivation, but also through cultural devaluation and political invisibility.

4.3. Research approach

I will now move on to present the three main frameworks that I used during research design, data collection and analysis: structural (and other) violence; social justice; and participatory action research.

4.3.1. Structural (and other) violence

In 1969, peace theorist Johan Galtung published what would become a seminal paper, *Violence, peace, and peace research*. In it, he defines violence as being ‘when human beings are being influenced so that their actual somatic and mental realizations are below their potential realization’ (Galtung, 1969, p. 168). From this overall definition he goes on to identify two kinds of violence: direct and structural (Error! Reference source not found.). He later expanded this definition, describing violence as ‘avoidable insults to basic human needs, and more generally to life’ (Galtung, 1996, p. 196).

Direct violence refers to physical or psychological harm inflicted upon individuals, including killing, assault, and manipulation, as well as threats to life. By contrast, structural violence is systemic and indirect, emerging from inequalities in access to resources, power, and opportunities. This form of violence results in unequal life chances, manifesting in areas such as healthcare, education, and employment – issues that are of central concern for people with disabilities (United Nations, 2018). Galtung (1969) describes structural violence as being ‘tranquil waters’ – quiet, unnoticed, and often accepted as the norm. This metaphor highlights how systemic harm can be embedded in institutions, policies, and cultural norms, without drawing attention or resistance. At its most efficient, structural violence becomes self-sustaining, requiring no additional reinforcement. However, when this system is disrupted or challenged, mechanisms are often deployed to restore stability. This frequently takes the form of direct violence or the threat of violence, which serves to reinforce and uphold the existing structure and restore stability to the system (Galtung, 1971).

Galtung later introduced a third type of violence: cultural violence (Galtung, 1990). Cultural violence refers to beliefs, ideologies, or social norms that legitimise direct and structural violence, making them appear natural, acceptable, or even necessary (or at least not wrong). A clear example of cultural violence is ableism, which valorises ‘ability, consequently justifying and normalising the exclusion, marginalisation, and devaluation of people with disabilities' (Campbell, 2009). This theme isexplored in more detail in **section 4.3.2**. Other examples of cultural violence include 'caste, patriarchy, slavery, apartheid, colonialism, and neoliberalism, as well as poverty and discrimination by race, ethnicity, gender, sexual orientation, and migrant/refugee status' (Rylko-Bauer and Farmer, 2016, p. 47), any of which, when present, intersects with the disabled experience.

Galtung (1990) suggests that while violence can start anywhere, there is often a 'causal flow' beginning with cultural violence, moving through structural violence and then into direct violence. This 'flow' is evident in the history of Liberia. As discussed throughout **chapter two**, these three types of violence are deeply evident in Liberia, shaping the lived experiences of people with disabilities in profound ways.

Table 3 Galtung's violence

Direct violence	Structural (or imperial) violence[59]	Cultural violence
▪ direct harm ▪ unstable (an event) ▪ easily observable ▪ observable actor committing the violence ▪ subject, object, action ▪ physical or psychological ▪ can be denial (e.g. of food, water in a siege or embargo)	▪ indirect harm ▪ stable (process) ▪ 'the tranquil waters' ▪ may not be an observable actor ▪ unequal power, unequal life-choices ▪ perpetuation of inequality ▪ inequality and distribution of power ▪ institutional and systemic ▪ uneven distribution of resources ▪ the power to decide how to distribute ▪ states on citizens or between states	▪ indirect harm ▪ stable ('invariant') ▪ makes violence 'feel right' ▪ supremacy and cultural hegemony ▪ systemic ▪ legitimisation of inequality and injustices (inferior, deserving of mistreatment, victim blaming) ▪ subjugating groups, second class citizens ▪ reproduction of inequality (Galtung, 1969, 1990)

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[59] Structural violence can refer to either intra- or inter-state violence. Some authors use structural violence for both (Wilkinson and Leach, 2015; Farmer, 2020), others refer to 'imperial violence' for the latter (Galtung, 1971; Hirschfeld, 2017). For the purpose of this research I will use structural violence for both types, as inter-state violence is broader than just one state exerting power over another.

Social suffering, a concept closely associated with structural violence, has long been theorised by medical anthropologists seeking to understand how pain, trauma, and marginalisation are not merely individual experiences but collectively and systemically produced. As anthropologists Veena Das, Arthur Kleinman and others have argued, suffering is not only personal but social – embedded within histories, institutions, and relations of power (Kleinman, 1997; Das, 2006). Social suffering moves beyond individual pathology or isolated events to capture how broader social and political arrangements – such as poverty, institutional neglect, or discriminatory health systems – come to be lived and felt by individuals and communities.

Kleinman notes that social institutions tend to recognise and respond to particular forms (or categories) of sufferers, disregarding others or treating them with what he terms 'bureaucratic indifference' (Kleinman, 1997, p. 321). This insight is particularly pertinent to people with disabilities who historically existed on the margins and who have often faced exclusion from policy and programmes. In my research I first sought to understand which forms of harm were acknowledged, which were overlooked, and how people with disabilities navigated these in times of crisis; and second to make visible the forms of suffering that are frequently rendered invisible by dominant discourses of crisis response and recovery.

Questions around whose suffering is recognised, responded to, or rendered invisible are central to Didier Fassin's work on humanitarianism and moral politics. He argues that humanitarian action often operates through a selective moral economy, in which certain forms of suffering are deemed legitimate and therefore worthy of intervention, while others are ignored or depoliticised in what Fassin terms the 'hierarchy of humanity', where some lives are rendered more deserving, more valuable, or more visible than others (Fassin, 2012a). Crucially, Fassin also argues that humanitarian responses often reproduce the very inequalities they claim to address. By focusing on alleviating immediate suffering without addressing its structural causes, humanitarianism can become a form of containment rather than transformation. It soothes the symptoms while leaving the systems that generate harm intact. This insight is particularly relevant to research on disability, where suffering is frequently framed in medical or charitable terms, detached from the political and structural contexts in which exclusion occurs. In such framings, people with disabilities may be treated as passive recipients of 'aid' rather than as active agents entitled to rights, participation, and justice.

Building on the theoretical foundations of suffering and violence, physician and health anthropologist Dr Paul Farmer popularised the use of structural violence as an explanatory model (Herrick and Bell, 2022). Expanding on Galtung's original theory, he has written extensively on structural violence as it pertains to suffering, epidemics and infectious diseases (Farmer, 1992, 2004, 2005, 2009b, 2020). For Farmer, structural violence is a way of describing 'social arrangements that put individuals and populations in harm's way... [they] are embedded in the political and economic organization of our social world' (Farmer *et al.*, 2006, p. 1686). Farmer's 'geographically broad and historically deep' approach was first set out in his 1992 book, *AIDS & accusation: Haiti and the geography of blame*, in which he states:

> *'an ahistorical analysis of their current dilemmas will fail to reveal the true nature of their suffering... the aftereffects of events that took place centuries earlier... may be shown to have sculpted the Haitian AIDS epidemic' (Farmer, 1992, p. 256).*

This approach argues that it is impossible to understand structural violence in a vacuum and events such as colonialism and slavery, as well as international power structures, have tangible impacts on the lives and suffering of individuals.

Epidemics cannot be fully understood without examining the historical, political, and social contexts in which they emerge. Disease outbreaks do not occur in a vacuum – they unfold within structures shaped by colonial legacies, economic inequality, conflict, and patterns of exclusion. These contexts determine who is most at-risk, who is prioritised in response efforts, and who is left behind. For example, histories of mistrust in public health institutions, driven by prior neglect or exploitation, can influence how communities engage with emergency measures. Similarly, pre-existing disparities – such as poverty, access to healthcare or information – shape how an epidemic is experienced. Understanding epidemics historically allows us to see beyond biomedical narratives and recognise how social injustice becomes embodied through unequal exposure to illness and unequal access to care.

More recently, Farmer published an expansive book, *Fevers, feuds and diamonds,* in which he discusses the legacy of structural violence in West Africa (Farmer, 2020). Here he argues that there are direct causal linkages leading from colonialism to the 2013-2015 Ebola outbreak. Anthropologists Annie Wilkinson and Melissa Leach also argue that the Ebola crisis was a product of structural violence in Liberia, one that 'emerged from the meeting of long-term economic, social, technical, discursive, and political exclusions and injustices ...[and] must be understood in the context of a regional history and global economy that have cultivated inequalities' (Wilkinson and Leach, 2015, p. 137).

Hirschfeld (2017) cautions against applying structural violence as an explanatory model for disease outbreaks such as Ebola, however. Their argument hinges on the idea that Ebola, being incurable and untreatable, does not lend itself to the kind of analysis Galtung envisioned – namely, violence caused by 'avoidable death'[60]. Hirschfeld asks, 'How many Ebola deaths were avoidable?', implying that few were. However, in the same discussion, they compare Ebola to cholera, describing cholera deaths as preventable through timely administration of fluids and electrolytes. This is, in fact, the same supportive care used to treat Ebola, suggesting that at least some deaths would have been avoidable with adequate health infrastructure (Farmer, 2020).

In line with Farmer (2020) and others, I argue that many Ebola-related deaths were indeed preventable – had robust health systems, surveillance mechanisms, and appropriate interventions been in place. Hirschfeld also suggests that Liberia does not share the colonial history of Sierra Leone and Guinea, characterising it as a 'haven for returned North American and Caribbean slaves' (Hirschfeld, 2017, p. 158). This framing erases the presence of indigenous populations and downplays the quasi-colonial

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[60] In his 1969 article, Galtung argues that, 'if a person died from tuberculosis in the eighteenth century it would be hard to conceive of this as violence since it might have been quite unavoidable, but if he dies from it today, despite all the medical resources in the world, then violence is present' (Galtung, 1969, p. 168). I do not agree with this argument, as I would contend that structural violence clearly existed in the 18th Century: impoverished people working and living in dangerous and unsanitary conditions clearly led to increased risk of contracting TB and poorer health outcomes due to lack of healthcare, impeding their 'potential'.

structures imposed by Americo-Liberians, supported by US interests (as discussed in **chapter two**).

While Hirschfeld rightly stresses the importance of grounding epidemic responses in local histories, their analysis focuses primarily on 'imperial' violence (see Error! Reference source not found.), giving little attention to intra-state structural violence. Epidemics take place in a complex space between the two. Their analysis overlooks how structural violence operates not only through global power relations, but also through domestic policies, historical inequalities, and failures of public provision. The 2013-2015 Ebola outbreak can be understood as a 'symptom' of long-term structural neglect – the legacy of two centuries of health inequity, exploitation, and governance failures (Ciment, 2014; Farmer, 2020; Mitman, 2021).

Figure 4 a deserted hospital and rusting ambulance in Foya

People with disabilities have been portrayed as 'victims' of structural violence (Eide *et al.*, 2017). This is potentially caused by a range of multiple intersecting factors including exclusion from health services (due to lack of accessible provision, stigma of health workers), lower levels of education (due to lack of accessible schools, poverty), lower rates of employment (due to lack of education, inaccessible work environments and practices) (WHO and World Bank, 2011; United Nations, 2018). People with disabilities are also more likely to be subject to direct violence, as victims of abuse, neglect and sexual and gender-based violence and trauma (Hughes *et al.*, 2012; United Nations, 2018). Direct violence is also clearly a cause of disability. However, very little empirical research using a structural violence lens has been undertaken in Liberia, an exception to which is Dean et al. (2022) who use structural violence to explore the syndemic interaction of neglected tropical diseases and mental ill-health.

Given Liberia's complex history of conflict, occupation, and external intervention, I argue that an analysis rooted in structural violence is essential. This approach is further informed by anthropological work in West Africa that interrogates the social, political and moral dimensions of epidemic response. In this context, Farmer's framework provides a means of understanding how exclusion is structured, maintained, and frequently obscured (Farmer, 2020). It offers a valuable lens through which to examine the systemic factors that contributed to the marginalisation of people with disabilities during the Ebola and COVID-19 outbreaks in Liberia.

4.3.2. Ableism

Cultural (and social) violence as related to disability is pervasive. Ableism is a key example. Ableism and disablism are not synonymous (although are of course connected). Disablism is direct and structural violence, as it views disability as a negative construct, where values and practices promote stigma and the unequal treatment of people with disabilities. Ableism by contrast valorises and makes compulsory 'ablebodiedness'[61] (McRuer, 2006, 2013) and it 'reinforc[es] impairment as an outlaw ontology' (Campbell, 2008, p. 12). This presumptive 'ablebodiedness' casts people with disabilities to the margins and frames the 'normative' body as the

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[61] Compulsory able-bodiedness is a central component of 'crip theory'. The concept is based on the theory of 'compulsory heterosexuality' (Rich, 1980), a core concept in feminist and 'queer theory'. This idea posits that in a heteronormative society, an individual's heterosexuality is either assumed or is enforced by the patriarchy. As a result, heterosexuality does not need to define itself, remaining unspecified, invisible and 'normative' (McRuer, 2013).

(unobtainable[62]) ideal and the default (McRuer, 2006; Goodley, 2014). As a consequence, disability (whatever the impairment) is rendered as a 'deviance' and inherently negative (Titchkosky, 2006), or as 'abject, invisible, disposable, less than human' (Dolmage, 2017, p. 7). In the context of neoliberalism, the autonomous 'able-normative' body is regarded as productive human capital (Goodley, 2014). Consequently, non-normative 'unproductive' or 'non-autonomous' bodies that do not align with the neoliberal-ableist ideal are devalued or discarded.

Internalised ableism emerges as a consequence of cultural violence. This belief can be held by people with or without disability. For the non-disabled person this can result in a sense of superiority, empowerment (to themselves) or privilege. For the person with disability it has quite the opposite effect: disavowal, self-blame, attempt to emulate ableist 'norms', or holding negative opinions about other people with disabilities (Campbell, 2008; Kattari, Olzman and Hanna, 2018). The consequent denial of the self has negative implications for people with disabilities, impacting on their feelings of self-worth and wellbeing, and increasing risk of somatic health problems such as hypertension (Nario-Redmond, 2019).

It has been argued that 'inclusion' efforts are themselves an ableist project, that the '*benchmark* of successful inclusion is the acquisition of new skills for performing the part(s) of a disembodied abled self… to adopt and emphasize those aspects of self and subjectivity that are able to mimic the qualities of ableist personhood' (Campbell, 2008, p. 7; emphasis in original). What counts as 'inclusion' and the behaviours people with disabilities must adopt to attain it are shaped by normative, non-disabled expectations (McRuer, 2013). 'Inclusion' often demands that people with disabilities conform to existing 'able' spaces, which remain unchanged, unexamined, or even unnamed – reinforcing the idea that no structural adjustments are necessary. For example, labelling the group identity 'disabled' may evade critiquing or even naming 'non-disabled' as a contrasting category. This in turn perpetuates 'non-disabled' as the normative dominant ideology, essentially legitimising 'compulsory able-bodiedness' (McRuer, 2006, 2013).

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[62] And because the 'normative' ideal body is unobtainable, it remains a site of oppression for everyone, disabled or non-disabled (McRuer, 2006; Goodley, 2013).

4.3.3. Criticism

Galtung's concepts of violence, particularly structural violence, have been widely used in health research (De Maio and Ansell, 2018). However, they are not without criticism. Galtung states that violence occurs when individuals are impeded from realising their potential (either through direct or structural violence). In his own words he concedes that defining what exactly these 'potential realisations' are and what level they should be considered sufficient 'is highly problematic' (Galtung, 1969, p. 169). He does not attempt to address this issue in the 1969 article, but while acknowledging the complexities of the subject, Galtung and others have offered potential quantifiable measures for affronts by direct violence, which include mortality rates, numbers of people killed by war, person-years lost to violence (Galtung and Høivik, 1971; Kohler and Alcock, 1976; Vorobej, 2008). For structural violence potential proxy measures include the difference between optimal and actual life expectancy, and maldistribution of food, health and shelter (Galtung and Høivik, 1971; Kohler and Alcock, 1976). However, because structural violence is complex and not directly measurable, no single variable is possible, and measures will always be a flawed aggregate of proxies (De Maio and Ansell, 2018).

Quantifying structural violence can make findings more appealing to policymakers, who often prioritise numerical data as a basis for concrete action. Similarly, public discourse may be more easily influenced by clear, digestible statistics. However, this approach risks being reductive, as structural violence is a complex phenomenon characterised by multiple interacting and interdependent factors. For example, a quantitative proxy focused on life expectancy may fail to capture the nuances of systemic inequalities, such as disparities in access to education, healthcare, and livelihood opportunities. Moreover, reliance on quantification could perpetuate or exacerbate exclusion, as marginalised and hard-to-reach groups – such as people with disabilities – may be overlooked in the data and ultimately left behind. Given these limitations, anthropologists like Farmer, Wilkinson, and Leach emphasise qualitative approaches that foreground the lived experiences of those affected, highlighting the social implications of structural violence in relation to health, suffering, and systemic harm (Farmer, 2009b; Wilkinson and Leach, 2015).

Philosopher AJ Coady is critical particularly of Galtung's conception of violence. Coady's multiple criticisms include what they consider to be a lack of difference between direct and structural violence, that they are 'far too few and too general to offset the striking differences between them' (Coady, 2007, p. 29). They go on to cite the dictionary to argue that definitions of violence should be restricted to a 'normal' understanding' (i.e. direct violence). In response, authors argue that this is a positivist claim (Dilts, 2012) and that Coady's interpretation of 'violence' is superficial (Vorobej, 2008), highlighting that while direct and structural violence are conceptually different, there is often a 'principal causal symmetry' between them (Vorobej, 2008, p. 93).

Feminist scholars have criticised Galtung's failure to explore gender in his concepts of violence. While in his later writing he highlights the patriarchy as an example of structural violence (Galtung, 1996), his explanation has been criticised for being 'confused and confusing about whether patriarchy is a cause of violence at all levels or a problem of women–men relationships that makes men violent toward women' (Confortini, 2006, p. 340). However some authors have expanded the concept of patriarchal structural violence, using feminist theory to reveal and deconstruct the normalised oppressions caused by socially constructed gender differences (Mazurana and McKay, 2000).

Critics of structural violence maintain that it is too much of a behemoth to be a useful approach. Some argue that the concept is, 'overly normative and too broad... [that] allowing the inclusion of everything would lead to the illumination of nothing' (Alexander, 2018, p. 30), as it conflates and collapses insults ranging from complete dominion through economic and social injustices to symbolic affronts, and at levels from the transnational, national, market and social (Wacquant, 2004). Critics further argue that Galtung's structural violence 'neglects the specific differences and historical variations of forms of injustice, their intersections, and the ways in which they are compounded' (Dilts, 2012, p. 195). Farmer's approach to structural violence, where he incorporates a central focus on the impact of history (and geography) on suffering and disease, evolves the concept of structural violence and adds nuance to its interpretation (Farmer, 2004, 2009b, 2020).

Others consider structural violence to be too much of a ‘black box’ to be a useful explanatory tool (Bourgois and Scheper-Hughes, 2004; Wacquant, 2004), arguing that it is ‘vague in its operational definition’ (De Maio and Ansell, 2018, p. 2), and poorly theorised (Hirschfeld, 2017).

4.3.4. Social justice

Achieving what Galtung (1969) describes as ‘positive peace’ requires the dismantling of oppressive institutionalised structures and attitudes. For Galtung, positive peace is not simply about the absence of harm but also fostering the conditions that enable individuals and communities to flourish (which might also be called addressing structural violence). It involves access to education, healthcare, political participation, and freedom from discrimination – all of which are systematically denied when structural violence remains intact. In this sense, positive peace aligns closely with broader conceptions of social justice and transformative change, rather than the maintenance of an unjust status quo.

Nancy Fraser’s (2005, 2009) multidimensional theory of social justice offers a useful framework through which to articulate and operationalise the aspiration of positive peace (see **Table 4**). Fraser identifies three interlinked dimensions of justice: redistribution, recognition and representation. Her framework considers the interaction of each of these injustices as interdependent, intersecting and interacting in a non-additive fashion (Fraser, 1998). It also cautions about taking an ahistoric stance, as these injustices are dynamic and shaped by history. In addition, individuals may be simultaneously disadvantaged on one axis and advantaged on another at different points throughout their lives.

Redistribution according to Fraser concerns the fair and equitable distribution of economic resources (money and goods) across a population. Recognition addresses ‘institutionalized patterns of cultural value’ (Fraser, 1998, p. 29) and the harms of misrecognition, which occur when cultural legitimacy is granted to some groups while denigrating or marginalising others (Armstrong and Thompson, 2009). Fraser (1998) locates this form of injustice at the social level – a perspective echoed in the social model of disability, which frames disability as a product of structural and attitudinal barriers, rather than of individual impairment (Shakespeare, 2013).

The third dimension, representation, refers to political voice and participation. This dimension asks who is included in decision-making processes and who is left out (Mladenov, 2016). For Fraser (2005), redistribution and recognition are impossible without representation. Representation transcends national boundaries to consider transnational structures of power and exclusion. This is particularly relevant to disability in the 'global South', where disabled bodies and lives are shaped by overlapping systems of marginalisation, including globalisation, colonial legacies, and development hierarchies (Meekosha, 2011a; Grech and Soldatic, 2015). Parity of transnational representation is a key concern of critical disability studies. This approach emphasises the disabling legacies of colonialism and neoliberal capitalism and the production of impairment through global structural violence (Meekosha, 2011b; Soldatic, 2013; Soldatic and Grech, 2014). Historically, citizens of Liberia have been subject to significant and sustained global structural violence (Farmer, 2020) and citizens with disabilities have been largely excluded from discourses and programmes aiming to ameliorate it and promote social justice (Carew *et al.*, 2019; Kett, Cole, Beato, Carew, Ngafuan, Sekkoh Konneh, *et al.*, 2021).

Fraser's concept of 'parity of participation' (Fraser, 1998) which underpins her social justice framework is particularly pertinent to disability research (Mladenov, 2016). Parity of participation describes 'social arrangements permitting all citizens to interact together as peers' (Armstrong and Thompson, 2009, p. 110): as full members of society. This speaks to both the social model of disability and the UNCRPD, which in its preamble states:

> *Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (United Nations, 2006; emphasis mine)*

Fraser also distinguishes between *affirmative* and *transformative* strategies for addressing injustice (Fraser, 1997). Affirmative approaches seek to correct inequities within existing systems – for instance, through targeted programmes or quotas – without challenging the structures that produce inequality. By contrast, transformative strategies seek to reconfigure those very structures, dismantling and rebuilding systems that perpetuate social injustice. In the context of disability and epidemic response, this distinction is critical: interventions that merely accommodate within exclusionary systems are unlikely to achieve the kind of structural change that Galtung's 'positive peace' demands. However, critics of Fraser's social justice model argue that her focus on parity may in fact diminish the possibility of radical transformative action, as it focuses on achieving equity of participation in existing structures rather than dismantling and rebuilding them (Zurn, 2003).

Table 4 Fraser's social justice framework

Social justice	
Redistribution (what?)	Ending socioeconomic injustices (e.g. exploitation, marginalisation, and deprivation) through redistribution of wealth, reorganising division of labour or transforming economic structures
Recognition (who?)	Addressing cultural injustices based in social recognition (e.g. cultural dominion, being rendered invisible, disrespect and disparagement) through cultural or symbolic change, positively regarding cultural diversity, or societal transformation
Representation (how?)	3 levels: 'ordinary-political' (inclusion in community and state-level decision-making); 'misframing' (who does/does not count as eligible to claim justice); and 'frame-setting' (who decides who does/does not count; controlled by states and global 'elites'; implications for globalisation)
Overcoming injustice	
Affirmative	Correcting social injustices and inequity through changes within existing systems or structures
Transformative	Radically dismantling and restructuring systems to overcome social injustices (Fraser, 2005, 2009)

Historically, people with disabilities in Liberia have not benefited from either affirmative or transformative actions to promote redistribution or recognition. They have not therefore achieved parity of participation (Mladenov, 2016). In countries with more functional welfare states, to use the UK as an example, affirmative actions such as the

Disability Living Allowance (DLA)[63] aimed to redress some of the extra (mobility and care) costs of living with a disability (Age UK, 2023). These social welfare payments were 'non-means tested, non-contributory and free from workfare conditionality'[64] (Mladenov, 2016, p. 1232). However, this kind of action can actually harm recognition, 'when applied to maldistribution, [affirmative remedies] provoke a backlash of misrecognition' (Fraser and Honneth, 2003, p. 76). Envy of 'unfair benefits' or 'special privileges' provokes ableism (Nario-Redmond, 2019).

Criticism

Fraser's theory of social justice, while widely used, is not without its critics. The necessity of the three components of injustice has been questioned by some theorists. Some scholars maintain that almost all (if not all) social justice can be achieved by proper distribution of 'social goods' (Caranti and Ali, 2021). This thesis has been rejected by Fraser, as she argues that most (if not all) examples of social injustice require more than only redistribution efforts to eliminate them (Fraser, 1998). Economist Amartya Sen is also critical of this argument, highlighting that access to 'social goods' does not equate to their effective utilisation (Sen, 1992). For example, advocates for the twin-track approach to disability inclusion (DFID, 2000) argue that to most effectively include people with disabilities, services (social goods) should be mainstreamed (equality of access) but also that specifically targeted activities are necessary to ensure that they can be utilised on an equitable basis.

Philosophers such as Axel Honneth take the opposite view, arguing that social injustices stem primarily from struggles for recognition. For Honneth, injustice arises through experiences of disrespect, which undermine individuals' self-confidence, autonomy, and social esteem across different spheres of life (Honneth, 1996). This again has been rejected by Fraser as it assumes 'a reductive culturalist view of

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[63] DLA was later replaced by the much more restrictive Personal Independence Payments.

[64] In their excellent paper, *Disability and Social Justice*, Teodor Mladenov describes the DLA as approximating a transformative mechanism because of these factors (Mladenov, 2016). However, in Fraser's definition of affirmative actions she specifically uses the example of the welfare state (Fraser and Honneth, 2003). I would therefore argue the DLA falls into the latter rather than former category.

distribution' (Fraser, 1998, p. 4) that does not account for instances where misrecognition do not figure in injustices of maldistribution[65].

Her critique of identity politics has led some to argue that this downplays the importance of social identities. For example, the disability movement started as a bringing together of people with disabilities under a banner to agitate for social change (Fraser and Honneth, 2003). Fraser counters by arguing that identity politics over-simplifies group identity and glosses over within-group difference and struggles (Fraser, 2000). She further argues that such politics downplay the complexity and multiplicity of people's identifications, and that it encourages 'both the reification of individual group identities and the displacement of redistribution' (Fraser, 2000, p. 113), which is for her overly fixated on protecting fixed group identities (Armstrong and Thompson, 2009). However, while Fraser highlights the importance of the complexity of individual lives, and the shifting nature of social identity (Armstrong and Thompson, 2009), this has not been examined in-depth. In addition, her emphasis on the 'institutional patterns of cultural value' risks downplaying recognition and identity formulation on a face-to-face level (Danermark and Gellerstedt, 2004).

Others suggest that the sheer complexity and hybridity of social orders make it difficult (perhaps impossible) to define what parity of participation would look like (Armstrong and Thompson, 2009). Instead, they argue that it is necessary to acknowledge that status orders overlap to differing degrees, are separate, or are even incompatible with each other in forming an overall understanding of parity of participation. Further, as social identities and orders shift over time, what constitutes parity of participation at one moment is liable to change. Critics of applying Fraser's social justice framework to disability argue that the heterogeneity of the disabled experience makes it challenging (again, perhaps impossible) to define what social justice would look like (Danermark and Gellerstedt, 2004). However, the application of social justice theory to empirical

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[65] The example Fraser gives is of a white male cis-gender worker who is laid off due to the closure of his workplace because of a corporate merger. Here he is not subject to misrecognition due to his status, so 'a theory of justice must reach beyond cultural value patterns to examine the economic structure' (Fraser, 1998, p. 5).

research with people with disabilities remains under-explored. This is one of the areas that my research has aimed to redress.

Another area of concern in Fraser's model of social justice relates to the assumption that not all forms of social injustice are institutionalised. In their critique, Zurn (2003) presents a hypothetical example of a person with a disability whose barriers to participation have been removed through well-implemented anti-discrimination legislation. Despite this, she is regularly infantilised by others who insist on offering unsolicited assistance. Zurn argues that although this constitutes misrecognition, it does not reflect institutionalised injustice, since the individual retains 'parity of participation': 'this harm to her sense-of-self is not institutionally anchored in ways that violate her capacity to operate as an equal in the major activities of social life' (Zurn, 2003, p. 185).

This position is problematic. First, it assumes that anti-discrimination legislation automatically ensures genuine parity. Second, and more importantly for this research, it overlooks how persistent ableist cultural norms – such as the assumption that people with disabilities are dependent or incapable – are themselves institutionalised, even if not codified in formal policy. As Fraser (2009) states, recognition justice requires dismantling institutionalised value hierarchies. The continued infantilisation of people with disabilities reflects a deeply embedded cultural devaluation that shapes social norms, behaviours, and everyday interactions. In this context, misrecognition cannot be dismissed as solely interpersonal, rather it is systemic and structural.

These critiques highlight the need for an approach that recognises how structural violence and social injustice are historically embedded and operate through entrenched cultural norms and exclusionary systems. Such violence shapes institutional practices, including epidemic responses, and impacts everyday social interactions. In response, my research adopts a participatory methodology that centres the lived experiences of people with disabilities. By doing so, it aims to identify mechanisms of structural harm and dominant narratives, as well as to create space for collective knowledge-building and action. The following section outlines the participatory action research approach, which positions people with disabilities not merely as participants, but as co-researchers and changemakers.

4.3.5. Participatory action research

Critical research should be transformational and emancipatory. This is in line with the aspirations of the UN Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006), as well as social justice (Fraser, 1998, 2005). One such approach is participatory action research. This asserts that by involving participants throughout the research process, it will be able to achieve understanding of situations and to enable research-informed transformative change (Kindon, Pain and Kesby, 2007; Dick, 2017). Enabling participants to critically appraise their own situations ensures the full and faithful representation of their experience in my research (Levitt *et al.*, 2017).

One of the central figures in participatory research, Paolo Freire's work focused on the empowerment of disadvantaged participants, emphasising that they have intimate knowledge of their lives and oppressions, and have the impetus to challenge social injustices (Freire, 1970). This is of key importance for disabled populations, as the demand of 'nothing about us without us' (Yeo and Moore, 2003) means that participatory, participant-led research is crucial in undertaking any kind of research with people with disabilities (Watson, 2013). People with disabilities know their own needs and experience, what has been called 'disability expertise' (Hartblay, 2020), and elevating their voices to be critical can enable them to challenge the exclusion and marginalisation which they often encounter.

Critics of participatory action research have argued it often falls short of bringing about transformative change (Kincheloe *et al.*, 2018). This may be due to factors such as sufficient time and funding to allow for changes to be observed. Further, selection of research is not value neutral, with the researcher always coming with their own agenda. Critics argue that this limits full participation as researcher priorities may not reflect (or may even conflict with) participant priorities (David, 2002). Mindful of these issues and criticisms, my research uses the photovoice method to work with participants (or my preferred term co-researchers) to collect and analyse data.

I chose to work within this method because it explicitly aims to redress many of the challenges encountered in participatory research. However, because I devised my research questions (see **chapter one**, **section 1.6**) prior to my fieldwork, there was a risk that my intended focus may not fully align with participants' priorities. This lack of priority may have resulted in co-researchers being disengaged with the research process, or risked attrition.

4.4. Methods

Primary research for my project comprised three distinct, but related, methods: photovoice, life history interviews, and key informant interviews (**Figure 5**). I will now discuss each of these in turn before moving on to my data analysis strategies.

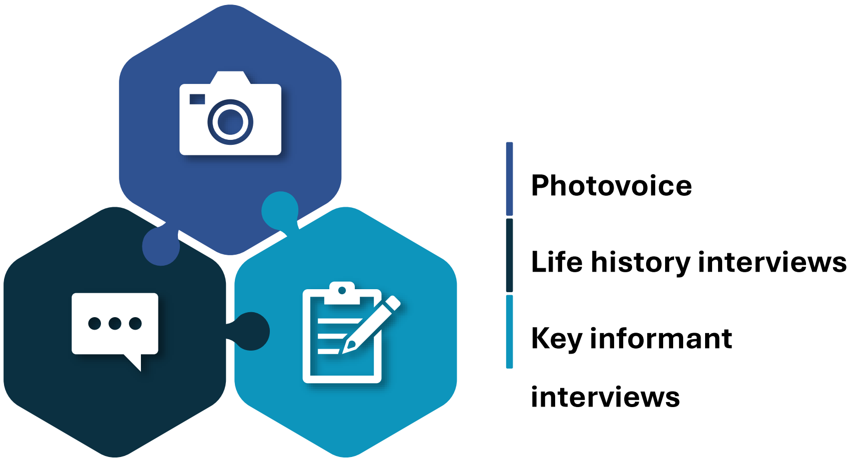

Figure 5 data collection methods

4.5. Data collection

4.5.1. Photovoice

Photovoice is an approach to participatory action research that equips participants with cameras to document key issues that affect their lives, and through group to analysis share their expertise as knowledge[66] (Wang and Burris, 1997). The photovoice methodology aligned with my critical research methodology. Photovoice, as with other forms of participatory research, gathers data *with* rather than *on* participants (Wang, 1999), and it aims to create transformative change for participants both within their communities and at policy level (Wang, Cash and Powers, 2000). Critical to my research has been to centre the voices and opinions of people with disabilities themselves, and a key part of this was the photovoice project (see fieldwork **section 4.7**). The approach identifies issues and concerns of participants through a dialectic process of critique

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[66] See **appendix one** for the training plan

and (re)analysis. The critical self-analysis of participants' own lives has the potential to be elevating and transformative.

Recruitment

Participants were recruited with the support of NUOD, who drew on their membership and contacts. Eight co-researchers were recruited for each photovoice group. They were all informed about the research, what their participation would involve and the time they would have to commit to the project. These groups comprised[67]:

Table 5 photovoice co-researchers

Women with disabilities	
Evelyn Quire	Fatuma Roberts
Jochebad Morweh	Leona Hansay
Rose B Dargbeh	Rosetta L Mensah
Soweo Z Johnson	Victoria G Nyemah
Men with disabilities	
Bill S Jallah	David Hne Wallace Sr
Diarran JT Appleton	Ephraim Sebo
Lahai J Gotolo	Melvin L Harding
Sylvester Mombo	Togar Bungar
Caregivers	
Evelyn NW Deh	Joshua S Gargar
Linda K Hoff	Naomi T Togbah
Paul LB Jackson	Philipmena Philip
Sabah E Roberts	Teta T Sannoh

Consent, ethics and safeguarding

Consent was very carefully taken with these groups, as the subject matter had the potential to be distressing. At the start of the first day, the full project was presented in detail, and there was space for questions, and they were given information sheets to keep. Once all their questions had been satisfactorily answered, they were then given a

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[67] Names have been given with permission

consent form. It was emphasised that their participation was voluntary, and they were able to withdraw from the project at without penalty. In addition to the written consent, verbal consent to participate was given at the start of each analysis session.

There are some ethical issues around photovoice as a method. Photovoice is a very intense method of research, and sharing and discussing photos could have become emotionally charged for co-researchers (Wang and Redwood-Jones, 2001), especially when discussing difficult topics such as the two outbreaks. Care was taken to avoid any potential psychological distress. Had co-researchers found the discussions distressing, it was made clear that people that they only had to participate to a level they were comfortable with. They could take time out of the sessions to take a breather, sit back from active analysis, or withdraw from the project entirely. NUOD is very well-connected and offered to provide support or referrals if co-researchers had become emotionally distressed.

Part of the photovoice training was a session on taking photos ethically. This session covered areas such as consent, faithful representation, and unintended consequences. Interestingly, rather than it being a somewhat dry session, co-researchers in all groups were vigorously engaged and the discussions around taking photos ethically was surprisingly lively. As per their training, when co-researchers took photos showing individuals, verbal consent was first taken from the subject, followed by written consent through a release form. The forms were given to me at the start of each session and are kept securely.

A safeguarding issue is the potential for co-researchers to put themselves or others at risk when taking photos. An example of this is a photovoice project conducted in the Philippines. This project explored what malaria meant to participants (Iskander, 2015). However, in this research some participants put themselves at risk by deliberately encouraging mosquitoes to bite to take the photo that best described their experience (Black *et al.*, 2018). This example was given in the training to highlight what not to do and it was emphasised that their safety and that of the subjects of photos was paramount.

Limitations

There are limitations to the photovoice method. Photovoice suffers from many of the criticisms levelled at participatory research, as previously discussed. However, there are some limitations that are unique to photovoice. While the method aims to democratise knowledge production, in practice, the extent to which it can empower participants is constrained by issues such as social hierarchy, literacy and confidence to engage with research. In addition, photovoice is an extremely time-consuming method and despite providing a small token to cover travel, participants needed to be able to commit to ten half-day sessions. This inevitably excluded some people from participating.

Photography is always open to the interpretation, and using the medium introduces possible representation and interpretation issues. While the interpretation of images is out of the control of the photographer, for the end of research exhibition, captions were presented next to each image. These which set out how the co-researcher wanted the viewer to interpret the photo, and the meanings they ascribed to it.

People sometimes question whether photovoice is accessible to people with all impairment types (visual and intellectual impairments in particular; Heffron *et al.*, 2018; Macdonald *et al.*, 2023; Sierra-Martínez, Baña-Castro and Fiuza-Asorey, 2025). This is an unfair criticism, my project included two co-researchers with visual impairments who took some fantastic photos. All it took was additional care in training and devising practical methods to take photos with them.

4.5.2. Life histories

Life-history interviews are a form of oral history research that centre on narrative and identity as tools for understanding complex social and cultural phenomena (Cole and Knowles, 2001; Jackson and Russell, 2010). By following a chronological approach, this method allows for the identification of intersections between personal narratives and sociopolitical moments, revealing how broader historical events shape individual experiences (Atkinson, 1998).

This approach is particularly well suited to research with marginalised populations, as it foregrounds the voices of those often excluded from dominant narratives (Goodley, 1996; Merrill and West, 2009). By situating a person's lived realities within a historical framework, the method enables an exploration of how structural violence and social justice unfold over time, influencing agency, opportunity, and inclusion.

Most frequently, research on disability has used the life history method to explore people's adaptation to an acquired impairment (Frank, 1984; Berger, 2008). However, more interestingly, the method has been applied in more critical and transformative ways with people with intellectual impairments to interrogate institutionalisation, explore disability 'identity' and challenge stereotypes and 'labels' (Goodley, 1996; Bj, 2010; Hreinsdóttir and Stefánsdóttir, 2010).

Recruitment

A total of 30 life histories were taken, ten in each project county. The sample was as gender balanced as possible (see **Table 6**). Six people were interviewed in a rural and remote areas in each county, and four in the county capital. In the counties, potential interviewees were approached through the NUOD county coordinator. In Monrovia, a subset of ten photovoice co-researchers was purposively sampled.

Table 6 life history recruitment characteristics

Monrovia	5 male, 5 female
Grand Cape Mount	Sinje (rural): 3 male, 3 female Robertsport (urban): 2 male, 2 female
Lofa	Foya (rural): 3 male, 3 female Voinjama (urban): 2 male, 2 female
Montserrado	Monrovia (urban): 5 male, 5 female

Consent, ethics and safeguarding

Safeguarding was a central consideration in this activity, given that the subject matter could have been distressing or retraumatising for participants. Obtaining consent was an ongoing process, ensuring that participants fully understood the purpose of the research and their right to withdraw at any stage. To try to avoid potential distress, the interviews were structured to gradually progress towards discussing the outbreaks, allowing participants to build trust so that they were comfortable talking to me. Breaks were taken before both the Ebola and COVID-19 discussions, during which participants verbally re-consented to talking about the subject. Only one person requested to only talk briefly about the Ebola epidemic, and we swiftly moved on.

Safeguarding mechanisms were implemented in with the support of NUOD county coordinators, who were available to provide support or referrals if participants experienced distress after the interviews.

Limitations

The life history method can elicit rich and complex insights into personal experiences, and social contexts and structures. Yet, it is not without its limitations. For example, the method relies heavily on memory, which is both inherently subjective and fallible, shaped by recollection, reinterpretation and the passage of time (Atkinson, 1998; Goodson, 2001).

It is not possible for any single interview to provide a comprehensive account of a person's life. The act of remembering is itself an active process of meaning-making where memories are selected based on a range of factors. Some of these are shaped by the participant, such as what they feel is important to share, what they are comfortable sharing. Others are shaped by the researcher. For example, the subject of the interview, the areas where they probe, and the way they analyse the data are all influenced by the researcher's own positionality and structured by the research question (Goodson, 2012). Life history interviews are also extremely individual and subjective, which means that they may have limited generalisability beyond the context where the interview took place.

To mitigate these limitations, I employed a range of strategies. These included having a relatively large sample of people. This goes someway to redressing outlier accounts and recollections, strengthening rigour. Triangulation with the other research methods, as well as existing scholarship and national legislation adds further reliability.

4.5.3. Key informant interviews[68]

Key informant interviews (KIIs) are a core qualitative research method, frequently used to gain expert insights into specific subjects, contexts, and complex social dynamics (Payne and Payne, 2004; Patton, 2015). This method typically involves in-depth or semi-structured interviews with experts, policymakers, community leaders and people with disabilities, allowing for a deeper exploration of decision-making processes, systemic barriers, and power dynamics. KIIs are particularly useful in exploratory research, where the aim is to gather context-specific information that may not be accessible through other data collection methods (Laws *et al.*, 2013). KIIs often form one component of a broader research project.

To ensure a comprehensive understanding of epidemic responses, it is crucial that KIIs capture a diverse range of perspectives (Levitt *et al.*, 2017). In this study, I conducted interviews with representatives from OPDs and other disability- focused organisations, community leaders, county and district health teams, mainstream development organisations, and UN agencies. This range of respondents helped to provide an in-depth understanding of how epidemic responses were designed, implemented, and experienced by different groups.

Recruitment

Prospective interviewees were selected through a range of approaches. First, I used my own contacts in Liberia, both for identifying participants but also to use their contacts for further interviews. I used a snowball technique to identify potential participants. At the end of every interview I would ask whether there was anyone else the interviewee thought I should be talking to and got their contact information. Finally, some interviews happened spontaneously. For example, after inadvertently going to the old address of the Ministry of Labour, I found myself in the same compound as the National AIDS Commission. I capitalised on the opportunity and ended up interviewing members of the leadership team.

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[68] Interview guides **appendix two**

Table 7 key informant interview sample

Monrovia	**Foya**	**Sinje**
National Disaster Management Agency (NDMA)	County health officer	Officer in Charge health facility
NDMA	OPD	Medical director health centre
National AIDS Commission	OPD	**Robertsport**
OHCHR	Hospital director	County health officer
Concern Worldwide	City mayor	OPD
Liberia Red Cross Society	OPD	City mayor
Bishop	Health centre workers	Grand Cape Mount County surveillance officer
UNDP	District commissioner and agriculture extension officer	NUOD county coordinator
Bishop	Disease surveillance officer	
MercyCorps	District health officer	
International Rescue Committee	Agriculture extension officer	
NUOD	OPD	
AIFO	**Voinjama**	
	NUOD Lofa county coordinator	
	Hospital administrator	
	National civil society union	
	Plan Liberia Lofa	
	Health workers	

Consent, ethics and safeguarding

All interviewees gave fully informed written consent. However, I remained aware that the topics discussed during the interviews may still have been emotionally distressing or retraumatising. As with the life histories, I carefully signposted when the sections on COVID-19 and Ebola were, and offered the same options – taking a break, skipping questions or the full section. Further, the interviews were conducted in a place of the participant's choosing to try to foster a safe and supportive environment.

Limitations

Key informant interviews tend to be with people in positions of authority or who have specialist knowledge (Akhter, 2022), for example representatives of NGOs or local governance structures. As a result, the extent to which their perspectives represent people's lived realities may be limited (Marshall, 1996). In addition, because these people speak from their own experience – professional and personal – their opinions hold limited generalisability across different contexts. Without triangulation, this method risks privileging 'official' narratives (Johnstone, 2007), which is a crucial concern in research exploring the experiences of people with disabilities who live within systems that both produce and legitimise those narratives.

To address these limitations, the data from the interviews were triangulated with the photovoice and life history components, both of which foreground the lived experience of people with disabilities. I also approached as broad a sample of people as possible to give diverse perspectives beyond 'official' narratives. This included heads of OPDs, community leaders and community health workers.

4.6. Data analysis

4.6.1. Stages of analysis

Data were analysed in several stages. The first stage was the photovoice analysis with co-researchers, which took place over the course of several weeks in my first round of data collection. These data were iteratively validated and built upon by the co-researchers during each analysis session. At the start of my second round of data collection, I reconvened the co-researchers for a follow-up session. This was an opportunity for me to catchup with everyone, but also was a space for reflections on their participation in the months following the exhibition. These sessions were interesting because co-researchers reflected on their experiences analysing data; for most it was a new kind of experience, one which they were keen to repeat, and for those people who had done photovoice before, they reflected on the differences in their participation.

Following my time in Liberia, I returned to the UK and conducted my own analysis. I first conducted line-by-line coding of the data using NVivo (version 11), and then used the reflexive thematic analysis approach to refine and synthesise the codes. From this work I generated a series of overarching themes and subthemes for both the Ebola and COVID-19 outbreaks (**appendices 4 and 5**).

The incorporation of different data sources enabled triangulation between the three primary data collection strands. I also reviewed relevant legislation (**appendix 6**) and other research conducted in the region around the experiences of people during the outbreaks, including where possible those of people with disabilities. This allowed results to be cross-checked and strengthen the credibility of the results.

Finally, to ensure rigour, I returned to Liberia in September 2024 and first presented my preliminary findings to the photovoice co-researchers for their validation. Their insights were incorporated into an updated set of results, which were presented at a multistakeholder ‘results sharing’ meeting for further feedback and validation (**appendix 8**).

4.6.2. Photovoice analysis

One of the strengths of photovoice is its approach to participatory analysis. This has been found to provide a depth and richness to the data that would be otherwise difficult to achieve (Suprapto *et al.*, 2020). During the photovoice project participants were led through stages to critically analyse their photos as a group. In practice this meant that two or three photos from the group were projected on the wall in each analysis session. These were first presented by the participant who stated the reasons for taking the photo and what it meant to them, and then it was discussed as a group with me facilitating the discussion. Participants volunteered their photos for discussion and all participants over the course of the project had at least one photo discussed.

Wang (1999) suggests that photovoice analysis should involve a three-phase process:

1. participants *selecting* photos,

2. participants' *presenting* their selected photos to the group, giving their context, then the group *contextualizing*, and
3. *codifying* their findings' (p.191).

The SHOWED mnemonic is a common participatory analysis tool for photovoice participants, which I used with my three groups of co-researchers. It comprises six broad questions (**Table 8**).

- What do you ***See*** here?
- What is really ***Happening***?
- How does this relate to ***Our*** lives?
- ***Why*** does this problem or strength ***Exist***?
- What can we ***Do*** about it?

(Wang, 1999; Hergenrather *et*

Table 8 SHOWED mnemonic.

4.6.3. Reflexive thematic analysis

Thematic analysis was popularised following Virginia Braun and Victoria Clarke's pivotal article, *Using thematic analysis in psychology* (2006). In the years following this publication the authors elaborated upon and refined their approach to 'reflexive' thematic analysis (Braun and Clarke, 2014, 2019, 2021, 2022). The strength of reflexive thematic analysis is that it is theoretically flexible and applicable to a variety of epistemologies (Braun and Clarke, 2006). This kind of analysis emphasises generating thematic patterned meaning across the dataset, rather than within individual cases (Braun and Clarke, 2022). Reflexive thematic analysis can draw in multiple sources of data, which supports analytic robustness (Levitt *et al.*, 2017), and in my research these included the results of the photovoice and life-history activities, as well as key informant interviews, national policies, international instruments, and other grey literature. Due to the flexibility (some would say ambiguity) of reflexive thematic analysis, critics argue that researchers must make explicit their epistemological and ontological standpoints to show methodological integrity (Levitt *et al.*, 2017).

Reflexive thematic analysis is explicitly interpretivist as it is concerned with 'the researcher's reflective and thoughtful engagement with their data and their reflexive and thoughtful engagement with the analytic process' (Braun and Clarke 2019, p. 594). This reflexivity welcomes the researcher's role and subjectivities in knowledge production and analysis, and the fact that consequentially no two analyses of the same data by different researchers will result in the same interpretation (Byrne, 2022). Reflexivity is challenging, however, and scholars warn that the researcher has to walk 'a cliff edge where it is all too easy to fall into an infinite regress of excessive self-analysis at the expense of focusing on the research participants' (Finlay, 2002, p. 532).

Reflexive thematic analysis comprises six broad (and often overlapping or recursive) stages:

1. Data familiarisation
2. Initial codes
3. Developing themes
4. Reviewing themes
5. Defining themes
6. Producing the report (Braun and Clarke, 2006, 2012)

The analysis takes a mixed approach: ‘inductive’ in that coding is drawn directly from the collected data, but also ‘deductive’ aspects drawn from the theoretical frameworks presented above (Vanover, Mihas and Saldana, 2021). Reflexive thematic analysis is compatible with both inductive and deductive analysis (Braun and Clarke, 2022). However, for both approaches, there are challenges – the former risks getting stuck in ‘surface structures’, the latter risks formulating themes that are overly constrained by theory (Graneheim, Lindgren and Lundman, 2017). To address this, my blended approach uses the core components of my methodological frameworks as a guiding interpretive lens, as well as generating themes from the data. Reflexive thematic analysis is also compatible with both descriptive (surface level, semantic) and interpretive (latent, hidden) coding (Braun and Clarke, 2012, 2022).

Figure 6 field research sites

4.7. Fieldwork

I spent six months in Liberia over two visits conducting primary research: October-December 2022 and February-May 2023. The majority of my time was spent in Monrovia (the capital), with six weeks of my second visit spent in Lofa and Grand Cape Mount counties (**Figure 6**).

Part one: October to December 2022

The main focus of my first visit to Liberia was to run the photovoice project and conduct key informant interviews. Over the ten weeks, I worked with co-researchers to learn how the COVID-19 and Ebola restrictions have affected them, as well as to understand their own priorities, with the aim of raising their awareness of their position as agents in the response and identify changes they want to see in current and future health responses.

For the photovoice project I worked with three groups of people. Two groups of people with disabilities were recruited. Due to the extreme gender inequality in Liberia (UNDP, 2020), separate cohorts of males and females were trained to use the photovoice method. There were two main reasons for this. The first was that having a group solely composed of women with disabilities would allow them to speak more freely than in a mixed gender group. The other reason was that I believed that men and women with disabilities would have had quite different experiences during the outbreaks, and I wanted to give sufficient time and space to explore these in greater depth. Caregivers and service providers for children with disabilities or people with complex needs have been underrepresented in disability research, particularly in low-income settings (Thrush and Hyder, 2014). Therefore, a third group of caregivers was included in the research to explore their distinct experiences (this group was mixed gender). Each group had eight participants who were purposively sampled with the support of the National Union of Organizations of the Disabled (NUOD) to ensure a range of impairment types. The photovoice project culminated in an exhibition, which was curated by the participants, and was attended by friends, family, development practitioners and the US Ambassador.

I also conducted key informant interviews (n=5). I was disappointed that I was not able to do as many interviews as I had planned in my first visit. However, in the end it was probably the wisest course of action as the photovoice project was so intense. I more than made up for this in my second visit.

At the end of November 2022, I came down with what turned out to be a severe case of shingles and was hospitalised at the AMI hospital (see **section 4.8.2** for some reflections). During this period, I was in extreme pain and unable to work while being treated. Thankfully, I had already mostly completed the photovoice data collection and group analysis and left hospital in time to organise the photovoice exhibition (I was really upset that I missed the celebrations I had planned for the photovoice co-researchers, however).

Part two: February to May 2023

After being at home for around six weeks, I returned to Liberia. Part two of the fieldwork was also an extremely intense experience but in an entirely different way to the first visit. During the time I was in Liberia I conducted 30 life history interviews[69] with people

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[69] I had initially planned to conduct 12 interviews with people with disabilities (six in Monrovia [urban] and six in Sinje [rural]), but this expanded substantially to 30 interviews as I decided that getting information

with disabilities in three counties: Lofa, Grand Cape Mount and Montserrado (see map **Figure 6**). In Lofa and Grand Cape Mount six interviews were conducted in rural areas and four in urban settings (**Table 9**). Each interview took place over several hours and I guided the participant through an in-depth exploration of their life and experience of key events (including but not limited to the Ebola and COVID-19 outbreaks) to generate rich narrative data. I wanted this activity to be an opportunity to understand the fluctuations of the experience of disability across the life course and the influence of external actors.

I travelled with my disability support assistant and a driver[70], first to Foya in Lofa county. I had chosen Foya as a research site because it was the place where Ebola was first reported on the 30th March 2014 having crossed the border from Guinea, and I believed that speaking with people with disabilities there and getting the story of their lives was extremely important and valuable. Foya was challenging to get to, as the roads between Monrovia and Foya quickly deteriorated from tarmac to dirt road and then to what was more pothole than road – there were places where the road was cut up by deep fissures and nearly impassable. I spent two weeks in Foya and then travelled to Voinjama (the capital city of Lofa) for an additional week.

Table 9 life history interview locations

County	**Location**
Montserrado	10 in Monrovia (urban)
Grand Cape Mount	6 in Sinje (rural) 4 in Robertsport (urban)
Lofa	6 in Foya (rural) 4 in Voinjama (urban)
Total	**30 interviews**

When I returned to Monrovia I completed ten life-history interviews with a purposively sampled sub-section of the photovoice participants. I based my selection on ensuring

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from people with disabilities in Lofa was also highly important. This was definitely the right decision even if I ended up with an extreme amount of data!

[70] Miles is not a driver, however. He is an electrician who happens to be an amazing driver (which was absolutely critical navigating the terrifying dirt road that is most of the way to Foya). I was always very clear when introducing him that he was the person driving me around, not a driver.

gender balance and a range of impairment types, but also on my knowledge of them as individuals that I had gained through the earlier project.

I then travelled to Grand Cape Mount for three weeks, where I completed an additional ten life history interviews[71]. Six interviews were conducted in Sinje, a rural area, and four were completed in Robertsport, which is the more urban county capital. I chose these research sites because they were areas that had had a lot of Ebola cases, but also because I was familiar with the locations and the disability community (Kett, Cole and Carew, 2017; Carew *et al.*, 2019; Kett, Cole, Beato, Carew, Ngafuan, Sekkoh Konneh, *et al.*, 2021; Kett *et al.*, forthcoming).

During this second visit, I also interviewed 35 people, ranging from county health officials to health workers, as well as mayors and district superintendents, civil society and development practitioners. All these, when added to the few interviews I completed during my first visit, brought the grand total of key informant interviews to 40.

4.8. Reflexivity

I do not believe that it is possible for a researcher to be an impartial bystander. My position as a researcher, my context, lived experience, and values will have influence on the project (Steinberg, 2014; Dutta, 2017; Mills, 2017). In the reflexive thematic analysis paradigm, researcher subjectivity is a ‘tool’ of the analysis, not considered as a bias (Braun and Clarke, 2022). I must therefore consider and set out what subjectivities I bring to my table and what impact these may have on my research. I believe that while it is possible to identify many of these values, it is difficult (if even possible or desirable) to negate them entirely, and they must be considered and made explicit throughout the research.

Gender theorist Judith Butler cautions against the ‘embarrassed [and…] exasperated “etc.”’ (Butler, 1990, p. 196). She contends that it is not possible for a list of characteristics to be exhaustive. With that in mind, and while acknowledging that any list is bound to be incomplete and that identities are not immutable, a short list here is

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[71] Grand Cape Mount was much easier to get to than Foya had been, which was very helpful as I had to suddenly and unexpectedly return to Monrovia to acquire a permit from the Ministry of Health.

probably helpful to situate myself within my own subjectivity and privilege. I am a white person from the 'global North', presenting as female and (usually) non-disabled, straight-passing and educated.

4.8.1. Invisible disabilities: 'I'm tired too'[72]

I also want this section to be an opportunity to reflect briefly on how my own experience of having a (for the most part) hidden disability has influenced the research (both positively and negatively). I have lived with multiple sclerosis (MS) for nearly two decades (since 2006). For the most part this is an invisible disability, I (usually) have no obvious physical limitations and until recently have not needed to use any assistive devices.

MS is a neurological autoimmune disease where the immune system attacks the fatty coating of nerve cells (myelin) causing lesions (**Figure 7**). The lesions disrupt the electrical conduction of the nerves, and this damage can cause a wide range of symptoms and loss of function. The main symptoms I experience are muscle weakness and tremors, nerve pain, problems with balance, and extreme fatigue. Also known as lassitude, fatigue as it relates to MS is not just 'tiredness'. Damage to the nervous system means that the brain has to 'work harder' to send messages along nerves, leading loss of function and often to fatigue. Fatigue can be caused by either physical or mental exertion and can have both physical and cognitive presentations. These include the worsening of existing symptoms or the triggering of temporary new ones. It can cause cognitive failure ('brain fog'), and often escalates rapidly (MSIF, 2020). It is also aggravated by heat and humidity, which predictably was a challenge when I was in Liberia, which is both hot and very humid.

Until I went to Liberia in had been effectively shielding for 18 months – since several weeks before the lockdowns in March 2020[73]. Living with MS means avoiding becoming ill when at all possible. A heightened immune response can be a catalyst to having a

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[72] Comment by my research support person while doing data collection in Lofa.

[73] I had been keeping a concerned eye on what was happening in China and beyond during the first months of 2020 and asked my partner to start working from home a few weeks before the world was locked down.

relapse, which can cause temporary or permanent impairment. During this time, I also had a protracted period of extremely low immune system, which made me afraid of leaving home at all.

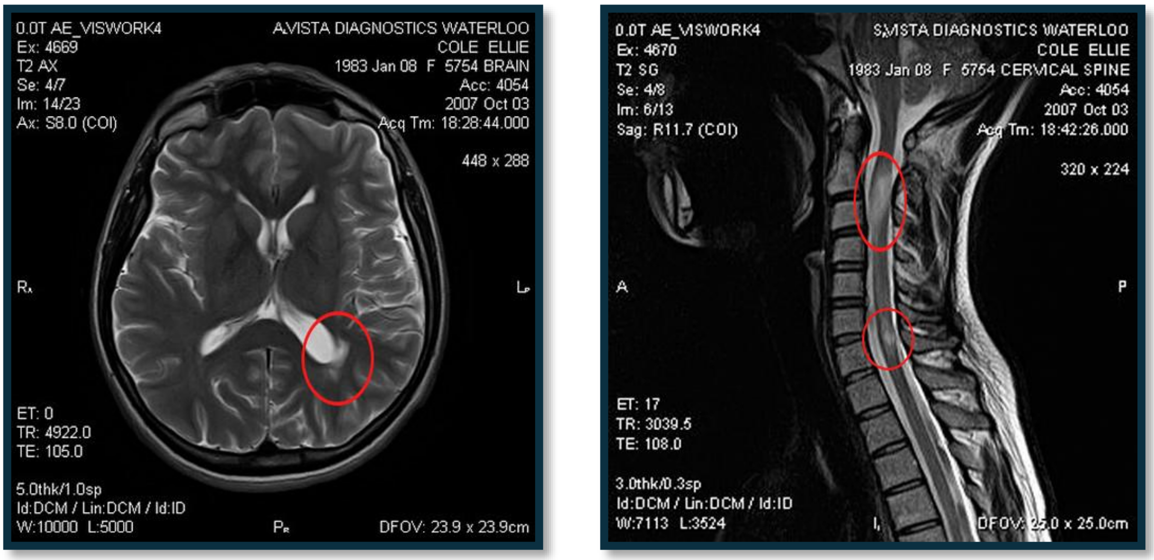

Figure 7 lesions in my brain and spinal cord in 2007

Before I arrived in Liberia, I vacillated about whether to disclose my disability status. I am very open about living with MS and felt that being transparent about my disability is essential to my living authentically. Openness for me fosters genuine connections, yet I also recognised that disclosure could shape perceptions of me in ways that were beyond my control.

Ultimately, I chose to disclose my status to my colleagues, and in many ways, it was the right decision. It created a sense of common ground and, to some extent, strengthened our working relationship, though there were still definite teething problems. One major challenge was that MS doesn't exist in Liberia[74], so no one has heard of it. Getting people to understand my limitations proved incredibly difficult – especially when they're often invisible. I think there was a degree of disbelief among some colleagues and co-researchers until they had spent more time with me and had quite literally 'seen' the effects of my disability.

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[74] One of the interesting things about MS is that the further away from the equator the greater the prevalence (Simpson *et al.*, 2019). It is uncertain what the cause of the disease is, but one theory is that it is associated with vitamin D deficiency (Sintzel, Rametta and Reder, 2018).

Even my research support person – who served as both a research assistant and provided disability-specific support – did not really understand the challenges I encountered. This was despite her having to physically push me back to the jeep on more than one occasion because my legs had given out. I sometimes have difficulty opening bottles and jars because I don't have good grip. During one of the life-history interviews I passed her a bottle of water:

> **Her:** You just lazy Ellie, this thing not hard to open.
>
> **Me:** I know how to open it, I just can't!

While this was said in at least half jest, it is somewhat indicative of our interactions around my disability.

In the end, I felt simultaneously on show and not seen. Almost without exception I was the only white person in the room, and my 'interesting' presentation (shaved head, multiple tattoos and piercings, stretched earlobes) drew a lot of attention. But my disability felt doubly unseen, obscured because it is (predominantly) invisible and also hidden away under layers of privilege. By contrast, almost all of the people with disabilities I met and worked with while I was in Liberia had a visible (often physical) impairment – even people with hearing impairments, which while effectively invisible, became clear when communication became a challenge. The one participant who also reported having a neurological disability had a very clear physical presentation of their disability. Visibility is certainly linked to what is considered 'valid' as a disability in Liberia[75]. Visibility often forces people to identify (or at least be identified) as disabled. This is without any real kind of financial or other state support, and with the often-resultant stigma and discrimination. However, social support from other people with disabilities was valued by many. Interestingly, one of the people I met during my research in Robertsport, Grand Cape Mount, had the most minor of impairments

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[75] Yet it is not just in Liberia – it is an issue that I personally grappled with for many years. The 2010 Equalities Act identifies three diseases as being automatically 'disabling' – MS, HIV and cancer. So when I was diagnosed in October 2007 I walked into the neurologist's office non-disabled and walked out an hour later as a freshly minted disabled person. Yet for years I had no real symptoms, apart from during the reasonably infrequent and temporary relapses, so never felt 'valid' as a disabled person.

(difficulties in functioning in one of her hands), which she had acquired later in life. Yet she identified as a person with a disability and was a member of a local OPD. This is despite the lack of any kind of financial support (which she may not have been entitled to anyway because her impairment was so minor) and the high degree of stigma against people with disabilities in general.

4.8.2.The shingles moment

Towards the end of my first round of fieldwork I suddenly noticed a rash on my back. It spread rapidly and became extremely painful. I thought I had some sort of chemical burn. It soon became clear that I needed formal medical intervention. As my luck would not have it, the day I decided I needed to go to hospital coincided with President Tubman Day[76] and everywhere was closed. The holiday led to insurmountable challenges being seen at the private AMI hospital (**Figure 8**). My colleague who was driving me around recommended another hospital, which was down a side-street in Sinkor. Unfortunately, again, because it was a public holiday the one physician at the hospital had done his rounds in the morning and then left. So, I ended up going home and having to wait another day. It was miserable. Even getting dressed the following day was a huge challenge:

> *Tried to get changed into the traditional shorts, socks, shoes combo but pretty early doors my bod [sic] had decided it had had enough and completely lost all structural integrity and I mean really. At one point I ended up on the floor trying to convince my muscles that yes, climbing on the (low) bed was a good and progressive call. And don't get me started on the socks. Socks + blistery [back] + misbehaving legs = a whole barrel of laughs. I have never felt so disabled. Anyway, got my[self] changed in a record-breaking 15 minutes.*
>
> *(Oct-Dec 2022 fieldnotes)*

Once at the hospital I was quickly diagnosed with shingles[77] and given very strong painkillers and antivirals. I was kept in hospital for several days until the pain was under

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[76] This is a national public holiday to celebrate the life and achievements of President William Tubman, held annually on his birthday (29th November)

[77] Shingles is an infection that is caused by the *varicella-zoster* virus, the same virus that causes chicken pox. The virus remains dormant in the blood system and can in rare cases reactivate, leading to an

control. This experience has stayed with me, and it still makes me very uncomfortable (literally[78] and figuratively). I was very conscious of the conspicuous privilege of staying in such a fancy hospital. My experience was horribly indicative of the two-tier health system in Liberia, and the resulting extreme health inequality. It was also a stark example of the structural violence of the health system. Those with money and power (which in my case manifested as health insurance, which certainly is still money and power) could access private health care that is leagues better than those without either and who are forced to rely on poorly-resourced general services for their health needs.

However, even power and privilege have their limits accessing health in Liberia. For example, the AMI hospital did not provide a full orthopaedic service. A couple of weeks before the shingles episode, my housemate had been knocked over while crossing the terrifying Tubman Boulevard (the dangerously busy main street running through Monrovia). He had broken his leg, cleanly, but still had to be medivacked to South Africa because the AMI – arguably the flagship hospital in Monrovia – did not have the capacity to stabilise fractures with pins. Similarly, multiple photovoice co-researchers and life history interviewees had been told that they would have to travel abroad to treat their impairments.

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outbreak of shingles. Symptoms of shingles include an often very painful rash that blisters, sometimes with headaches and chills. I only experienced the rash, which was extremely painful.

[78] I still need very strong painkillers.

My shingles experience brought into sharp focus many of the intersecting themes that my research seeks to explore. It gave me firsthand experience of the profound inequalities embedded in the Liberian health system. I was constantly reminded of the fragility of health infrastructure that often fails to meet even the most basic needs, and my own moment of physical vulnerability in the lived complexity of embodying both disability and illness in a setting shaped by scarcity cut through by my own privilege. This experience underscored the reality that health access in Liberia is not only stratified by wealth and status, but shaped by a broader system that normalises inequality, leaving many people with disabilities entirely outside the bounds of care.

Figure 8 the AMI hospital in Monrovia (photo taken from AMI website)

4.8.3. Reflections beyond health and disability

My identity as a researcher living with a disability is only one aspect of my positionality. As a white, educated person from the 'global North', whose research was funded by a UK institution, I came to Liberia in a position of privilege and power. This firmly situated me as an 'outsider' to many of the people I met, and inevitably shaped how I was perceived, and the knowledge that was produced. This was a tension I had to navigate throughout my research.

However, the insider-outsider dichotomy has been widely criticised for being overly simplistic and reductive. Increasingly, scholars argue that researchers often occupy a space beyond this binary (Milligan, 2016), with some maintaining that the hyphen itself is a place to be occupied, ‘a third space, a space between, a space of paradox, ambiguity, and ambivalence’ (Dwyer and Buckle, 2009, p. 60). A researcher’s standpoint is therefore dynamic, constantly shifting in relation to an ‘other’ and the context of the encounter. Milligan (2016) describes this as researchers taking different ‘positionings’ depending on the situation. I moved between being regarded as a researcher, disabled, foreigner, and (because of how I look) curio. Consequently, my ‘positioning’ was shaped by every interaction, shifting constantly.

As an example, my ‘positioning’ as a female-presenting person enabled a kind of connection with my female photovoice co-researchers which was not possible with the male co-researchers. Certainly, this shared gender-based connection created a space of trust in which some very personal (and on one occasion rather bawdy!) conversations emerged.

Nevertheless, while these ‘positionalities’ enabled or constrained knowledge production, they could not entirely ameliorate the power asymmetries that continued to shape my encounters and underpinned these relationships. Indeed, they ran the risk of reinforcing assumptions and hierarchies, as my foreignness, education and complexion carried symbolic and material power embedded in histories of (neo)colonialism and globalisation (Bourdieu, 1989; Mignolo and Escobar, 2013; Olivier, 2019). The decisions I made throughout my research were mediated through my positionality and acknowledging this required sustained reflexivity and a recognition of the entrenched power dynamics and structural inequities which persist even in fully participatory research.

4.9. Conclusion

In this chapter, I outlined the methodologies and methods used to design and carry out my research, reflecting on both their potential and their limitations. I provided an overview of my six-month fieldwork in Liberia, including the period of hospitalisation following a severe bout of shingles. I also reflected on my own positionality, acknowledging how my personal history and lived experience shaped every stage of the research process, from the original design through to data collection, analysis and interpretation.

The following chapter presents the first set of findings, focusing on how people with disabilities in Liberia experienced the Ebola outbreak. Using reflexive thematic analysis, I identify and explore the key themes that emerged from interviews and narratives, highlighting the structural, social, and relational dimensions of exclusion and resilience during the crisis.

Chapter five: Ebola thematic analysis

5.1. Introduction

This chapter will discuss the ways in which people with disabilities experienced the Ebola outbreak in Liberia. When I picked my research locations, I deliberately chose areas that had been badly affected by Ebola. Unsurprisingly, therefore, almost all the people with disabilities I spoke to had encountered the disease. For some, there had been cases within their community; for others, it had directly affected their family, and one person disclosed that she was an Ebola survivor. Understandably, all the people I spoke with had strong and often traumatic memories of their lives during the Ebola time.

5.2. I conducted a reflexive thematic analysis to generate a series of themes from the life history interviews. Initial coding of the data, grounded in participants' narratives, produced a set of descriptive codes, which were then distilled and structured into four central themes with a number of interconnected subthemes (Appendix three). From the interviews with people with disabilities, three main stages emerged: first, that the Ebola response was 'done to' people with disabilities and that it was not responsive; second, that the result of this was 'enforced inactivity'; that people with disabilities developed strategies for regaining agency through conforming with or resisting the response actions; and finally is Liberia 'free at last?'. These themes were not always temporally consecutive, and often overlapped, but I will present each in turn as there was often forward progression over the course of the outbreak.The response is not responsive

In the construction of the first theme, several subthemes were developed. The first two subthemes I will discuss are that 'thoughtless response', and 'people becoming things'. These two subthemes taken together describe how much of the initial Ebola response was 'done to' people with disabilities. I will then move onto the 'there is no escape' subtheme, which provides insight into how the people with disabilities I spoke with felt trapped by the humanitarian response as well as by the disease. Finally, I will discuss that while people with disabilities felt that the Ebola outbreak was exceptional, other diseases and the need for health did not stop.

5.2.1. Thoughtless response...

On the 24th March 2014, after 22 suspected cases of Ebola and ten deaths, the Government of Liberia released a 3-month Ebola Response Plan (WHO, 2014a)[79]. A national Ebola Task Force was also established by the Minister of Health and Social Welfare (MOHSW) with the remit of coordinating the national outbreak response (WHO, 2014b). However, the Task Force faced organisational challenges due to its large size and lack of previously established protocols for the management of health emergencies (Nyenswah *et al.*, 2016; Kieh, 2017). It wasn't until July 2014 that an incident management system (IMS) was implemented by the MOHSW with the support of WHO and the US Centers for Disease Control. IMS monitoring did not include indicators on disability, and in my interviews with people from institutions that had the responsibility for coordinating national Ebola response activities, without exception they believed that because it was a nationally implemented 'blanket' response it by definition 'included everybody'. Very rarely did any representatives of the health system mention targeting specific populations. One of the few examples is the Officer in Charge (OIC) of a hospital in Sinje, who targeted women for some additional outreach activities due to their perceived inequitable exposure to Ebola. The OIC considered this to be enough. However, as will be demonstrated, this was often not the case.

After WHO finally declared the outbreak to be a public health emergency of international concern (PHEIC) in August 2014, the number of international organisations responding to the outbreak increased sharply. The initial response by both government and non-government actors was characterised as 'chaotic', due in part to the large numbers of actors (Benton and Dionne, 2015). County health teams did not

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[79] An updated *Ebola Preparedness and Response Plan* was published in September 2015 (Republic of Liberia, 2015b) – after the outbreak had finished. In the plan, people with disabilities are only mentioned once in the 'logistics' section, where it acknowledges that they may require increased amounts of food and water, as well as access to more healthcare and other services than non-disabled people. A much more extensive section is focused on the psychosocial impacts of Ebola on both health professionals and the general public.

wield sufficient power to control the international responders, which led to a plurality of humanitarian organisations with large numbers of duplicated activities (Ling *et al.*, 2017). Activities and resources were also unevenly distributed, meaning that some of the communities I visited had received nothing at all. People with disabilities I spoke with tended to view the response as something of a monolith, not always making a distinction between state-implemented response activities and those of humanitarian organisations.

Many of the people with disabilities I spoke with were highly critical of the early Ebola response. There was a general sense, particularly in Foya (the entry point of Ebola into Liberia), that international organisations 'landed' with no consideration or consultation with individuals or communities. One of the people with disabilities I spoke to on whom the responders almost literally landed works as a blacksmith in central Foya.

> *'when the people brought that [ETU] camp there, they put our shop also in the same fence, so, they build booth around our blacksmith shop... we used to be knocking iron while people are crying outside the fence, their people dying, and where we were working people used to pick up dead bodies in the day sometimes, they used to take out dead bodies sometimes 18 persons you will see them lying down... I was not too happy to be there because people can't be crying while we are knocking iron, then which mean we are not feeling for the people who died' (33-year-old man with a physical impairment, Foya district)*

This person felt that he had been put in a position by the response where he was forced to show disrespect to victims and their families. He also felt powerless to do anything about the Ebola treatment unit (ETU) being built around his blacksmith shop and even went to Médecins sans Frontières (MSF), which was operating the ETU, to ask for his shop to be relocated. Initially they refused, saying that it was 'not in their budget'. MSF eventually capitulated, but this is indicative of the often thoughtless international response at the start of the outbreak, which had a lack of consultation with local communities (Richards, 2016; Abramowitz, 2017).

In response to the swift spread of Ebola, the Government of Liberia put extensive restrictions in place. These included a mandatory national night curfew that lasted for six months (Reuters, 2015), extended school closures, and, between July 2014 and

January 2015, public gatherings were banned (Blair, Morse and Tsai, 2017). Sharing accurate health messages that reaches everybody is a critical component in combatting outbreaks of infectious diseases. These messages included social distancing, strategies for dealing with sick or dead people, and basic infection prevention procedures (IPC; WHO, 2023a). Knowledge of these messages was pretty much universal in the people I spoke with, and everyone rattled off a series of restrictions.

This included the notorious bushmeat ban. Public health messaging to avoid bushmeat[80] was widespread at the start of the outbreak. This is despite this being a vital source of protein for many, particularly in rural and remote areas, and the messaging was widely considered to be inaccurate by citizens (Leach, 2015b; Wilkinson and Leach, 2015; Bonwitt *et al.*, 2018). One OPD head in Foya asked me how, if Ebola had come from eating bushmeat, why had it not happened before? She went on to emphasise that people had always eaten bushmeat, so the ban was confusing. Health messaging that was perceived to be inaccurate led to heightened scepticism and mistrust of the government and the Ebola response in general (Bonwitt *et al.*, 2018).

Information about Ebola was usually received through radio broadcasts, with fewer people saying that health workers or other actors had visited their communities. However, this health messaging did not always reach people with disabilities, particularly at the start of the outbreak.

> *'they started giving people ideas [awareness] on it. They started telling people, even though for the disable people, they were not really recognized [included]. So, during the Ebola time, disable people most of them died, plenty died from it, yes.' (28-year-old woman with a neurological impairment, Monrovia)*

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[80] The ban on bushmeat fed into the 'narrative of disgust' prevalent in the 'global North' (McGovern, 2014). In 2014, VICE News released a breathless mini-documentary on the continued sale of bushmeat in Liberia despite the ban. There was shot after shot of piles of dried meat on market stalls, carefully edited to provoke disgust in the viewer, but essentially the documentary fell only just short of blaming Ebola on the ignorant and conspiracy-believing citizens (*Monkey meat and the Ebola outbreak in Liberia*, 2014).

To support individual IPC activities, sanitation packages should have been provided to households and communities. The items sometimes varied slightly, but the core components of the packages were buckets, soap and chlorine. The provision of these supplies apparently came from a range of sources, including government, relief organisations and sometimes individuals such as politicians. Responses were mixed around whether people received all the items, and while most usually got some but not all, a large minority received nothing. One OPD in Foya received a grand total of one bucket. As a result, people who could afford to do so resorted to buying their own supplies, which meant reallocating already very scarce resources. Further, when people with disabilities did report interacting with other organisations, these tended to be in the provision of supplies, and only very superficial engagement (e.g., they provided buckets once and left), and many couldn't remember who provided the items at all.

I will now move onto my second subtheme, which also argues that the Ebola response was 'done' to people with disabilities – that people became 'things'.

5.2.2. People becoming things

> *'on the daily basis they used to pass with people here in car, dead bodies, put them in the Ebola bags I say um...life is important-oh[81]' (30-year-old woman with a physical impairment, Foya district [translated from Kissi])*

At peak transmission in August and September 2014, between 300 and 400 Ebola cases were being reported in Liberia every week (WHO Africa, 2015). The already strained health system was put under extreme pressure and collapsed. As a consequence of the high numbers of Ebola victims and the need for extremely strict IPC measures, people became 'things' to deal with, losing their status as 'people' (Fairhead, 2014; Lees *et al.*, 2020). For the people with disabilities I spoke to, many had witnessed the industrial, dehumanising machine that was the Ebola response.

> *'they used to come for people in the ambulance, sometimes 40 people they carry them, none of them will survive and our house is right here in Foya where they open the cemetery, where they go and used to do the burial of the Ebola patients. Sometimes they used to carry them full in*

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[81] In Liberian English, people add an 'oh' after a word to give it added emphasis.

> *cars, full up, yes and they were placed in tarpaulin, this plastic tarpaulin and they will be carry them just like animals and some of them you will see them hanging their foot on the car like this and when the car is moving their foot will be dancing in the car like this... they are not animals but human being carry in cars and pack up like animals they were carrying to go and butch up, you see them pack up and they are carrying them before you look again, you see another car coming again' (43-year-old man with a visual impairment, Foya district)*

> *'But look at the way they carrying this one them again to go bury... they will not dig the hole, they will just do it chakla-chakla* [scatter]*, they put it there—they put the foot will leave outside. That time my big brother—my pa small brother, he plant the cassava, he na* [never] *eat the cassava because the fly, it can just sit down, soon as you reach to that area, you will just see the flies, coming down on that—we na* [never] *eat that cassava, it leave there it spoil' (30-year-old woman with a physical impairment, Foya district)*

She went on to say that to the present time her family does not use the cassava farm because they believe that it is still contaminated. This permanent 'spoiling' of land was mentioned by more than one person. This may be both due to a lack of information around how long Ebola lasts after burial but also because of the disrespectful way in which people who had died were treated after death.

This uncaring treatment of people who had died was raised in many of the interviews. Liberia implemented 'safe burial' protocols in line with WHO epidemic response guidelines, which did not account for people's faith and usual burial practices. Much has been written about the problematic implementation of 'safe burials' in the early stages of the Ebola crisis (see for example, Fairhead, 2014; Leach, 2016; Abramowitz, 2017; Allen and Lacson, 2017). Many people implied that the government response, particularly in the hot stages of the outbreak, stole victims from their families, and by doing so stripped them of their dignity by not according them the rights and respect that should have been conferred. I spoke to a woman in Robertsport who was quarantined for 21 days (the maximum incubation period, as per protocol) after being suspected of carrying Ebola. During this time, she was not able to visit her very sick mother.

> *'the day that my 21 days finished, that the day I carry one carton of chloral [chlorine], one carton of tide soap with one bag of rice to my mother… I went there on Friday, the same Friday she died, then Saturday they called me… Before I [could] go there they finish burying her, they say the Ebola people take her and carry her and bury so I never met the body.*
>
> ***Ellie: Do you know where she was buried?***
>
> *I don't know.' (45-year-old woman with a physical impairment, Robertsport district)*

It has been claimed that funerals were important sites of transmission risk (WHO, 2015a). However, not properly attending to a person who has died is disrespectful and often considered 'negligent' (Chandler *et al.*, 2015), and the lack of accommodation for burial practices led to many clandestine burials (Moran, 2017). In Kissi 'tradition' (one of the main groups in Lofa county), funerals allow the person to enter 'the village of the dead', but in order to do so the correct rites must be held (Fairhead, 2014; Leach, 2016). Failure to show the proper respect can result in torment and curses on the person's descendants.

In addition to 'safe burial' protocols, a universally hated mandatory cremation order was implemented in Monrovia (Leach, 2016; Abramowitz, 2017)[82]. Cremation is not a usual practice in Liberia, and people felt 'basic human dignity was being violated by rapid, unwitnessed cremation' (Moran, 2017, p. 412). The consequence was that such widespread opposition led families to conduct unsafe 'clandestine burials', which some have argued contributed to the spread of Ebola (Shultz *et al.*, 2016).

> *'what was more painful in the Ebola many people's grave was not discovered by their love ones, because as you die the government is not giving the body to you and they will carry it [away]… we heard they were burning the body' (52-year-old man with visual and physical impairments, Monrovia)*

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[82] A mandatory cremation order was issued by then-president Ellen Johnson Sirleaf in August 2014 in response to heavy rains causing recently buried persons to resurface (Nyenswah *et al.*, 2016). The degree was only rescinded in December 2014 after a new public cemetery was opened in Monrovia.

The preceding subthemes have presented how the initial Ebola response was 'done to' people with disabilities with little thought or recourse. My next subtheme discusses how the people with disabilities I spoke with often felt trapped, both by the disease and also by the humanitarian response itself.

5.2.3. There is no escape…

> *'this deadly disease that is coming, it don't have boundary, [you can't] say 'oh I'm a disabled person so it can't come to me', no no no no it come to anybody,' (41-year-old woman with a physical impairment, Voinjama district)*

People with disabilities, particularly in Foya, felt that Ebola was brought directly to their door. The first ETU was constructed in Foya as it was the initial epicentre of the outbreak (Abramowitz, 2016), meaning that Ebola patients from all over the county and beyond were brought there by ambulance. Indeed, even by July 2014 (over six months into the outbreak) the Foya ETU remained only one of two operational units in the whole of Liberia (the other was in Monrovia; Nyenswah *et al.*, 2016)[83], so this feeling of invasion is somewhat unsurprising.

> *'When you used to come [from] Voinjama[84], you will see ambulance coming [from the] Voinjama, Quaaonies, Zorzor side carrying patients in, carrying them in Foya because in Foya they had the [ETU] center… sometime they carry them, they will not survived' (43-year-old man with a visual impairment, Foya district)*

The unrelenting fear that the Ebola outbreak caused was nearly universal and had deeply traumatic long-term psychological consequences (Shultz *et al.*, 2016; van Bortel *et al.*, 2016). This trauma was understandably still evident in many of the people I interviewed.

> *'the sickness make just like they take rope they tie you, you don't able to move like the way you used to move' (51-year-old man with diabetes and a physical impairment, Sinje district)*

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[83] Initially, these two ETUs had a capacity of 20 beds each. In August 2014 MSF would go on to open a large 120-bed ETU in Monrovia (Nyenswah *et al.*, 2016).

[84] The capital city of Lofa

> *'a lot of cases was in the community. In fact almost every time we used to hear ambulance sound, they coming for patient, because everybody was afraid, people was very dying, people were dying, people were dying, seriously… Yes. People were really dying so every time we were hearing ambulance coming in the community, Ebola cases in the community' (28-year-old woman with a neurological impairment, Monrovia)*

However, it was not just the disease that people felt trapped by. People also felt trapped by the response itself.

> *'I was way down there [on the road] when I saw that car coming with the people in the white—white clothes, they plaster their head, you can't even saw their face… I run, I go back to my house I go sit down. I start thinking, thinking, thinking, thinking. I say ohh god, when you want finish us just finish us one time' (30-year-old woman with a physical impairment, Foya district)*

Feelings of being trapped understandably led to hopelessness, but which surprisingly sometimes transformed into an almost positive resignation.

> *'I don't worry over things that will bring extra problem to my thinking… anything that is supposed to kill you, you cannot dodge it, that thing is designated for you, you can't dodge it, so I told my wife if I will die by Ebola, I don't care how much time, I still home, it will be free' (52-year-old man with visual and physical impairments, Monrovia)*

Ebola and the Ebola response bred disease exceptionalism. Yet, life and other diseases still continued. My next subtheme presents how these were experienced by people with disabilities.

5.2.4. Ebola is different …but there are other diseases

> *'people used to have malaria, their skin can be hot, but the Ebola you tried it, you finished' (57-year-old man with a physical impairment, Sinje district)*

The Ebola outbreak was a humanitarian emergency of a scale that Liberia had not experienced since the end of the second civil war. It was widely argued that the West Africa Ebola outbreak was the first time the disease was recorded in the region (Piot, Muyembe and Edmunds, 2014; WHO, 2015a; Richards, 2016; Elston *et al.*, 2017). However, while many believe this to be the case, others challenge this account, arguing that a lack of testing during previous haemorrhagic fever outbreaks and the large presence of vector mammals in the region makes this claim by no means certain (Baize *et al.*, 2014; Farmer, 2020). Most people I spoke to had not heard of Ebola before the outbreak (including several of the health professionals), but some knew about recent outbreaks in DRC either through listening to the BBC or from family in the US. For many I spoke to, Ebola was an exceptional disease, the likes of which Liberia had never seen before. Just the name alone could bring around somatic symptoms (van Bortel *et al.*, 2016).

> *'As soon as they say Ebola—Ebola, that people when you see them, you will—you will get [high blood] pressure.' (30-year-old woman with a physical impairment, Foya district)*
>
> *'The way in which Ebola came to Liberia and it was affecting people, the news alone could make everybody sick really because the whole body when something worries you, you start getting headache, you start experiencing fever and all that' (39-year-old woman with a physical impairment, Monrovia)*
>
> *'I came down with fever because of the stress, the stigma… so we were living in fear' (nurse at the old MSF hospital, Foya district)*

Figure 9 Foya-Borma hospital

Mistrust of hospitals and the formal health system led to a severe reduction in healthcare utilisation (Elston *et al.*, 2017). I spoke to the Director of the Foya-Borma hospital (where the first case of Ebola in the country was diagnosed, **Figure 9**), who told me that during the outbreak demand for healthcare plummeted due to people's fear of the hospital. Many of the people with disabilities I spoke to were mistrustful and afraid of hospitals during the outbreak. The fear took two forms: fear of contracting Ebola whilst there, and fear of being presumed as having the disease and taken to the ETU (from where people felt that they inevitably would not return).

> *'everybody was afraid of the hospital for you to go the hospital you think that when you go to the hospital you going to die because that particular time... [if someone goes] to hospital you think that person you will never see again until judgment day, and that happen [to] many' (51-year-old man with diabetes and a physical impairment, Sinje district)*

> *'to get to hospital sometimes when you are vomiting, when you feeling your body hot, the way sometimes we used to be afraid. Sometimes when you get over [to the hospital], they used to say 'that Ebola', because those were the signs they used to tell us' (38-year-old man with a physical impairment, Foya district)*

Instead of going to hospital, people with disabilities resorted to self-medication. The majority of people I spoke with said that they procured a range of drugs from pharmacies or drug peddlers, stocking up in advance when they were financially able. Interestingly, no one said that they visited informal healers, although some told me that they used 'bitter root' to stay healthy. This finding is slightly different to a previous research project with people with disabilities in Liberia, which found that in areas that had a large number of Ebola cases, while the majority of people (68%) reported self-treating when ill during the Ebola time, almost a fifth (18%) stated that they visited 'traditional' healers (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021).

Medical professionals were disproportionately impacted by Ebola, making previously extreme shortages even more acute. By some estimations, health workers were up to 32 times more likely to be infected than the wider population (WHO, 2015b). In Lofa county in the first six months of the outbreak, health professionals who contracted Ebola had a case fatality rate of 81.8%, which is stark when compared with an overall fatality rate of

53.3% (Kouadio *et al.*, 2015). As a result, many health facilities closed[85]. By some estimates, the pre-existing weakness of the health system, combined with the burden of Ebola, led to a 50% disruption in the delivery of general health services (Ako-Egbe, Seifeldin, Saikat, Wesseh, Bolongei, Ngormbu, George, Ocan and Lasuba, 2023).

> *'[even if] you go the hospital, they won't treat you because the people feel that you are an Ebola patient and they will lock you up.' (47-year-old man with a hearing impairment, Monrovia)*

Figure 10 Ebola awareness poster, Sinje district

Almost all of the health professionals that I spoke to knew a colleague who had been affected by Ebola. A nurse at the Foya-Borma hospital told me that as a trainee, she had been put into 21-day quarantine after she had unknowingly treated one of the first victims. She had never heard about Ebola until the moment she was put into quarantine. Hospitals and health facilities were sources of Ebola transmission (Chandler *et al.*, 2015), and a lack of personal protective equipment (PPE) meant that it was often almost impossible for health professionals to follow the strict IPC procedures[86] that such an infectious disease requires to stop its spread. As a

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[85] JFK hospital in Monrovia, the largest public hospital in Liberia, closed temporarily in July 2014 after two of its physicians were killed by Ebola (Beaubien, 2014)

[86] A PPE survey conducted by the Ministry of Health and Social Welfare (MOHSW) in 2014 found that of the health facilities surveyed, over half (57%) lacked triage and isolation protocols for suspected Ebola

consequence of the lack of PPE health professionals were deeply afraid of going to work. Worryingly, the Director of the Foya-Borma hospital told me that at the start of the Ebola outbreak gloves were not considered mandatory, likely due to financial or procurement challenges.

The government and international organisations were broadcasting narratives of disease exceptionalism over mass media, on signs, through posters, murals painted on walls, and in the awareness-raising that was taking place nationwide. However, humanitarian organisations' responses also pulled health workers away from general health services to vertical Ebola programmes (Hayden, 2014), decimating the public health system and ultimately leading to many more deaths than those directly caused by Ebola (Heuschen *et al.*, 2021). Several people I spoke to similarly felt that the response focused solely on Ebola to the detriment of all other illnesses.

> *'more people died from the illness of malaria, some people they did not have the Ebola. Some people they were suffering from low [blood] pressure and the way they used to throw them in the car and just carry them to the rehabilitation centers [ETUs]... [there were] no drugs for them and there was lacking of treatment, so most of them used to die outside' (47-year-old woman with a physical impairment, Monrovia)*
>
> *'I remember that when cholera catch you, God forbid... when cholera catch you [in] three good minutes you gone, we experience that... Ebola is dangerous, but Ebola if you protect yourself Ebola will not give you hard time' (51-year-old man with diabetes and a physical impairment, Sinje district)*

This person is the head of a small community of 27 people off a major road out of Sinje. Thankfully, Ebola never reached his community and barely reached the surrounding villages (he could only name one woman in one of the neighbouring communities who had contracted the disease). I wondered at the time whether his opinion would have been the same had he had more direct contact with Ebola. He had clearly had very

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cases, 43% had insufficient access to PPE and almost a quarter (24%) of facilities had no running water (Nyenswah *et al.*, 2016). As a consequence of the lack of PPE, nurses at JFK hospital in Monrovia went on strike (France-Presse, 2014).

direct experience with cholera in his community though, as he appeared haunted when talking about it.

The above subthemes showed how people with disabilities felt powerless to do anything about the initial Ebola response. The consequence of living under the thumb of the Ebola response is the second major theme constructed in the thematic analysis.

5.3. Enforced inactivity in the Ebola time

The next theme I will discuss relates to the 'enforced inactivity' experienced by many of the people with disabilities I encountered during my research. Inactivity for people with disabilities during the Ebola outbreak was enforced, first by humanitarian and government actors, and then later by internalised feelings of helplessness and hopelessness. The consequence of this enforcement was feelings of criminalisation for people not considered to be compliant. Finding food during this 'enforced inactivity' was an almost insurmountable challenge. These are the three subthemes that, when taken together, describe the inactivity and its consequences for people with disabilities.

5.3.1. 'just sitting down'

> *'you can't go nowhere, even to go look for food nothing, just sitting down' (50-year-old woman with a physical impairment, Monrovia)*

The phrase 'sitting down' was uttered in almost every interview I conducted. 'Sitting down' is a loaded phrase in Liberian English that refers to inactivity, but often in terms of idleness, laziness or unemployment. For many, this enforced idleness was a tense existence, leading to feelings of powerlessness and hopelessness.

> *'people with disability we suffered at the time, where to get food to eat? Who will you go to give you food to eat? And now you got to stay home, you have to sit down to your house, it was a very tough time for us' (30-year-old man with a physical impairment, Foya district)*

But conversely, some people I spoke with felt that home was a place of safety rather than imprisonment.

> *'[the ambulance] will be carrying them for burial and we hide ourselves, sometimes we go in the house and lock door. Yes, just so we cannot see*

> *the dead bodies that they are passing with' (43-year-old man with a visual impairment, Foya district)*

The ability to physically 'lock the door' on what was going on outside was a way that people tried to protect themselves from trauma. It also sometimes made people feel self-sufficient.

> *'I used to keep all by myself in here, in my place, this is my place, this my home... Whole day I indoor, I got my bathroom inside, I fought hard I got my little small, small, things them I put it here and I was just indoor here. I fought hard and got one kerosene stove, I had it here I could do everything inside' (59-year-old woman with a physical impairment, Robertsport district)*

More common than feelings of self-sufficiency, however, was vulnerability, which permeated many of the interviews. This was either implicit in people's narratives, or made explicit, such as by this wheelchair user in Monrovia:

> *'I was not even going to work. I was sitting home. Because looking at me, my movement, when I'm going to the toilet, I was have to touch things, I will have to touch the commode. So, with that and looking at how one can get infected with the Ebola virus it was so risky for me, so I had to stop work. I even drop from the university, I drop from out of school because at the university there was only one general bathroom where everybody used, so it was so it was so risky, when I thought about it, I said no I couldn't continue' (39-year-old woman with a physical impairment, Monrovia)*

The Vice-Chair of an OPD in Kolahun, a small rural area outside of Foya, spoke about the heavy dependence that some of their members had on their family. This means that if a person cannot provide the same level of support, either through 'enforced inactivity' or due to contracting or dying from Ebola (as was the case for people in Kolahun), people with disabilities can be left in an extremely precarious position. In addition, previous research conducted with people with disabilities in Liberia immediately following the Ebola outbreak found that despite the existence of a National Social Protection Policy and Strategy[87] (Republic of Liberia, 2013c), few looked to the

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[87] The strategy was a five-year document spanning 2013-2018. While the strategy was in effect during the Ebola time, it expired three years later and has not been renewed.

government for financial support, likely because this support was never offered due to lack of implementation (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021). Instead, many of the people I spoke to relied on specific organisations which have provided support in the past (for example, Catholic missions or Plan Liberia).

The act of 'sitting down' had severe social consequences. State-imposed quarantines contributed to social breakdown and loss of community cohesion, particularly at the start of the outbreak (Pellecchia *et al.*, 2015). The effect has been described as 'a tragedy for community fabrics' (Leach, 2015c, p. 818). People understandably feared human touch, and the measures aimed at keeping people safe (e.g. restrictions on gatherings, curfews and closure of places of worship) contributed to the weakening of community bonds (Leach, 2016). Sustained lack of physical contact has been described as 'touch starvation' and can have long-term psychological consequences. This effect has been documented for the COVID-19 pandemic (Durkin, Jackson and Usher, 2021; Golaya, 2021), but a lot of people I spoke to mourned the loss of physical contact during the Ebola time. This ranged from shaking hands with strangers to sleeping next to loved ones, and for many eating as a group is an important community activity. During the Ebola outbreak all of this stopped and there were deep feelings of loss and loneliness.

> *'imagine husband and wife no close contact, your own partner you lying down, [your]self you scare, thinking that the person will bring the virus to you too, you thinking that. He himself think that you will give it to him' (50-year-old woman with a physical impairment, Monrovia)*

> *'When my friend when he reached to me [and] he want shake my hands, I say yes thank you I can't shake your hands, when you rush to hug me I say no.' (51-year-old man with diabetes and a physical impairment, Sinje district)*

5.3.2. Treated like a criminal…

> *'the Ebola was making us to be so confine as though we were in prison' (47-year-old man with a hearing impairment, Monrovia)*

A consequence of 'enforced inactivity' was perceived criminality. People who were considered as not complying with the curfews and quarantines were treated like criminals. This was both internalised, as in the quote above, and by a person in Foya who talked about feeling like ‘a suspect’ of having Ebola because her husband had contracted the disease and felt that she was ‘being chased’ by authorities to enter quarantine (this was despite her husband being away for work when he had contracted Ebola). This criminalisation was also externalised by people in authority. Another person in Foya spoke of the random violence that this ‘criminalisation’ perpetuated.

> *‘the UN army, they [came] to Foya, the Liberian Army [came] to Foya, they started beating on people. I can remember one night they beat on people because they say 8 o’clock [curfew] you don’t need to be on the street again… they will grab you and start flocking [beating] you, checkpoint was all over the town… when you do not answer proper question they will flock you sometime, and sometimes they go and lock you up and put you in jail’ (43-year-old man with a visual impairment, Foya district)*

Enforcing inactivity gave police and others additional power, which they did not wield equitably. Multiple people talked about how violence was used to (unfairly) enforce the state-implemented response actions. These authoritarian restrictions and casual violence invoked memories of the civil war. Several people I spoke with used war language and imagery to describe their experience of the Ebola response.

> *‘Ebola time when we were here we see many things happening, we see the soldiers, government people, soldiers in the cars they running up and down going to the border for people not to cross and come on this side and going everywhere just like war fighting in the country everybody was just upside down’ (51-year-old man with diabetes and a physical impairment, Sinje district)*

This succinctly summarises the feelings of chaos at the start of the outbreak; everything was ‘upside down’. The Liberian Army was sent in to enforce border closures and curfews, and to stop people moving from place-to-place, which understandably made (sometimes deeply traumatic) memories of the civil wars resurface, especially among some of the older people with disabilities I spoke to.

> *‘the Ebola thing even though it was not like war but [in] some way somehow it almost like war because Liberia knowing that our situation,*

> *economic situation now we are not other countries... we were not really prepared' (39-year-old woman with a physical impairment, Monrovia)*

War metaphors were used to invoke not only the authoritarian and 'criminalising' response, but also about Ebola itself.

> *'What I actually remembered about Ebola time, the fear... we thought the world was coming to an end and then our thinking that we said this one will not finish, the war [of] Ebola was not going to finish because people dying with it on a daily basis.' (30-year-old man with a physical impairment, Foya district)*

5.3.3. Finding food

The inactivity enforced by the state-implemented Ebola response had predictable knock-on effects. One of the most concerning of these was dramatically heightened food insecurity. Like most citizens of Liberia, the lockdowns and curfews were extremely hard for people with disabilities. The Ebola outbreak negatively impacted on already high levels of poverty in the country, which pushed many into food insecurity and precarity (Korkoyah and Wreh, 2015; Elston *et al.*, 2017). The Grand Cape Mount county coordinator for the National Union of Organisations of the Disabled (NUOD) talked about how the outbreak caused the prices of everything to increase, which impacted extremely negatively on people with disabilities, many of whom who were already impoverished. At the end of 2014, a World Bank survey found that three quarters of Liberians were food insecure, and that food insecurity was greater in rural areas (World Bank, 2015).

There was some acknowledgement by the Foya District Health team that people with disabilities 'suffer in emergencies', but no examples of attempts that were made to alleviate their suffering were given. A UN WOMEN survey conducted in early 2015[88] found that being a person with a disability was one of the key demographic drivers of vulnerability to the impacts of the outbreak (Korkoyah and Wreh, 2015). Food insecurity increased severely for many people with disabilities I spoke to. The suffering that 'sitting down' caused was severe and widespread. Many people spoke of extreme difficulties

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[88] The survey was conducted in five counties, three of which were Lofa, Grand Cape Mount and Montserrado (Monrovia county)

finding food, and in some cases, farms were left to 'spoil' as people were unable to reach them.

> *'I can remember we eating just cassava just to sleep on it because there was no food and we could not go to do any farming, you see by then even our rice our little rice that we scratch it remained there the bug ate it up, because there was no way for you to go out... That is how that year, we get into serious hunger, serious hunger, it wasn't easy, it wasn't easy.' (43-year-old man with a visual impairment, Foya district)*

The strict state-imposed curfews were extremely difficult for people with disabilities. It is often harder and more time-consuming for people with certain impairments to mobilise, so having sufficient time to source food and get back home in time for curfew was a huge challenge.

> *'at times they had to quarantine the whole country, people because you have to go out and get food for your family, so wherein you go do your business and you supposed to be home by 3 o'clock and [you] have not buy anything... so you will have to come home, when you come home your family don't have food to eat that day, you will have to sit down. A lot of bad things happened' (28-year-old woman with a neurological impairment, Monrovia)*

For some people with disabilities I spoke to, the reliance on others to find food was an extra level of precarity. Understandably, people were not always willing to put themselves at risk for the person with disabilities, even if they would be paid for it.

> *'during the Ebola period, even if you have the money, and looking at my condition I was unable to go to the market, I will send somebody. Sending somebody too is risky, people will even refuse to go. They will say no I can't go among that crowd to get your food' (39-year-old woman with a physical impairment, Monrovia)*

For people who were not able to mobilise, and not financially able to pay for someone to buy food, this was an impossible situation, and I was told anecdotally that some people with disabilities starved to death during the Ebola outbreak.

Quarantines were frequently characterised by inadequate supplies of food and water, which could be slow to arrive if it arrived at all (Kutalek *et al.*, 2015; Cohn and Kutalek, 2016). Unpredictable and insufficient supplies of food forced people to break quarantine or curfew (Pellecchia *et al.*, 2015). There were multiple cases where people had to 'escape' to find food. Some people I spoke with resorted to extreme measures such as fleeing to the bush or piling into packed vehicles in search of food. One woman in Robertsport 'gamed' the response by pretending to have come into contact with Ebola:

> *'one woman died down the beach and that was [because of] Ebola... one of my friends came... she say you see in front there, the people [are] putting names down for food... say you touched that dead body or you were in the hospital with the woman... they give us five bags of rice, seven cartons of chlora, three cartoons of tide soap with one gallon of oil with two Ebola buckets' (45-year-old woman with a physical impairment, Robertsport district)*

Organisations such as the World Food Programme (WFP) were slow to arrive, particularly in the rural and remote areas, and initially only distributed food to Ebola survivors. This led to understandable resentment.

> *'WFP brought rice and distributed it to [only] the survivals. Vegetable oil and give it to the survivals but not those that wasn't affected.' (30-year-old woman with a physical impairment, Foya district)*

When food relief did arrive for the wider population, people with disabilities were often not considered when deciding on distribution locations, which were inaccessible to many. OPDs in both Foya and Monrovia had to advocate for different food distribution sites. This eventually happened, but it took time.

> *'the disaster management unit under the government was not really proactive in a sense that the UN Convention Article 11 that speak to disaster that whenever disaster like this take place in a country people with disability should be well taken care of, but we have to even cause noise, serious noise before WFP start to give us food rations' (52-year-old man with visual and physical impairments, Monrovia)*

An OPD leader in Robertsport told me that his organisation acted mainly as a conduit for supplies during the Ebola time. They had received some food from the president, which they distributed to the members, but it was still a challenging time as its 'people couldn't hustle' to find money for food. This OPD was the only one outside of Monrovia that reported receiving any food for distribution. Robertsport is the capital city of Grand

Cape Mount County and is relatively easy to reach by road, even in the protracted rainy season. This is unlike much of Lofa, which is effectively cut off from the capital due to the terrible condition of the roads turning them into mudslides for much of the year. The president of NUOD reported that they had received food from the government for distribution to its member OPDs. However, NUOD (based in Monrovia) was criticised by its members in rural and remote areas saying that they felt abandoned and had not received any of the (allegedly repeatedly promised) food supplies, ‘no one catered to us… no one came’. The Vice-Chair of this rural OPD near Foya went on to say that had the international community not come with food ‘everyone would [have] die’, and because they did come ‘some survived’. The inference here is that while food eventually arrived, it came too late for some.

This section has summarised the ‘enforced inactivity’ and loss of agency caused by the Ebola response and some of the key culminations. The final major theme that was generated in the thematic analysis presents the actions that people with disabilities took in an attempt to regain lost agency during the Ebola time.

5.4. Strategies for regaining agency

The final subthemes I will discuss relate to the strategies that people with disabilities used to regain the agency that they lost due to ‘enforced inactivity’. Agency can be conferred by choice. While these choices can appear minor, they can be an important psychological step towards regaining agency. To demonstrate this, the first subthemes I will discuss are *personal responsibility* and *becoming the response*, which show how some people with disabilities internalised and chose to strictly enact the response protocols. I will then move onto the ways in which people with disabilities ‘resisted’ the response. Finally, I will discuss how the proliferation of conspiracy theories about Ebola can be considered a symptom of the ‘enforced inactivity’ and how these narratives were a strategy for regaining agency for some people with disabilities.

5.4.1. Personal responsibility

> *‘[it doesn’t matter] whether you are my brother, whether you are my sister, you are my mother, you are my father… we call 4455 [the Ebola hotline]’ (51-year-old man with diabetes and a physical impairment, Sinje district)*

As the outbreak progressed, increasing emphasis was placed on community engagement. As has been widely reported, community and individual buy-in was a key factor in the success of eradicating Ebola in West Africa (Leach, 2015b; Gillespie *et al.*, 2016; Laverack and Manoncourt, 2016; Richards, 2016; Abramowitz, 2017; Wilkinson *et al.*, 2017b; Bedson *et al.*, 2020). This buy-in necessitated active engagement and was a way in which many people with disabilities I spoke to in all areas felt that they regained some semblance of control over their lives.

> *'My family, we go by the health protocols, the health protocol what they told us and that the law we went by and all of our families, we stayed home to our houses and that is what we use to do... because why, life is more important... but from the beginning we denied that* [and it] *caused many people to die, the denial' (30-year-old man with a physical impairment, Foya district)*

For many, this was not just 'sitting down'; it was urgent and necessary. Internalising the health protocols reconceptualised the act of 'sitting down' from something that was enforced upon them into active participation. This was a way that people regained agency, through feeling that they were contributing to the response. Some disabled community leaders also proactively acquired sanitation supplies before any NGOs arrived. Enacting the response also increased trust in the health messages and health professionals.

> *'we say no, we need to be taking our rules... Ebola damaged us and it damaged us seriously and people look at the doctors every day on radio. They says don't eat certain fruits, when the bat eat it we should not eat it... when you see the animals lying down dead that [you didn't'] kill it, don't eat. Certain thing they were telling us, don't eat the bat, don't eat this so we put ourselves under control for that' (51-year-old man with diabetes and a physical impairment, Sinje district)*

Strict enactment of the health protocols did not come without pain and loss. One disabled community leader spoke of the grief of 'compliance'.

> *'it really disturbed [upset] and one of our disable members [we] hear that Ebola killed her, we couldn't touch her. We called the [Ebola] team they come from Sinje, they come and do the burial... everything we do, her sacrifice, they said that we shouldn't touch her as usual. They came*

> *they put her in that something, they zip it they carry her and bury her. She [was a] member of the disables' (58-year-old man with a physical impairment, Sinje district)*

His feelings of grief were still very much evident when talking about his disabled friend. The implication is that despite doing everything right, 'her sacrifice', Ebola still caught her, and she died. Yet despite this loss, he continued to follow the rules and enforced the response actions in his community.

Anthropologists have strongly argued that it was people and communities that were at the heart of the Ebola response, and that community engagement and mobilisation was central to ending the outbreak (Leach, 2015b; Richards, 2016). Rapid community learning took place during the outbreak (Leach, 2016), and this learning was evident in almost all of the interviews I conducted[89]. However, despite the outbreak response ostensibly becoming more community-driven and promoting knowledge sharing between response actors and communities, none of the community leaders I spoke with said that they were consulted at any point during the outbreak about how best to keep their communities safe by either government or humanitarian organisations.

Sometimes people's sense of personal responsibility went beyond individual and community 'compliance' with the health protocols and led them to become active participants in the formal response itself.

5.4.2. Becoming the response

Some people with disabilities I spoke with took it upon themselves to become part of the response as a strategy for regaining agency. A surprising number of people I spoke with in Monrovia reported becoming active participants. This is probably due to many being members of the local OPDs (in some cases, the head of their organisation), so they generally had more authority and autonomy than many of the people I spoke with in remote and rural areas.

Some people became part of the 'official' response team.

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[89] The only time that learning was not in evidence was when people fled or went into the bush to avoid the outbreak.

> *'[I was trained] by the MoH [MOHSW] and WHO and we were trained and after that we were given our identification clothes… Then we will go the field and then we will be given targeted area, to target. We will target five or ten houses in a day… [for] three months' (32-year-old man with a visual impairment, Monrovia)*

These individuals (in Monrovia and Robertsport district) mainly took on awareness-raising roles. Motivations for becoming part of the response were close encounters with Ebola or having been part of previous awareness programmes, so were already known to community awareness teams.

Others took responsibility on themselves in a more informal way.

> *'community members you know any sickness, they considered any sickness as Ebola. So when you come down, even with running stomach, nobody want to associate with you they considered it as Ebola… we started going around the community members to tell them no, is not everything is Ebola and it took time before people could accept it' (69-year-old man with a physical impairment, Monrovia)*

That this person felt that it was down to him to educate his community members speaks to both the fear of Ebola but also the limited health literacy of many people. He is well-regarded in his community, but despite this, acceptance still took time, which also speaks to how entrenched the Ebola awareness or misinformation could become.

There were also feelings of solidarity and support with other people with disabilities, such as this man who supported people with visual impairments.

> *'I was the—helping them to measure how much chlorine to put in the water, so that when you wash your hands with the water...you make sure how much you put there because I was with blind people, and since they don't see, I was their eyes… the disable community they are helpless, they can't see, so since I working with them, the responsibility now is on my head—on my shoulder to make sure that it is done properly' (47-year-old man with a hearing impairment, Monrovia)*

Very few of the development practitioners said that they specifically considered people with disabilities when implementing their response activities. Those that did usually had a pre-existing focus on disability (such as Plan Liberia) or were disability-specific organisations such as Associazione Italiana Amici Di Raoul Follereau (AIFO). During the

Ebola time, AIFO restructured an existing programme that was being funded by the Italian Agency for Development Cooperation to train people with disabilities to be 'social animators'. This would enable people to regain agency through becoming part of the social mobilisation response. Unfortunately, for the people with disabilities I spoke to, this project was implemented in the central region (Bong and Nimba counties) and not in Lofa or Grand Cape Mount (or Monrovia).

Where the government and humanitarian responses interacted with disability organisations, they almost solely used them as a resource for awareness raising and information dissemination. There was no evidence of a bidirectional information link where individual OPDs recommended strategies for better reaching people with disabilities.

Where disability was acknowledged in the rural and remote areas, it was dependent on powerful individual champions. The NUOD county coordinator for Grand Cape Mount County (which includes Sinje and Robertsport districts) is an example of this. She told me that during the Ebola time she effectively forced herself into county IMS meetings to observe and was eventually invited to report on the situation of people with disabilities (this was not the case in Lofa, which lacked a similarly high-profile individual). The county coordinator also worked with the health system Ebola response in Jene Wonde[90]. Because she was well known by the County Health Team, they 'carried her' to speak with the town Chief and at town hall meetings to raise awareness in a community that was very resistant to the formal Ebola teams. However, tensions between the NUOD county coordinator and membership exist, with the latter saying that they are rarely consulted about issues that directly affect them, including deciding on a location of a new county headquarters which is probably going to be supported by the government's 'county development fund'[91].

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[90] Jene Wonde is a village in Grand Cape Mount which was severely affected by Ebola, losing at least 10% of its inhabitants (official totals are difficult to come by). This was due in large part to disbelief and consequent suspicion and hostility towards Ebola response teams (Williams, 2014).

[91] The County Development Fund (CDF) has served as a decentralised development financing mechanism since 2007. The 2025 budget allocates a total of $2.8million for the CDF ($186,000 per county; Republic of Liberia, 2025). Funds allocated through the CDF are distributed equally among all

These two subthemes summarise the ways in which people with disabilities internalised and enacted the response protocols. This is not the only strategy for regaining agency, however. I will now move on to the ways in which people with disabilities actively 'resisted' the response.

5.4.3. 'Resisting' the response

Noncompliance with the Ebola response was framed as 'pathological exhibitions of resistance' (Abramowitz, 2017, p. 427)[92]. In Liberia these actions (and inactions) included Ebola denialism and conspiracy, lack of trust in global and national health practices, but also historic animosity and non-interaction with the formal health system (Leach, 2015a; Wilkinson and Leach, 2015; Abramowitz, 2017; Wilkinson *et al.*, 2017b). In addition, lack of trust in the Liberian government inhibited compliance with IPC practices (Blair, Morse and Tsai, 2017). Supporting this, I spoke to a representative from USAID who argued that some decisions made by the national government during the Ebola time, combined with its lack of capacity, contributed to Liberians' 'resistance' to the response. As a result, USAID had to invest heavily in social mobilisation activities. Ebola has been framed as a 'social phenomenon, not just a virus' (Fairhead, 2015, p.

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counties, irrespective of their size, poverty levels, or developmental needs. In counties where natural resource extraction takes place, the CDF is often supplemented by concessions from international corporations. These county-level concessions frequently exceed the funds allocated through the CDF itself. Critics argue that the CDF has been mismanaged, citing instances where funds have been diverted to the construction of county executive buildings rather than projects that directly address community needs. Additionally, concerns have been raised about stalled or abandoned projects, highlighting inefficiencies in fund allocation and oversight (Karweaye, 2021).

[92] Some scholars argue that the word 'resistance' is politically loaded (Calain and Poncin, 2015) and during the Ebola time was used as a weapon to explain perpetuating the 'othering' and 'backwardness' of populations who showed a lack of compliance with the 'supreme Western biomedicine. As Abramowitz (2017) notes 'resistance' was the only (poorly defined) qualitative indicator in the UNMEER daily situation reports. Some suggest words like 'reticence' are less politically loaded (ACAPS, 2015) and should be used to distinguish 'reluctance from oppositional resistance' (Wilkinson and Fairhead, 2017, p. 15). For the purposes of this section, however, I will use 'resistance' because I believe that it reflects the more 'active' strategies the people I spoke with displayed.

15), and addressing the underlying causes of ‘resistance’ was key to ending earlier outbreaks (Hewlett and Hewlett, 2008).

Fairhead (2014) describes hiding or fleeing as an act of ‘resistance’. One person with disabilities I spoke to disclosed that she was an Ebola survivor, and that she had hidden from the Ebola teams.

> *‘I started feeling sharp pain in my head then my eyes starts to burn just like pepper… I did not come outside until more than three weeks… another neighbour’s husband came down with the symptoms… he died, they took his body from the community and they quarantine the whole the area, and I was in there but my children did not tell anyone that I was in there… I thought that they were going to take [me to] the Robertsfield highway and burn my body, because that was how more people bodies were burned and their family did not see the end of their body’ (47-year-old woman with a physical impairment, Monrovia)*

She hid herself away not only from the response but also from her children (they were told that she was sick with malaria). However, given that her children did not ‘give her away’ when the community was put into quarantine speaks to the fact that they may have known more about her sickness than she thought. This person went on to express the same fears as many others, of being ‘disappeared’ by the response and of being cremated and lost to her family (which was a valid anxiety in Monrovia at that time). However, she now deeply regrets not identifying herself as a survivor because of the financial support that they received. The financial support that survivors received was contentious, with the Vice-Chair of a rural OPD in Foya district, accusing survivors of selfishness as they ‘put the money into use for themselves’.

While fleeing has been described as ‘resistance’, it also was associated with contributing to the spread of Ebola (Shultz *et al.*, 2016). Several of the people I spoke with in rural and remote areas talked about how others fled to the bush to avoid the Ebola teams. In Monrovia, a man with psychosocial disabilities I spoke to chose to ‘flee’ the capital after seeing a ‘truck of dead bodies’. In addition to being a form of ‘resistance’, fleeing is an act of physical agency, as it is a choice to bodily remove yourself from the situation.

> *‘I could not stay in this community. Just then a friend of mine has asked me to go and do his palm nursery in Cape Mount… I was there for five and half months… the best anybody can do for me just be here in peace and my mental health under control’ (68-year-old man with a psychosocial impairment, Monrovia)*

Rejection of the biomedical health response to Ebola has sometimes been described as ‘resistance’ (Wilkinson and Fairhead, 2017). Whilst all the people I spoke to could rattle off a (predominantly accurate) list of Ebola ‘signs and symptoms’ (although some said that they initially believed that Ebola was airborne), these did not always align with the behaviours that people enacted. Distinctions between ‘Western’ and ‘traditional’ medicine are sometimes less clear-cut or hierarchical in terms of health-seeking behaviour (Fairhead, 2014), and several people with disabilities spoke about alternative treatments for Ebola. These included ‘bitter root’, a drink that is widely used in rural and remote areas as a treatment for a variety of illnesses, such as fever or ‘runny stomach’. The other treatment that was mentioned on more than one occasion was ‘salt and lime’, which is as it sounds – a drink of a large quantity of salt mixed with lime juice. The person who survived Ebola ascribes her recovery to ‘salt and lime’ after she was sick for weeks.

> *‘one day I just told my daughter I say you go Fiamah [part of Monrovia] buy lime… she put the water, hot water in the bottle like this; [I had] no strength to squeeze the lime, no strength, I took the half bag of salt I put in that water with that lime, I mixed it, that how I was, drinking that water the whole day [and] the vomiting stop, the toileting [diarrhoea] stop.’ (47-year-old woman with a physical impairment, Monrovia)*

This is an example of how two things can be believed concurrently. This person displays a pluralistic attitude to her health-seeking, which is common in Liberia (Leach, 2015a). While she ascribed to all the preventative measures and ‘Western’ medicine, she also places equal weight on the efficacy of local medicine.

Agency and risk

Regaining agency also took the form of enacting risky behaviours as ‘resistance’. One woman with disabilities in Foya said that she refused to comply with any of the health protocols at all because she did not believe that Ebola was real until her husband died from the disease.

> *'at first the entire house they never trust none of it, no washing hands, [still] eat dry meat [bushmeat], eat pumpkin[93], move freely... [we] did not follow the precaution for the first time [at first], the rules' (30-year-old woman with a physical impairment, Foya district [translated from Kissi])*

For other people feelings of disease exceptionalism led to risky behaviours. The Executive Director of the National AIDS Commission told me rates of HIV spiked because people didn't care – HIV was considered to be 'not as bad' as Ebola. If left untreated, this would undoubtably lead to disability and death.

Other behaviours appeared small but could have had profoundly devastating consequences. Such behaviours disclosed by people with disabilities included allowing visitors inside the home without sufficient infection prevention practices (one person said that she just 'wiped down' the seat that the visitor had been sitting on) or ignoring distancing rules (such as travelling in packed vehicles with strangers). Others did not call 4455 (the Ebola hotline) when they encountered a person showing Ebola symptoms, presuming that it was malaria. Many people talked about family members who took risks.

> *'my uncle died inside [the house]. He goes [to] help one of his tenants, and the tenant was having it and he didn't know, and he [the uncle] was a doctor, he got his drug store and he got plenty women, he got plenty children, he got houses all over... he said [to the tenant] what happened? He said I don't know I just feeling weak, he said okay I will treat you. Instead of carry the person to the hospital, himself started treating the man' (42-year-old woman with a physical impairment, Monrovia)*

An inference here is that if even 'big men', people of authority and pillars of the community, can die, then no one is safe. This feeling was expressed by several of the people with disabilities I spoke with, and the result was that this knowledge compounded their fear.

5.4.4.Secrets, suspicion and blame

A counternarrative to personal responsibility is secret-keeping and blame. Secret-keeping and the assumed lack of compliance with the prevention measures often led to

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[93] The health advice was to not eat any fruit or vegetable that a bat might have bitten

blame. A person I spoke to described how a nurse family member had, despite her mother's wishes, secretly tended to a sick pastor.

> *'So she kill her ma, kill herself, she kill her son, kill her aunty, and she kill her—her pa… Yeah the ma advise her stay—now but the person she said she went to treat was pastor, every one of them was meeting that there at the time, so she was not expecting, she was not really expecting it. They been knowing the man, but they did it secretly' (41-year-old woman with a physical impairment, Voinjama district)*

Informal treatment of community members by health workers was a way that Ebola spread through Lofa (Kouadio *et al.*, 2015; Coltart *et al.*, 2017). However, in the above example there is the issue of power imbalance caused by the authority (profession and gender) of the pastor. One can question how much of a choice the nurse actually had in her decision to give care. Nonetheless, the nurse is blamed for keeping secrets and not listening to family authority. Gender has been associated with blame, with women facing 'accusations that they were "wicked" or "careless" in the wake of their own and others' illnesses' (Minor, 2017, p. 28). This is clearly implied in the quotation above. The gendered caring roles are of crucial importance. Caring for sick family and community members is a necessary and compassionate act which was often undertaken by women (Richards, 2016). It was also but was regarded as a critical transmission pathway. However, in Liberia there was almost identical proportions of men and women who contracted Ebola (50.2% compared with 49.8%; WHO Ebola Response Team, 2016). Almost all examples of blame in my interviews were ascribed to women; where men were deemed to be the cause of spreading Ebola to their family it tended to be framed in a much less negative way.

> *'one woman entered in the town with the sickness so because my father is a pastor where all of them fell into that sickness they encountered with the virus, my big brother little kids, his little children, all of them were affected with Ebola' (33-year-old man with a physical impairment, Foya district)*

Blame is not ascribed to the pastor. Indeed, the implication is that the father did his duty, and it was through his professionalism during the difficult time that he caught and spread Ebola to his family. This is also echoed in the previous quote about the uncle and his tenant.

Blame and suspicion were also linked. The formal health response and health messages deliberately created a deep suspicion of outsiders to try to reduce people's contact with others and stop movement of people between communities and across borders. Many people spoke about outsiders not being allowed into their communities, but on two occasions, these suspicions proved warranted.

> *'[a woman] escaped her community and was brought into our community… after few days she came down with [Ebola] and as we are speaking, she is dead and gone. So that alone panic the community because we felt that the Ebola had hit the community… [the Ebola team] spray that whole place [dwelling]… people were afraid to move in there until close to a year.' (52-year-old man with visual and physical impairments, Monrovia)*

> *'When it got in to my community there, there was time a lady who was, a lady who was living not too far from us, when she took, when she took sick, they did her test, she was diagnose of [Ebola]… we become robust in [not] accepting strangers now' (32-year-old man with a visual impairment, Monrovia)*

Thankfully, on both counts, the community outbreak was contained.

Suspicion and mistrust were widespread during the Ebola time, and sometimes this changed the narrative of the outbreak. This took the form of conspiracies and rumours, which is the final subtheme that I will discuss.

5.4.5. 'poisoning the well': trust, conspiracy and rumour

Many people in Liberia denied that Ebola was real, or harboured conspiracy theories about the origin of the disease (Chandler *et al.*, 2015; Leach, 2015b; Wilkinson and Leach, 2015). This is in part because of the deep mistrust that Liberians, particularly in the region around Lofa county, had for the state which was often either deeply oppressive or entirely absent (Sirleaf, 2018). Many people felt that the state was self-serving and self-enriching and did not have the interests of ordinary citizens at heart (Leach, 2015a). Trust in government during the Ebola outbreak was extremely low (Blair, Morse and Tsai, 2017), and previous research with people with disabilities found that not only did they mistrust state institutions and the democratic process, but that this served to compound the already pervasive poverty that they experienced (Kett *et al.*, forthcoming). These, taken together, can explain the propensity of people with disabilities to extol conspiracy theories, particularly in the rural and remote areas where poverty was most extensive.

Taking control of the narrative was also a way in which people with disabilities regained agency. This often took the form of counternarratives to the ‘official’ explanation for the Ebola crisis, which were constructed through interactions with others – ‘spreading news’ about the outbreak. Many of the people I spoke to, particularly in Lofa, said that at the start of the outbreak denial and disbelief was ubiquitous. Interestingly, only one person I spoke to in Monrovia said that they believed Ebola conspiracies, which may potentially be due to an average higher educational attainment than in more rural and remote areas. That said, it was not only poorly educated people in rural and remote areas who did not believe that Ebola was real. The Lofa County Health Officer reported that some lawmakers believed that it was a lie and an attempt by the government to extract money from the international community.

It has been argued that widespread mistrust of health workers contributed to the spread of Ebola (Shultz *et al.*, 2016). Health workers were accused of being complicit in starting or spreading Ebola, in disseminating misinformation, and that they were stealing body parts in ETUs (Leach, 2015b; Wilkinson and Leach, 2015; Abramowitz *et al.*, 2017). However, none of the people I spoke with talked about not trusting health workers. In fact, it was sometimes the opposite – that they did not feel they had enough support. This might be due to the fact that people with disabilities in general have a greater need for health services (WHO and World Bank, 2011), and therefore are more likely to interact with the formal health system, so there may have already been a greater level of trust.

In their research about social learning during Ebola, Abramowitz and colleagues (2017) argued that conspiracy theories proved ‘sticky’. For them this meant that it was possible for people to simultaneously adopt and follow IPC practices whilst also holding on to conspiracy theories about the origin and spread of Ebola. This was the case with some of the people I spoke with, who felt no cognitive dissonance holding deep-set conspiracy theories whilst also complying with the health protocols. This was particularly evident in the 'poisoning the well' conspiracy[94]. People I spoke to in all the areas outside of Monrovia said that people poisoned wells during the Ebola time. The reasons for poisoning the well varied, with some believing that it was a money-making enterprise by people involved in the Ebola response.

> *'they will come and put poisonous substance in the well, unknown to you. You and your family drink the water in the morning, you'll start to go to the latrine, you'll start to puu* [toilet]*, to vomit. Then those—because they were on the scene like contact tracer and they will call the health team [and tell them] that we have a case in this community and they [the contact tracer] will get money.' (30-year-old woman with a physical impairment, Foya district)*

Others believed that it was a government conspiracy to extort money from the international community.

> *'in the Ebola more people died that putting poison in the water—in their drinking water, so we were not used to drink from all the well... we learn that people want for more—more death, more Ebola, more Ebola victims, because when people die plenty they send more money. That what we learn-oh, when people die plenty in the country, they send more money.' (57-year-old man with a physical impairment, Sinje district)*

In the media, it was reported on multiple occasions that mobs had attacked people they suspected of poisoning wells (Azango Azama, 2014; Kanneh, 2014; The Inquirer, 2014). These alleged perpetrators were often arrested by the police but always released without charge due to lack of evidence. Despite this, there was widespread panic, which in some cases was fuelled by reckless news reporting. In response, the head of the police in Monrovia was compelled to hold a press conference to try to debunk the conspiracy.

> *'We do not know the origin of such sharing information which engulfs the city a fortnight ago that resulted to mob violence against some of our citizens howbeit innocently. The Police are therefore, warning rumor mongers and negative talebearers to refrain from putting other citizens in*

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[94] This is not to be confused with the 'poisoning the well fallacy'. This is a rhetorical *ad hominem* fallacy where an audience is pre-emptively primed with negative information about an opponent to tarnish their credibility.

> *harm's way through their wagging and poisonous tongue' (Director of Police quoted in The Inquirer, 2014)*

The quotations above reflect the two main locations of conspiracies: individuals (contract tracers, well poisoners); or institutions (government or health response). In addition to well poisonings, people I spoke to mentioned individuals deliberately infecting others with Ebola, that it was chlorine used by the health responders that killed people, that Ebola was brought to Liberia by unidentified organisations or that Ebola was a lie and a conspiracy to impoverish the population. Interestingly, some of these beliefs have persisted well beyond the end of the outbreak, which speaks to a continued mistrust of state institutions.

The preceding subthemes have presented the strategies that people employed to regain agency and control as the Ebola outbreak progressed, whether it be strict compliance with or resistance to the Ebola response. Cases of Ebola peaked in October 2014 and then began to decline rapidly (Nyenswah *et al.*, 2016), due in no small part to community and individual action. It would take many months for the disease to disappear completely from Liberia, however.

5.5. Free at last?

Liberia was finally declared free of Ebola on the 9th May 2015[95]. Everyone I spoke to said that they were extremely happy and relieved when the outbreak came to an end. I asked when the outbreak felt over for them. Most people said that it was when the government/WHO declared the country to be Ebola-free (42 days after the last case was diagnosed).

> *'UN disease control was announced that Liberia was free from Ebola… I feel that we have been release from prison' (47-year-old man with a hearing impairment, Monrovia)*

However, others said that the end of the outbreak was more qualitative. For these people, they felt that it was finished when people started moving around and were

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[95] There were a few additional breakout cases of Ebola in June and July 2015, but these were contained without further spread of the disease (Nyenswah *et al.*, 2016).

allowed more freedom, thereby completely regaining the agency that they had forfeited during the Ebola time.

> *'[I felt] Happy because I can go one-two—one-two to my little boyfriend then [laughs] sometime—sometime somebody will call you bah [buddy] I want see you-oh' (50-year-old woman with a physical impairment, Monrovia)*

Through the happiness and relief, there was also some pessimism (or pragmatism) about the potential for Ebola to become endemic to Liberia.

> *'they were still giving us information they say Ebola can't totally finish, they say it will not finish. It will be like other sicknesses, sometimes they come, they go, they come, they go. That's the information but we praying to God that it should not come again' (38-year-old man with a physical impairment, Foya district)*

Many people with disabilities and interviewees all felt that Ebola had caused Liberians to become 'stigmatised in the world', and once the stigma was lifted, Ebola was truly finished.

> *'I know Ebola was over [when] I got in the airplane nobody look at me this way and that way and I could proudly say I am a Liberian. So that's when I know Ebola was over.' (68-year-old man with a psychosocial impairment, Monrovia)*

5.6. Conclusion

The West Africa Ebola outbreak was unprecedented in size and scale. By the end of the epidemic, there had been a total of 28,652 recorded cases and 11,325 deaths (CDC, 2019). Liberia was disproportionately affected, accounting for 10,678 cases (37.0%) and 4,810 deaths (42.6%). The outbreak was a humanitarian emergency of a scale that Liberia had not experienced since the end of the second civil war. The impact was devastating to health systems and personnel, with Liberia losing 8% of its doctors, nurses, and midwives (Elston *et al.*, 2017).

This chapter has presented some of the experiences and opinions around people with disabilities' experiences in the 2014-2015 Ebola outbreak. I will next move on to how the same people with disabilities experienced the COVID-19 pandemic.

Case studies

A set of three case studies is also presented here, drawn from the life history interviews. Each of these studies offers a unique perspective on the themes explored these chapters. The case studies comprise two women and one man, each from a different county, and representing rural, urban and capital city settings. These case studies have been selected as their narratives add further depth to the themes set out here and illustrate the complexity of people's experiences during the two outbreaks.

Esther[96], Grand Cape Mount

Esther was born in Robertsport, Grand Cape Mount County in 1964. She grew up in a large family of twelve children, although three of her siblings died during childhood. At the age of two, Esther experienced a sudden illness that left her unable to stand or walk. She was eventually diagnosed a bone problem. Over time she regained some mobility, but her legs remained uneven in strength and appearance. Esther longed to go to school like her siblings, but the long distance to school and lack of transport we insurmountable barriers.

When she was 26, Esther moved to Monrovia in search of independence and education. She lived with her uncle in Sinkor who forced her to do household chores, rather than sending her to school. A woman later took Esther into her home and enrolled her in night school but she soon became pregnant with her first child, who tragically died young. Esther had six children in total, although several died in childhood, some during the civil wars.

The civil war profoundly shaped Esther's life. During the 1990 crisis she fled Monrovia to Cape Mount, hiding in the bush with her family. She lived with constant fear and displacement, running between villages. Even after the peace accords were signed in 2003, Esther never truly felt the war had ended.

Esther's community in Monrovia suffered during Ebola, and she witnessed widespread deaths and the collection of bodies by ambulance teams. Fearing the disease, Esther left Monrovia and returned to her village in Grand Cape Mount, where she self-isolated

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[96] Names have been changed

for months, relying on food that she had previously purchased. She described the experience as deeply frightening.

Her recollections of COVID-19 were far more limited, as she continued to live in her village. While she was aware of the virus and public messaging around masks, she did not wear one, believing that only God controlled life and death. Esther isolated herself in her home throughout the outbreak and she relied on food supplies brought by her daughter and husband before restrictions were imposed.

Esther later became involved in a local OPD and feels a sense of community. She has also served as treasurer, managing small funds when available, although she said that government funding dried up in recent years.

In recent years, Esther's condition has worsened and she lives with chronic pain and restricted mobility. She still lives in her small community with her elderly sister, and her husband works in Monrovia with the Albino Society. Her daughter and other relatives provide food and occasional financial support when possible.

Joseph[97], Lofa

Joseph was born in a rural village in Foya District. He was the youngest of seven siblings, two of whom (including Joseph) and his elder sister, live with physical disabilities.

During the civil war, Joseph and his family were forced to flee into the bush, where they survived for four months with little to no food. The experience was profoundly traumatic for Joesph, and he witnessed severe violence. His grandfather and cousin were killed during this time. Eventually, the family managed to escape to Sierra Leone, where they lived as refugees before returning to Liberia after the war ended in 2003.

Joseph acquired his disability at around the age of ten. Initially, his family attributed his condition to a curse and accused his grandfather of witchcraft. Although doctors diagnosed him with polio, his family was slow to accept the diagnosis. Joseph's father struggled to accept his disability and denied him education, insisting he pursue blacksmithing instead. However, despite the barriers and stigma from his peers, Joseph was determined to pursue education. He worked on farms and took small jobs to pay

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[97] Name has been changed

his school fees. Joseph eventually graduated in 2013 – the first in his family to complete secondary education.

When Ebola entered Liberia, Joseph initially denied its existence, as did many in his community. However, as deaths increased and health messages spread, he began to accept the reality of the crisis. He recalled the fear of seeing health workers in PPE and felt like the world was coming to an end. His family adopted infection prevention measures and were supported by NGOs that provided some supplies. Joseph's family was not directly affected by Ebola, but his father died during the outbreak. Joseph's family was not permitted to bury his father until he was tested for Ebola, and despite the test result being negative, he was still buried by a burial team in full PPE.

At first, Joseph and others in his community denied COVID-19, much like they had with Ebola. However, Joseph was much quicker to accept he health messages than he had been before. He described how NGOs provided some infection prevention supplies, but these weren't enough and he had to procure additional items at his own expense. Joseph admitted being afraid of hospitals during the outbreak, fearing that he would be vaccinated against his will, believing myths that people would sometimes die after taking the vaccine. Despite this, he eventually decided to take the vaccine for his own safety.

Joseph now lives in Foya with his fiancée and two children. He sought further education, but financial barriers prevented him from attending university. Instead, he became active in the community and in his OPD, where he was elected to Secretary General in 2011. His work now focuses on disability rights, advocacy, and supporting others with similar experiences.

Satta[98], Monrovia

Satta is a woman who was born and still lives in Monrovia. She acquired a physical disability at the age of five when she began experiencing pain and weakness in her legs. After multiple hospital visits, she was diagnosed with a neurological condition.

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[98] Name has been changed

Satta started school at age 7. Her early schooling was marked by exclusion and bullying. Stigma and bullying was pervasive during her early schooling – her classmates mocking her as a ‘cripple girl’. It was not until she started at the Lombardia Institute[99] when she was 12 that she felt that she started to learn. The school was open to children without disabilities, which inadvertently reinforced feelings of exclusion. For Satta, the stigma persisted, and non-disabled children actively avoided her, and making derogatory remarks. Satta describes a persistent sense of social isolation, still struggling to form close friendships.

With the financial support of a Catholic priest and NCD, Satta graduated from high school at 18 and then pursued computer skills and training in tailoring and fashion design, hoping to become independent. However, when she was 16, Satta had become pregnant. Her daughter became her primary motivation, prioritising her daughter’s needs over her own, giving up food, education, and comfort to ensure her she was cared for.

The Ebola outbreak had a profound impact on Satta and her community. She witnessed the death of a friend’s entire family and she herself narrowly avoided exposure. Her mother, terrified of infection, enforced strict hygiene measures at home, and the family avoided healthcare facilities out of fear of being detained or disappeared. She remembers the fear, the hunger, and the emotional toll of isolation during Ebola. For her family, the economic shutdown was devastating and finding food became a daily struggle.

Satta felt that Liberians took COVID-19 seriously from the start. The devastating memories of Ebola deaths meant that as soon as news of the virus spread, communities began implementing precautions. Satta attended multiple trainings that targeted people with disabilities. She also supported her community by distributing food and hygiene items, some funded with donor support. Satta noted that people with disabilities were often excluded from mainstream community initiatives, and she

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[99] a school specifically focused on educating children with disabilities

herself mainly worked within the disability community, running training for around 50 people with disabilities.

The lockdown posed significant challenges. The strict curfew was enforced by security forces, often violently. Satta had to pay sharply inflated and unaffordable motorbike taxi fares to get into Monrovia. School closures affected her daughter, who received home teaching from Satta as her school did not offer online classes. Yet, unlike Ebola, when supplies were scarce, Satta had much greater access to food and hygiene materials during COVID-19. Supplies were provided by government, NGOs, and politicians. While she did not contract the virus she knew people who survived. She did not take the vaccine, however. Satta's father became unwell after vaccination, which fuelled her suspicion that it was dangerous.

Now in her late twenties, Satta continues to dream of financial independence. She aspires to return to education, but economic constraints have forced her to prioritise her daughter's education over her own. She hopes to one day sew clothes professionally and support herself through tailoring, but currently lacks the funds to purchase a sewing machine.

Chapter six: COVID-19 thematic analysis

6.1. Introduction

The previous chapter presented findings on how people with disabilities had experienced the Ebola outbreak. Three main phases emerged from the thematic analysis, which followed something of a chronological path: the response was first enacted upon people with disabilities; people lost agency and were forced to 'sit down'; finally, people with disabilities found strategies to restore their agency.

This chapter will move on to discuss the impact of the COVID-19 outbreak response in Liberia for people with disabilities. In addition to presenting results from the life histories and key informant interviews, this chapter will also include outputs from the photovoice project (outlined in **chapter four**). These photos and associated captions were showcased in the final exhibition in December 2022, which was titled '*Give us a* *voice: the experiences of people with disabilities during COVID-19*' and was curated by the co-researchers themselves[100].

As with the Ebola data, I conducted reflexive thematic analysis on the information shared by the people I spoke to around their experience of the COVID-19 pandemic. The analysis of these data first generated a series of codes drawn directly from participants' accounts, which were then refined and organised into four overarching themes, each comprising several related subthemes (**appendix four**): 'same difficulties, different disease'; 'Ebola gave us expertise'; 'health and disability during COVID-19'; and a series of 'opinions and comparisons'. Unlike the data on Ebola, however, these themes do not tend to have a chronology but rather were present from the outset, occurred simultaneously, or at various but not always chronologically linked points. As with the previous chapter, I will discuss each of these themes in turn, with reference to the several subthemes that were generated through the thematic analysis. Where experiences happened at a given point in the outbreak, I have highlighted them as such, but what follows is a grouping of themes rather than a chronological narrative.

6.2. Same difficulties, different disease

In this first theme, four main subthemes emerged: 'curfew challenges'; 'adequacy of awareness'; 'fear and anxiety'; and 'belief, denial and conspiracy'.

6.2.1. Curfew challenges

> *'we were force to sit down home. It put some economic burden because the entire country was going, worldwide going through such persecution called lockdown' (32-year-old man with a visual impairment, Monrovia)*

COVID-19 reached Liberia on the 16th March 2020. A politician returning from Geneva allegedly breached health screening protocols at Roberts International Airport (Koinyeneh, 2020). A national health emergency was declared the following week after two more cases were confirmed (Republic of Liberia, 2020a). The restrictions were wide ranging and included school closures, restrictions on public gatherings, closure of places of worship and entertainment, social distancing, bans on street-selling, and closures of borders. At that point these restrictions were only applicable to residents of

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[100] See **appendix five** for all the photos that were included in the exhibition and their associated captions

Montserrado (capital county) and Margibi (neighbouring county and location of the airport).

Confirmed cases remained very low for several weeks (there were only three cases reported by the end of March; WHO, 2020a). The first death from COVID-19 was reported on the 4th April, and following a swift increase in the number of cases, the government took action. President George Weah declared a national emergency on the 8th April (FrontPageAfrica, 2020a), extending the health emergency restrictions nationwide, and a three-week lockdown was imposed. Following the end of the lockdown a protracted national curfew was enforced[101]. The state of emergency was initially to last for three weeks, but ended up not being lifted until the 12th July 2020 (WHO, 2021b).

The following subthemes will present the ways in which people with disabilities experienced the curfew and other measures.

Surveillance and security

> *'we had a lockdown in COVID-19, yes. COVID-19 by 3 o'clock everybody should leave the street so by the latest 2:50pm you should be at your house, so it was a bit challenging for me... everybody [was] rushing because police people were in the street, army people in the street... when they catch you in the street at 3 o'clock, they will beat you, they will beat you, so everybody was rushing' (28-year-old woman with a neurological impairment, Monrovia)*

This first photo depicts a skills-training with disabled and non-disabled people, which took place at the National Union of People with Disabilities (NUOD). While the link between the photo and the caption isn't immediately clear, the full text discusses normalising disability and sensitising people around disability issues, particularly hearing impaired and Deaf people. However, the caption also succinctly presents how information was not always accessible to all people with disabilities.

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[101] Initially the curfew lasted from 3pm until 6am but was later relaxed to 6pm. However, this curfew remained in force until the state of emergency was lifted over three months later.

...During COVID-19, the Deaf community was left [out] of information that were given to the public, there was no information and there were no sign language interpreters. They were not informed. At least five Deaf people were beaten by our own police because the Deaf people did not get the information about the 3pm curfew and there was no one to inform them...

(female photovoice co-researcher with a physical impairment)

Photo 1

People with hearing impairments are some of the most marginalised in Liberia, due to often significant communication barriers, and were effectively excluded from much of the COVID-19 response. Sign language is not widely spoken in the Deaf community, apart from by those who attended Deaf schools[102]. Yet even for those who speak sign, this did not guarantee that they had full information. For much of the outbreak, there was no sign interpretation on daily televised COVID-19 updates, and this led to Deaf people being beaten in the streets of Monrovia by police for violating a curfew about which they had no information[103]. Violence perpetrated by police and army was widespread and was not limited to people with hearing impairments.

> *'there was a lockdown, yeah. You cannot move out, you cannot go anywhere, so it is was a very serious one again, and they just started beating people, chasing people [at] 3 o'clock... you will just be seeing the army people... police passing and when they see you, you are in trouble for that day' (43-year-old man with a visual impairment, Foya district)*

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[102] At the moment Liberia does not have its own recognised sign language – American sign language is taught in Deaf schools.

[103] This only changed following concerted advocacy and sensitisation by NUOD

People with disabilities often reported being discriminated against in the enforcement of the curfew, but sometimes being treated equally with non-disabled people was just as challenging.

> *'they [the police] will not say "you cripple", "you not cripple", they will treat you the same way. So that time it was difficult for me to find food, because that time now I was [by] myself, I was doing everything for myself' (42-year-old woman with a physical impairment, Monrovia)*

The perceived 'equal treatment' of people with disabilities does not account for the additional challenges that people with disabilities experienced complying with the curfew, particularly around the extra time it often took people to travel.

Liberians in general were overwhelmingly in favour of police enforcement of the COVID-19 restrictions (85.1% [85.1% male, 85.0% female]; Afrobarometer 2023) and while very much in the minority, not all the people with disabilities I spoke to regarded the police as a violent entity.

> *'the police, when they were concern as soon as they see us, they will ask "why is it you are out after three?" And then if you give them a genuine explanation, they will help you and carry you home' (32-year-old man with a visual impairment, Monrovia)*

Other security measures were conducted informally. For example, protecting people with disabilities' communities in order to combat criminal groups that were capitalising on the curfew.

> *'[a] person with disability at my junction to come in here, you wouldn't find motorbike to bring you in... you have to walk to come and sometime coming you will be hijack by the Zogo[104], and sometime you reach safely, and sometime they have certain security called Kapawo-Kapawo [a vigilante group], they were all in the community watching to see you*

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[104] 'Zogo' is a colloquial term for disadvantaged and vulnerable individuals living on the fringe of society. Zogos are often labelled 'street thugs', involved in theft and harassment of citizens. They are often youth, including former child soldiers, and there are extremely high rates of drug addiction, illiteracy and unemployment ('The Zogos of Liberia', 2019). UNDP estimates that there are at least 75,000 Zogo in Liberia, and over nine-out-of-ten (91%) are male (Saydee, 2023).

> *[safely] home' (47-year-old woman with a physical impairment, Monrovia)*

This use of surveillance community 'task forces' was a common practice (Mclean, 2024), but the use of this external group was unusual. The same vigilante group was employed in a different community in quite a different capacity: enforcing the response restrictions.

> *'The only person in the community I don't know [were the] Kapawo-Kapawo... [the community leader] employed [these] people in the community and he put bucket to the entry so when you passing, they tell you say wash your hands. [If] you say 'no' they will beat you, so you just forced to wash your [hands] before you pass.' (42-year-old woman with a physical impairment, Monrovia)*

Like Ebola, COVID-19 bred suspicion and caused individuals to surveil one other. A COVID-19 hotline was established on 4455 (the same number as the Ebola hotline), and reporting of neighbours who showed symptoms was encouraged (Republic of Liberia, 2020a). Encouraging these behaviours (and potentially using the 4455 number) led to the resurgence of a legacy fear from Ebola of being disappeared.

> *'and because of the Ebola some people who were even being called – I mean called by the emergency number – to carry them [away]. Some people it was just diarrhea, and some people went and never came back... nobody wanted to be called for 4455' (52-year-old man with visual and physical impairments, Monrovia)*

The curfew and its violent enforcement severely impacted on people with disabilities' access to vital items, including food. The next subtheme that I will discuss examines the ways in which people with disabilities were exposed to and dealt with provision scarcity.

Supplies and scarcity

> *'...because of the lockdown, you will stay home and once you stay home now you become hungry and sometime you die from hunger. Because without food you can't live' (47-year-old man with a hearing impairment, Monrovia)*

The World Bank (2021) estimated that 118 million people globally were forced into food insecurity in 2020 as a result of the pandemic. Even before the pandemic, Liberia was already extremely food-insecure, with 20% of households experiencing food insecurity and of these, 60% of households were extremely food-insecure, with food insecurity greater in rural areas (UN Liberia, 2020).

To try to address food insecurity, the Liberian government implemented a ‘stimulus package’ that aimed to provide food and pay the energy bills for the most at-need households (Parley, 2020; UN Liberia, 2020), including those with disabilities. However, less than 10% of households reported receiving any government assistance (Sanny and Bloh, 2021), and almost none of the people I spoke to reported having received anything.

> *‘...every one of us feel bad, because for disable, where to go to find food? Nowhere. So, we are sitting down whole day. We can’t go anywhere, where you will get food? So we were really feeling bad. It was not good for us and even the able people, but I’m talking for disable people because I’m a disable person’ (38-year-old man with a physical impairment, Foya district)*

In their research with rural populations in Liberia, Aggarwal and colleagues (2022) found no evidence of an increase in food insecurity during the lockdown. However, the authors argue that is not due to effective government interventions during this time, but rather that 40% of households in the survey were already food-insecure. Many people with disabilities I spoke with reported being extremely food-insecure during COVID-19, and that their situation had deteriorated due to the curfews and other restrictions. Some people in rural and remote areas felt that food was scarcer during COVID-19 than it had been even during the Ebola outbreak.

People with disabilities also reported that the curfew prevented them from working on their farms, causing crucial food supplies to spoil and further worsening food insecurity. This finding also contrasts with Aggarwal et al(2022), who identified subsistence farming as a protective factor – while households experienced a decline in food expenditure during lockdown, their overall food consumption remained stable. However, their study did not include people with disabilities whose experiences may differ significantly[105]. Much of the research on disability and food insecurity during COVID-19 focuses on countries in the ‘global North,’ but consistently finds that living with a disability significantly increases the risk of food insecurity (Loopstra, 2020; Friedman, 2021; Choi, Carr and Namkung, 2022; Kent *et al.*, 2022).

The vibrant image that this co-researcher chose to share is starkly at odds with her difficult caption. She is unfailingly colourful and optimistic, and her chosen clothes very much reflect this – you can see her personality shining through. Her life during COVID-19 was severely curtailed, and like several people I spoke with, she was completely reliant on family members for food and therefore her survival. The co-researcher covers a lot of ground in her caption, clearly making the link between the poverty that she experiences and her being a woman with a disability. She, like many others, also highlights the knock-on effects of the curfew – that her inability to participate in income-generating activities led directly to her experiencing housing insecurity.

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[105] Some care should be taken interpreting these results as while the research was conducted in rural areas in Liberia, it was in different counties (Bong and Nimba) to where I was collecting data. People in rural and remote areas in Lofa and Grand Cape Mount may have had a different lockdown experience.

Photo 2

This is my house that I am renting and it is in a swamp. There is no restroom. During the rainy season we put sand in bags and use them to stop the house from flooding. The water can overflow and enter the house and sometimes water snakes come… Even to get fresh water it was very difficult. There is no pump in the community, so we use the rainwater to drink and cook…

In the covid time we could not get out. There were no foods distribution, and I had to call my brother who could fetch food. Having enough money for rent was very difficult… Is very challenging to live as a single woman with disability in Liberia…

(female photovoice co-researcher with a physical impairment)

As had happened during the Ebola outbreak, households should have received several COVID-19 prevention items, including buckets, hand sanitiser and soap. Most people with disabilities I spoke to said that they had received at least some of these items, particularly people living in Monrovia. Distribution of items was patchy in the rural and remote areas, however. People with disabilities in the capital tended to report that their items had been donated by the Liberian government, whereas people in rural and remote areas were more reliant on NGOs and other informal actors (such as faith organisations). Notably, several people with disabilities said that they had received supplies from politicians who were standing in elections held in December 2020[106].

> *'others were coming in, along with other humanitarian like Momo Cyrus[107], yes. He brought 30 bags of rice for us, chlorine, chloral, hand sanitizer, yes he brought them nose masks. And one other guy again was an aspirant, who run for the senatorial position for 2023 he also brought*

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[106] The Special Senatorial Elections, by-elections for the House of Representatives, and a national referendum were held on the 8th December 2020. Following the elections, Liberia saw an unprecedented spike in confirmed COVID-19 cases (NewDawn, 2020).

[107] A Liberian senator.

> *this nose mask, locally made nose masks' (43-year-old man with a visual impairment, Foya district)*
>
> *'you know, at that time Liberia was in their politics thing, yeah, political season people were doing politics business everybody wanted to show themselves, politicians. So they were carrying food to people…' (28-year-old woman with a neurological impairment, Monrovia)*

This is an interesting finding, because previous research with people with disabilities found that being perceived as political pawns bred disenfranchisement and mistrust of politicians and the democratic system (Kett *et al.*, forthcoming). However, in times of humanitarian crisis, this patronage seemed to have been greeted much more positively than it might have been in other circumstances.

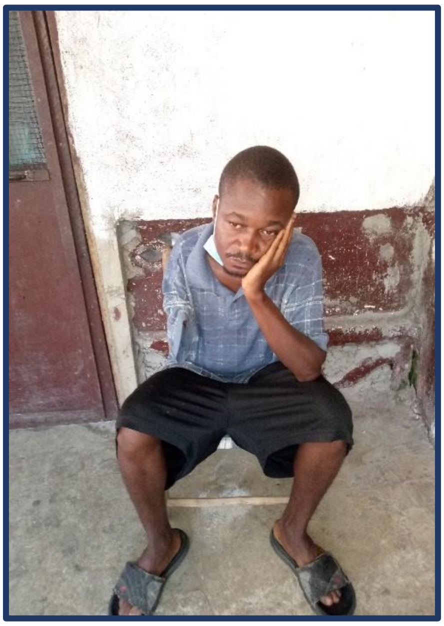

Photo 3

In the photo I feel sad and frustrated and isolated… In Covid I was unemployed the little work I [had been] doing I could not do. As a person who is physically challenged and as a tutor I could not find work…

I was worried about my family, how they would survive in a situation like this. I woke up every morning wondering where to go, what to do. I was hopeless. I can hustle, but I'm not used to going into the street asking for help. I don't want to ask them. Who will be reasonable and understand? It is a desperate time.

(male photovoice co-researcher with a physical impairment)

The image and words that this co-researcher chose to share shows the indignity associated with the curfew and other aspects of the COVID-19 response (in this case, school closures and social distancing). The impact of COVID-19 on the education system was extensive. Schools closed in March 2020 but did not reopen until December 2020[108]. In addition to the lack of education for children, this also resulted in many

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[108] Worryingly, UNICEF reported that nearly half (43%) of children and young people did not return to school when they reopened (UNICEF, 2022). This has huge implications for Liberia's development over the coming decades.

teachers going without pay for seven months (FrontPageAfrica, 2020b), forcing them into precarity. Like many, in order to survive, this co-researcher was forced to participate in activities that he would not otherwise have engaged in (hustling or begging) and that he personally found degrading. A representative from UNDP highlighted an indirect impact of curfew. Many people with disabilities in Monrovia rely on begging for money and food. With fewer people on the streets, this put people with disabilities who begged under extreme economic stress. A similar situation arose during Ebola, where people with disabilities were not able to 'comply' with restrictions on movement and had to beg for survival – knowingly putting themselves at risk (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021).

One woman in Foya told me that she was forced to resort to sex work to find money for food.

> *'during that time there was lockdown again and for her, she escaped to go look for food. So when she went, she came across somebody, a male, the man had an affair with her and he gave her three hundred[109] because she go out to look for food' (30-year-old woman with a physical impairment, Foya district [through a translator])*

By contrast, a notable minority of people with disabilities in Monrovia said that they did well during COVID-19, sometimes having enough food to share with their family.

> *For COVID-19 I got food, yeah. The government gave food to organizations, I got food… I also used to bring food to [my parents] because I really used to get food, I shouldn't lie, to admit I used to get food not only from government, but different, different people were bringing food, yes, they were bringing food' (28-year-old woman with a neurological impairment, Monrovia)*

This quote shows the duplication of resource distribution, as well as the range of actors who were providing food. This was similar to the experience during Ebola. However, from what people told me, this duplication only really seems to have happened in Monrovia, which appears less to do with better planning in rural and remote areas and

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[109] Liberian dollars (approximately US$1.50). The man who paid this woman for sex had promised her LD$500 but reneged on his promise.

more due to the lack of relief activities overall (this will be discussed in more detail in the following chapter).

People who were able to get surplus food or supplies during the outbreak sometimes shared with others, not just their own families or other people with disabilities.

> *'[WFP sent] a truck load of food, rice and this. So, I did not look at only person with disability, the old folks and people in the community because... Covid was not limited to certain groups. So, we shared at that shop that you passed by there where we shared the food and it was a great thing for the community. Up to this time here, people are still saying that, that day you did something in our lives.' (69-year-old man with a physical impairment, Monrovia)*

> *'during the COVID-19 the sanitizer, it was many. Even myself, people used to send me plenty... [I] used to give it to people free.' (57-year-old man with a physical impairment, Sinje district)*

These quotes are examples of support extending beyond the disability community. These situations offered a mechanism through which people with disabilities were able to bolster their own relationship with community members, as well as promote community cohesion overall.

This section has explored some of the challenges faced by people with disabilities during the protracted curfews. I will now move on to discuss how adequate COVID-19 awareness-raising activities was for people with disabilities.

6.2.2. Adequacy of awareness

> *'I used to give them [a] hard time. "You just came here to talk plenty, [how] are you helping? What you got to give me now?"' (50-year-old woman with a physical impairment, Monrovia)*

People with disabilities I spoke with in both urban and in rural and remote areas were critical of awareness, particularly activities conducted by 'formal' providers (such as government health workers or large NGOs). They argued that activities were too often overly focused on providing information rather than supplying desperately needed food- and non-food items (buckets, sanitiser, etc.). Other people, however, were more satisfied with the awareness raising. Some highlighted the range of formats that were used, and the positive impact this had on understandings of COVID-19 and transmission pathways.

> *'they [had] talk shows, they had announcements in the communities, even they had people writing some health tips and sending it I don't where it came from*[110] *but when they send it you forward it to your friend and it was just going viral like that.' (39-year-old woman with a physical impairment, Monrovia)*

> *'people started bringing those flyers and posting it, some places, some NGOs, some organizations even the president of this country sang about it this COVID-19, yes so, how people started coming now and we ourselves started saying this thing it is not, we cannot deny it again' (30-year-old man with a physical impairment, Foya district)*

For some people with disabilities, denial and disbelief about the existence of COVID-19 meant that awareness-promoting activities were initially not effective (see **section 6.2.4**.). This has clear parallels with Ebola as discussed in the previous chapter.

Civil society, including OPDs, were regarded as useful intermediaries for awareness dissemination by a range of actors including government, health and development professionals, as well as civil society themselves. However, in interviews, this was often potential rather than actual cooperation and only a few organisations reported directly working with OPDs. During COVID-19, individual people with disabilities were sometimes recruited to be part of mainstream awareness and information campaigns, although they were often focused on disseminating information to other people with disabilities. Interestingly, a much larger number of people with disabilities spoke about how they had become involved in COVID-19 activities. While this engagement had taken place during Ebola (and as discussed in the previous chapter was a strategy for regaining agency), during the COVID-19 outbreak it happened more frequently and from much earlier in the response.

> *'[I was] part of the awareness team, I was working with the Liberia Crusaders for Peace... Yeah, for this we were sensitizing disable people... I was assigned in Barnesville. I will do to centers, disable*

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[110] This is concerning because it shows how misinformation can (and did) easily spread.

> *centers that in Barnesville and sensitize them' (32-year-old man with a visual impairment, Monrovia)*

Caregivers I spoke to also took part in awareness-raising activities. The image that this co-researcher chose uses her children to reenact how she instructed people on prevention strategies. She felt that her role as a care provider was expanded to provide awareness-raising, and that it was her responsibility to share this information. Taking on additional responsibilities was not without its challenges, which will be discussed in the following section.

Photo 4

I was a member of an awareness team carrying out both awareness and sensitisation about health measures, some as you see it being displayed in this picture: wearing of masks, washing of hands constantly, and also the social distancing aspect of the protocol... I extended in my community as a caregiver, especially those of them with visual impairment as well as the community dwellers.

(female photovoice caregiver co-researcher)

One of the 'wins' that the president of NUOD shared with me was that continued advocacy led to the government eventually including sign language interpreters (SLIs) on televised COVID-19 updates, making health information accessible to people with hearing impairments. Sign language is not universally spoken by people with hearing impairments in Liberia, however, and knowledge of sign tends to be concentrated in Monrovia for people who have attended Deaf schools. That said, even if it happened late into the outbreak, it is still a great win, as having SLI on COVID-19 broadcasts dramatically increases accessibility for some. Also, beyond making COVID-19 information accessible to people with hearing impairments (an often hard to reach population, as evidenced by the physical violence they experienced after unwittingly violating curfews), it is also a visible way of raising the profile of disability in the general public.

Information from ‘formal’ sources did not always reach people with disabilities, however, and some people took matters into their own hands. Several of the people I spoke to said they had led awareness projects rather than just being part of them. This additional agency and responsibility was a change from Ebola.

> *‘for the Ebola, we were not really involve into awareness but for the Covid, we were really involved in to awareness. Yes. We got the support and I even remember that my organization, we run a project from Sweden, we run the project and we were able to get some money we carried on awareness even in even in the county and I was on the team, we went in the county come we carried buckets we carried tie soap we even carried rice to the people in [two other counties]’ (28-year-old woman with a neurological impairment, Monrovia)*

People with disabilities who received funding were universally based in Monrovia. However, people in rural and remote areas also reported leading awareness campaigns despite the lack of funding, as it was considered a necessity.

> *‘We just organize ourselves to be educating our people because we ourselves we have disables in those communities that sometimes they don’t come for the meeting, so we used to go in the field to educate them. Not only the disable but the able people that are that there we gather them we talk to them.’ (38-year-old man with a physical impairment, Foya district)*

This section has presented some of the experiences of awareness raising for people with disabilities during COVID-19. I will now move on to how this awareness affected people with disabilities’ compliance with the response.

Following the rules (or not)

Many people in Liberia found it challenging to comply with the lockdown restrictions (Sanny and Bloh, 2021). Compliance with infection prevention precautionary strategies in West Africa was generally low during COVID-19 (Lokossou *et al.*, 2021), with some studies finding that Liberians were almost a third (30%) less likely to adopt precautionary methods than with the Ebola epidemic (Skrip *et al.*, 2024). This was due to a range of factors, including the perceived low-risk of COVID-19 (Lokossou *et al.*, 2021), which was compounded by the financial and food insecurity experienced by many (Davis *et al.*, 2021).

People who have less trust in government are less likely to comply with already challenging restrictions (Hartwig and Hoffmann, 2021), and this was evidenced in Liberia during the Ebola crisis (Blair, Morse and Tsai, 2017). However, while many people with disabilities I spoke to were generally mistrustful of the state, almost everyone said that they 'followed the rules' during the COVID-19 epidemic. This includes people who had been resistant to following the health protocols during the Ebola outbreak.

> *'because of the way Ebola treated us in Liberia, so when COVID-19 came, we take it very serious. For Ebola, were playing we were not serious about it, that's why most people died. But for the COVID-19, we took it very, very serious. The moment it came, they told people that COVID-19 is in town, you need to do this, you need to do that, you need to do this, we took it very serious.' (28-year-old woman with a neurological impairment, Monrovia)*

Time was a huge issue for many people with disabilities I spoke to (as well as caregivers and service providers). People had to monitor their time strictly and truncate their activities whether tasks were completed or not, otherwise they risked being subject to violence.

> *'at the time because there was no free movement and it affected greatly, I was shorten with some things, to get food at the time it was difficult... Sometimes in the morning we go and sell small, [and] quickly we leave from there... you go and do one to two things and leave from there' (47-year-old man with a physical impairment, Foya district)*

This was sometimes particularly challenging for people with caregiving responsibilities.

While caregiving was only one aspect of people's identities during COVID-19, many described how these responsibilities became all-consuming, eclipsing other parts of their lives and often taking a significant personal toll. This co-researcher echoes the experience of many of the caregivers and service providers who felt that the burden of providing care during the curfews was relentless, and added to, rather than replaced, responsibilities. This is a pressure that disproportionately affects women (Hrynick, 2020). She also highlights the risks to herself involved in movement.

Photo 5

> *I am a caregiver to my mother and grandmother at home and I am also a student…*
>
> *During the COVID-19 I was risking my life waking up early in the morning going to town to get goods to put in my shop. In that period, I was doing a business to help take care of my mother and my siblings. Sometimes I went to check on her and the kids [on 12th Street]*[111]*… I had to rush back home because of the 3pm lockdown.*
>
> *…during the COVID-19 the Duport Road clinic played a major role in accepting and treating patients and telling patients what to do. We were lucky to have the Duport Road clinic…*
>
> *(female caregiver photovoice co-researcher)*

Given the relatively low (confirmed) prevalence of COVID-19 in Liberia (WHO, 2023b), a surprising number of people I spoke to said that they had known someone who had contracted or died from the disease (although no one claimed that they had caught COVID-19). This could either be due to the underreporting of actual cases[112] (because of a lack of testing capacity), or people mis-labelling COVID-19 as other viral respiratory infections. Lower respiratory infections (such as pneumonia) are the third highest cause of death in Liberia (WHO, 2024). This included one very sad experience.

> *'one of our brothers got sick in the Covid here. He died, we couldn't touch him… they put mosquito net all on him. He [was] alone, was there flies has sitting all on him, so they decided to put mosquito [net] on him, he left there and died' (58-year-old man with a physical impairment, Sinje district)*

It was not clear whether this person had died from COVID-19, but the implication was that, despite following public health guidance, his friend still died – and his body was

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[111] 12th Street is nearly 9 miles away from Duport Road, and taking a cab or motorbike taxi in perpetually heavy traffic takes a very long time.

[112] At the time counting stopped, the country had just over 8,000 cases confirmed and 295 deaths (Johns Hopkins, 2023).

not treated with dignity. The echoes of the experiences during the Ebola crisis were strong, particularly in the sense of isolation and the deep feelings of loneliness and loss.

While almost everyone complied as best as they could with the health protocols, a few were deeply resistant.

> *'they said we should use nose mask on your nose then you know, I see people moving with it, but for me, I don't want to lie I* na *(never) use it, I never use it at all.*
>
> ***Ellie: Why?***
>
> *...I feel that I should just continue to live normal life... I believe that only god will kill me. If I can go through Ebola which was difficult, people died and I see that I* na *(never) died, so Covid they say tie your nose, I don't do that... god is my protector, nose mask is not my protector' (59-year-old woman with a physical impairment, Robertsport district)*

This woman, because she had survived Ebola, believed that she was effectively invulnerable to COVID-19, unless it was 'God's will'. Wearing facemasks became compulsory on 21st April 2020, with a maximum fine of 1,500 Liberian dollars (Johnson, 2021). The restriction was enforced by police in Monrovia, with violators being turned back or arrested (Mondaye, 2020). There were also reports of police violently enforcing the rule or soliciting bribes from violators (Johnson, 2021). However, non-compliance was not always active resistance – poverty was also a driver. Locally made facemasks reportedly cost 50 Liberian dollars (around 20p), an expense that, amid competing survival needs, may have been deprioritised.

This section has discussed how people with disabilities complied with the COVID-19 restrictions. The following section will present the fear and anxiety associated with the outbreak and the impact this had on behaviours and actions.

6.2.3. Fear and anxiety

> *' COVID-19 sound [more] dangerous than Ebola. It looks [more] dangerous than Ebola because Covid can pass through air...' (47-year-old man with a hearing impairment, Monrovia)*

When COVID-19 first arrived in Liberia many people were extremely scared. People had seen the news of so many people dying in Europe and the USA and were worried that the same would happen in Liberia. Many of the people with disabilities I spoke to said that they had experienced extreme fear and anxiety, particularly at the beginning of the outbreak. They were often extremely concerned about the transmission pathway of COVID-19; that it was airborne was a deep cause of anxiety.

> *‘they say [COVID-19] here is in the air and as breeze passing, [it] is among the breeze. When you inhale it you finish. So many days I was not coming outside because I say I don’t want to come outside when breeze blowing then I inhale the breeze… I felt bad because that sickness they say you can’t run from it, you can’t hide form it anything you do so I just there praying to God’ (42-year-old woman with a physical impairment, Monrovia)*

As with Ebola, anxiety about COVID-19 caused somatic symptoms.

> *‘because of the worry of Covid, I came down with heavy [blood] pressure… [you are] hearing the thing every day, every day people are dying, is right now and you cannot go out… [I] worry again because I have my daughter in Monrovia… my family members are scattered all over the world and like America people was dying there’ (43-year-old man with a visual impairment, Foya district)*

This man told me that it was not until the restrictions were lifted that he felt like his blood pressure started returning to normal. And for some, the fear of the disease had never left.

> *‘up to now I’m not feeling alright again because when the COVID-19 come and killed the amount of people, maybe the new one it may do more than that… now even when I get fresh cold, I start to get worry, when my head seh (hurt) me I start to get worry. I say it must not be [the] virus’ (57-year-old man with a physical impairment, Sinje district)*

Fear of COVID-19 also had severe indirect health consequences (further discussed in **section 6.4.2**)

'This is the street leaving my community... I find it difficult to help people with disability because during the raining season the road can change to drainage, the whole dyke erodes away. Every year we have to fill in the dyke... During the Covid, people were afraid to clean this road because they thought they could get Covid from the dyke in the road. Because of that the community was dirty and mosquitos were plenty in the community, people came down with malaria, plenty.'

(female caregiver photovoice co-researcher)

Photo 6

The caption beside this co-researcher's image clearly shows the indirect health impacts of COVID-19 anxiety. The image shows the road leaving her community, and fears of contracting COVID-19 caused community members to enact avoidance behaviours meaning that the dyke was not filled in, which led to standing water and a consequent outbreak of malaria.

This section has shown how fear and anxiety related to COVID-19 was widespread. I will now move on to how disbelief and conspiracy affected the behaviours of people with disabilities.

6.2.4. Belief, denial and conspiracy

The COVID-19 'infodemic' was on a global scale (Horton, 2020b; United Nations, 2020). The conspiracy theories promulgated in Liberia are likely to have been at least in-part driven by misinformation emanating from other countries (probably predominantly the USA, given the large Liberian diaspora) and on social media (Obi and Endong, 2021). When COVID-19 reached Liberia, many people, particularly in rural and remote areas, expressed disbelief.

> *'When COVID-19 started we firstly, we overlooked it, when the virus outbreak... We said, what is COVID-19? What kind of COVID-19 and [at first] we said what is the meaning of COVID-19? ...we denied it [at first],*

> *we denied like the Ebola time' (30-year-old man with a physical impairment, Foya district)*

Many of the conspiracy theories that people expressed were similar to those that circulated during the Ebola time. However, a further large part of misinformation was related to the safety or efficacy of the vaccine.

> *'I was afraid [of the hospital] because they will go and inject you, give you injection and that injection you will get that COVID-19 and die' (30-year-old man with a physical impairment, Foya district)*

> *'Like from the early stage we never knew the Covid vaccine that was given, we taught it was harming because most often we used [to] hear that the vaccine that was given it was going to killed more people more than Ebola. So, more people like myself I was little bit afraid of taken Covid vaccine' (47-year-old woman with a physical impairment, Monrovia)*

Low trust in government is likely to have fuelled hesitancy and rumours about the COVID-19 vaccine (Seydou, 2021). This was exacerbated by President George Weah's very public reluctance to be vaccinated (Clayeh, 2021). Many people I spoke to highlighted the importance of very public vaccinations for high-profile individuals to assuage people's fears about the safety of the vaccine. In addition, a lack of familiarity with non-routine vaccines in Liberia may also have contributed to hesitancy, and some have argued that had the Ebola vaccine been more widely distributed it might have been easier for people to accept the COVID-19 vaccine (Skrip *et al.*, 2024).

While most people eventually changed their minds about COVID-19 conspiracies, this was not always the case. For example, one person I spoke to in Monrovia still believes that COVID-19 is a government plot.

> *'I felt that it was another money eating [embezzlement] secret again that [President] George Weah brought to Liberia... Covid, I took Covid as a joke.*
>
> ***Ellie: And did you change your mind?***
>
> *Even up till now my mind has not really been change' (32-year-old man with a visual impairment, Monrovia)*

Finally, in the very last life history interview I conducted the person surprised me with a conspiracy theory about the vaccine that I had never heard in any of the other 29 interviews.

> *'I never take it*
>
> ***Ellie: Why didn't you take it?***
>
> *Some people say when you take it you can get pregnant, so I never take it.' (45-year-old woman with a physical impairment, Robertsport district)*

This section has discussed the conspiracy theories that again proliferated during COVID-19 despite their experience with Ebola. The next theme will present how people with disabilities' experience with Ebola affected their behaviour to COVID-19 and the response itself.

6.3. Ebola gave us expertise

One of the key findings from the interviews was that almost everyone I spoke to felt that because of their experience during Ebola they were equipped to deal with COVID-19. This second theme discusses the ways in which people felt capacitated to cope with the COVID-19 epidemic. This theme comprises three subthemes: 'because of Ebola we know what to do'; 'being proactive and prepping'; and 'changes from Ebola'.

6.3.1. Because of Ebola we knew what to do

> *'**Ellie**: Did you feel like you had knowledge from Ebola?*
>
> *Oh yes!' (28-year-old woman with a neurological impairment, Monrovia)*

When COVID-19 reached Liberia, there was a huge concern that a rapid increase in the number of cases would put enormous strain on the health system (Lokossou *et al.*, 2021), which was ill-equipped to manage significant numbers of severe respiratory illness[113].Modelling of the potential epidemic trajectory was similarly pessimistic as the Ebola forecasting had been (Cabore *et al.*, 2022)[114]. However, these dire predictions did

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[113] For example, at the start of the outbreak there were only 'up to six' ventilators in the whole of Liberia (presumably mostly in Monrovia) and inadequate supplies of PPE (Brown Wilson *et al.*, 2021)

[114] This model predicted that Liberia would have over 600,000 cases by the end of 2022 (Cabore *et al.*, 2022)

not appear to come to pass. There are several reasons why the estimate may have been the case. One is that the cases are artificially low due to a significant lack of testing capacity[115]. Another reason is that Liberia is an extremely youthful country, so the number of people displaying acute symptoms would be low, and some argue that one of the reasons was people's experience of managing Ebola (Impouma *et al.*, 2021).

Almost everyone I spoke to said that they were confident that they had known what to do in the face of the second outbreak. Similar feelings of confidence have also been reported in Sierra Leone and Guinea (Mclean, 2024). This 'Ebola expertise' resulted in people with disabilities enacting protective behaviours immediately based on their knowledge of the Ebola response protocols. While these were not always complete (for example, facemasks were not widely used during the Ebola outbreak in Liberia), people put their faith in the preventative measures, and there was an understanding that their 'Ebola expertise' could be transferred to this new outbreak.

> *'So Covid, from the experience we had from Ebola, Covid even though they were not the same, but the preventives measures were all alike, so we started again with preventives measures' (39-year-old woman with a physical impairment, Monrovia)*

Having the confidence itself was empowering. Often, the people I spoke to expressed pride in their knowledge, and their 'Ebola expertise' translated into agency to act from the start of the outbreak. Many people I spoke to said that they had been unprepared for the Ebola outbreak and that they didn't want to be in the same situation again.

> *'I said the reason why most people died of Ebola, lack of knowledge, really don't have the idea and no Center was here. But for Covid, we were already prepared, yeah. Like when you go on the battlefield you already got bulletproof jacket, you got lot of things so when bullet comes, it can't hit you' (28-year-old woman with a neurological impairment, Monrovia)*

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[115] In 2022, WHO estimated that only 14.2% of COVID-19 infections were being detected in Africa due to low testing capacity and inappropriate testing strategies (WHO Africa, 2022b)

Others also ascribed the country's 'Ebola expertise' as the reason why Liberia was less badly affected by COVID-19 than other countries (further discussed in section 2.4.3 and elsewhere; Skrip *et al.*, 2024).

> *'But for COVID-19 as soon as we gather the information, everybody became concerned and begin to follow all rules mentioned. Yes, so that was the reason that help COVID-19 that [it] didn't kill people as compared to Ebola in Liberia, yes. Because COVID-19 killed people in other countries around the world, but Liberia, no, not too much as compared to Ebola' (30-year-old woman with a physical impairment, Foya district [translated from Kissi])*

This subtheme has discussed how people with disabilities felt confident in dealing with COVID-19 due to the knowledge they had gained from their Ebola experience. I will now move on to some of the ways that this translated into practical action.

6.3.2. Proactive and prepping

> *'Personally, I bought my bucket, put tide soap, with some tide soap for washing hands... soon [as] we heard it, we [bought] our buckets then, even before they said we should buy our buckets, I bought my bucket' (47-year-old man with a physical impairment, Foya district)*

News and information received from abroad gave people with disabilities advanced warning about the potential impending health crisis. Their 'Ebola expertise' gave them some insight about what would be needed for the 'inevitable' arrival of COVID-19, and (when able) many bought food and other supplies proactively.

> *'When the Covid was coming, I observed the Ebola time the way we suffered, I went Monrovia... I go do some [small work], that how I came with few bags of rice I stored it for our eating.' (41-year-old woman with a physical impairment, Voinjama district)*

Through these proactive behaviours, people reported an independence that was less present during the Ebola outbreak. These behaviours are another way in which people's response to the second outbreak was 'flattened' compared to during the Ebola time.

People did not just stockpile food. Based on their prior knowledge, they also (when able) acquired non-food items.

> *'I had one bucket, I have enough drugs for fever, for malaria, for fresh cold, for running stomach, whatsoever you can think about, pains tablets and things. Soon [as] I feel funny like I want to get pain or do something I take in the tablets' (59-year-old woman with a physical impairment, Robertsport district)*

Self-medication is common for 'generic symptoms' (Wilkinson *et al.*, 2020), such those listed by this person. These would also include many of the typical symptoms of COVID-19 and may lead to an inaccurately low confirmed prevalence. As discussed in the previous chapter, and in Kett et al (2021), self-medicating was common practice during Ebola, and this experience guided what and how much medication needed to be stockpiled.

The 'Ebola expertise' also meant that people knew what was needed and what was missing. In cases where individuals and communities did not receive these supplies, out of necessity they had to either procure them or make their own.

> *'... in our house we were not having bucket, so we create bucket for ourselves, we create tide soap, chlora on our own' (42-year-old woman with a physical impairment, Monrovia)*
>
> *'in the village we buy our own bucket, all these things we buy our own but one NGO help us with two buckets... they brought chlora, they brought small soap and something like that they leave it with us, but the balance ones we ourselves fight for it to get it' (51-year-old man with diabetes and a physical impairment, Sinje district)*

This community leader raises an important point: being proactive is not an easy task in situations of deep financial insecurity. The supplies that this NGO brought were insufficient, and the village had to 'fight' to get more. People who did not have enough money were stuck inside with no food or had to go without sufficient PPE, both of which are potentially life-threatening.

'Ebola expertise' also extended to government. Research has shown that countries with prior experience with widespread epidemics have more timely policy responses, irrespective of when the epidemic took place (Tsuei, 2020). This was the case in Liberia. Preparedness plans were put in place prior to COVID-19 reaching the country, and in January 2020 a 'Special Presidential Advisory Committee on Coronavirus' was established to oversee COVID-19 preparedness and response (Brown Wilson *et al.*, 2021; Sanny and Bloh, 2021). This committee included many of the same people who had led the Ebola response (Maxmen, 2020). In February 2020, the government established a 'Special Presidential Advisory Committee' (UNOHRLLS, 2020), formed as part of the COVID-19 Response Plan, which was a multi-sectoral strategy to tackle the (at that point potential) outbreak.

This section has discussed how 'Ebola expertise' translated into preparatory action for both people with disabilities and the state. The following section will explore other changes that occurred between the two outbreaks.

6.3.3. Changes from Ebola

After the end of Ebola it was recognised that Liberia had been unprepared for such a devastating outbreak (Republic of Liberia, 2015a). To attempt to address weaknesses in public health infrastructure, the National Public Health Institute of Liberia (NPHIL) was established by an Act of government (Republic of Liberia, 2016a) and was later to play a key role in the government response to COVID-19. NPHIL's mandate is in part concerned with surveillance, prevention and response to disease outbreaks. To that end, NPHIL was where the COVID-19 incident management system (IMS) in the country was based, but in an interview, a Director at NPHIL told me that they were challenged by insufficient funding and a lack of space from which to work.

Liberia also instituted the 'Health Workforce Program Strategy 2015-2021' (Republic of Liberia, 2014). This strategy aimed to build on lessons learned from the response to develop a resilient and responsive health system and was intended to complement the 'Investment Plan for Building a Resilient Health System' (Republic of Liberia, 2015a). Some have argued that the comprehensive infectious disease training that physicians received (which was not guaranteed before the Ebola outbreak), enabled health facilities to quickly implement stringent IPC protocols to address COVID-19 (Dahn *et al.*, 2021)[116]. However, like so many health system strengthening initiatives, challenges to coordination of multiple donor streams with conflicting priorities (for example,

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[116] Professor Bernice Dahn is the former Liberian Minister of Health, so this paper is by no means impartial, but it does potentially offer a unique 'insider' account.

technical assistance over much needed physical infrastructure), as well as short-term funding lifecycles, negatively affected the overall success of the Strategy (Dahn *et al.*, 2021).

Several interviewees noted shifts in power dynamics between the Ebola and COVID-19 responses. While the Ebola response was largely donor- and UNMIL-driven, the COVID-19 response was more government-led. This shift likely stemmed from several factors: UNMIL had fully withdrawn by March 2018 (UNMIL, 2018b), and donor support was significantly lower, both because the pandemic severely affected ‘global North’ countries and because funding was spread across many more nations, unlike Ebola, which was largely contained to three. The disparity is stark: in 2015, humanitarian aid for Ebola in Liberia totalled $241 million, whereas in 2020, it received just $12.7 million for COVID-19 (OCHA, 2024).

There was some increased visibility for the disability community during COVID-19. For example, NUOD had the opportunity early in the outbreak to bring several OPDs together at City Hall to disseminate infection prevention information. During COVID-19, there was some visible improvement in government and NGOs providing food and non-food items (such as buckets and chlorine) to NUOD[117] in Monrovia for distribution to its member OPDs, which are nationwide. This was due in part to international disability NGOs, such as AIFO, putting more focus on food and item distribution than they had done during the Ebola time.

Improvements in visibility were not universal and sometimes required substantial effort. As during the Ebola outbreak, the NUOD county coordinator for Grand Cape Mount attended district IMS meetings uninvited. While she eventually gave reports about the disability community, she initially was just the recipient of information. These meetings consisted of district health teams and governance structures but also included civil society organisations. Her attendance at these meetings would have increased the visibility of disability, particularly when she was able to report on their situation, but the

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[117] the national umbrella OPD

extent to which this visibility transformed into actions to support people with disabilities is uncertain.

Development organisations also learned from Ebola. Many people talked about improved agility to pivot donor funding to their COVID-19 response, meaning that they could move much more quickly to serve their target populations more effectively. However, a representative from AIFO told me that funders left during the COVID-19 outbreak and some never returned. As AIFO is one of the key NGOs working with the disability community in Liberia this has potential repercussions for the long-term support for people with disabilities.

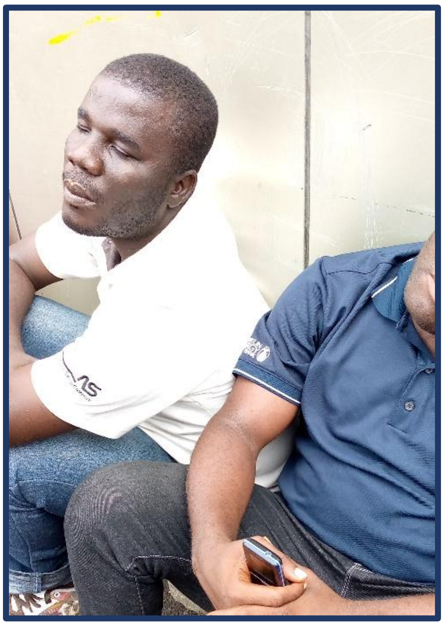

Photo 7

The curfew meant highly restricted movement. Our [NUOD] members are sitting home, what can we do for them to eat? We decided on an SOS appeal on the radio. People came to help...

We went to individual houses to give a bag of rice, soap bucket sanitizer and lectured [awareness] a bit. They said that before they had the bucket they didn't know anything about covid. Provided bucket and food so that they could stay home and stay safe until the lockdown lifted.

(male photovoice co-researcher with a visual impairment)

This co-researcher is 'reenacting' deciding how NUOD could support people with disabilities during the curfew. It is interesting that he suggests that the membership apparently had little understanding of COVID-19 before they received supplies from NUOD. This contrasts markedly with my conversations with people with disabilities as well as with other research in Liberia, which found that people were knowledgeable about symptoms, transmission and prevention even from the start of the outbreak

(Brown Wilson *et al.*, 2021). The authors suggest that 'Ebola expertise' may have contributed to understanding the new epidemic.

Rural and remote areas left behind

> *'Montserrado is not Liberia' (Advisor, Kolahun OPD)*

Many people with disabilities in Monrovia told me that they found getting food during COVID-19 much less difficult than they had during Ebola. For some the food supply was almost plentiful. This was very much not the case for many people in rural and remote areas, some of whom told me that finding food was even more challenging than during the Ebola outbreak, particularly during the lockdown/curfews phase of the COVID-19 response. However, there wasn't always a large observable negative change for people in rural and remote areas – their experience in both outbreaks was extremely challenging. It was instead that improvements to the response in Monrovia meant that it left rural and remote areas behind.

NUOD inadvertently contributed to widening the already large urban-rural inequality during COVID-19. When the organisation received food or other items, these were often only distributed within Monrovia, leaving their rural and remote members in extreme food insecurity. This was due to the limited number of items but also to capacity issues around distribution and the terrible and often impassible roads. However, this only increased the 'gap' between Monrovia and rural and remote areas. Many people I spoke to felt abandoned by NGOs and international organisations. As a member of a small rural OPD near Foya said, 'we are on our own here'.

People with disabilities and OPD representatives I spoke to in rural and remote areas felt abandoned or de-prioritised. The NUOD county coordinator for Lofa told me that they had not received anything from NCD or NUOD in Monrovia, despite repeated promises. Nonetheless, they distributed what protective materials they could, and Plan Liberia in Voinjama supplied a small amount. When NUOD representatives eventually came to Lofa, they only conducted awareness activities and did not provide the much-needed materials or financial support. This is reflected in the opinion of the Executive Director of a Foya-based OPD that training has no impact, and they have 'talent but no money' and were 'begging for empowerment' (which would require money). She also told me that her organisation had received a grand total of one bucket during the COVID-19 epidemic.

6.4. Health and disability during COVID-19

The next major theme that I will discuss focuses on health and disability. This theme comprises two subthemes: ‘disability and (dis)ablelism’ and ‘attitudes towards ‘formal’ health’. This latter theme is further split into two subthemes: ‘local vs “Western” treatments’ and ‘vaccines’.

6.4.1. Disability and (dis)ableism

Health economists have estimated that ‘COVID-19-induced disability’ may account for 30% of the global COVID-19 health burden (Briggs and Vassall, 2021). The authors go on to argue that different contexts can lead to wildly different health outcomes, and that in low- and middle-income countries with more youthful populations the health burden caused by COVID-19 is likely to fall on people under the age of 60. While the overall burden of COVID-19 in Liberia appears low, it is likely be masked by suppressed health-seeking behaviours and people not presenting at hospitals for treatment (Shapira *et al.*, 2021; Fejfar *et al.*, 2023), as well as acquired impairments not necessarily being attributed to COVID-19. A recent research project found that from a sample of Liberians who had recovered from symptomatic COVID-19, half (50.2%) experienced one or more symptoms associated with ‘long-covid’ three to six-months post-recovery, and three quarters of these (77.6%) reported that this had a ‘somewhat’ or ‘quite a big’ impact on their daily lives (Gwaikolo *et al.*, 2024)[118]. This is an interesting finding. While it might be predicted that 80% of people in the sample who were hospitalised because of COVID-19 went on to display post-illness symptoms, even for people who were not admitted to hospital, over a third (37%) had at least one persistent symptom.

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[118] The authors acknowledge that care should be taken interpreting these results as they are not really generalisable to the whole of Liberia. The sampling frame is taken from a Ministry of Health listing of confirmed cases, the majority of which were concentrated in Montserrado (capital county). While this is the most populous area of Liberia, it is also one of the few locations with comparatively easier access to PCR testing (the study was undertaken before rapid antigen testing became available).

People with disabilities continued to encounter discriminatory attitudes when accessing health services.

> *'she[119] find it difficult, she said sometimes they discriminate her because of her disability; they prioritize the able people first' (30-year-old woman with a physical impairment, Foya district [translated from Kissi])*

This is in line with previous research in Liberia (pre-pandemic) which found that people with disabilities were often on the receiving end of poor attitudes and discrimination when accessing healthcare (Carew *et al.*, 2019; Kett *et al.*, forthcoming). It is disappointing that the data for the pre-pandemic research project were collected in 2016, and it appears that little has changed since.

While OPDs were regarded as important routes through which information could be disseminated to people with disabilities, this was often the extent of their role within the response. Interviewees from NGOs and government departments often had little direct engagement with OPDs, making their perspectives more theoretical than practical.

Where interviewees from NGOs reported working with people with disabilities and OPDs the mode of transmission continued to be predominantly top-down, with less in the way of bidirectional knowledge-sharing. In a research project undertaken before the pandemic, people with disabilities reported being less included in community life (Carew *et al.*, 2019). This continued during the COVID-19 outbreak, where many people told me that they felt excluded from the mainstream response and sometimes from community life itself. The disability community was still very much siloed, and as a result, they only looked to their own people and organisations for support.

> *'in Liberia people always put people with disabilities aside. So, in the disable community we always feel like a different country, so we always do things in our community, like [we are] a different community even though we are in Liberia... in the [general] community people don't give a person with disability responsibilities' (woman with a neurological impairment, Monrovia)*

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[119] The translator is speaking English referring to the woman in the third person here while relaying what she is saying.

Response activities were not always accessible to people with disabilities in both outbreaks. For example, OPDs were not consulted in deciding the location of food relief trucks and vaccine distribution sites and on multiple occasions they were not accessible. This meant that people with disabilities were often not served by the humanitarian response as they were unable to access the support that non-disabled people benefitted from. In Foya, governance structures (such as the district commissioner and paramount chief) said that they were not able to provide supplies for people with disabilities during the COVID-19 outbreak. While this was usually couched as a cost issue, the ableism in the response is clear – in the allocation of very scarce resources people with disabilities were still de-prioritised. This kind of discrimination goes directly against the principles of the UNCRPD, which Liberia has both signed and ratified (United Nations, 2006). It also violates the Constitution, which, while not making explicit reference to disability, grants all citizens the right to equality and non-discrimination (Republic of Liberia, 1986).

Some development actors did report an increased focus on disability during COVID-19. Like many others, the Liberian Red Cross Society (LRCS) also stated that their response ‘reached everyone’ but backed this up by highlighting deliberate recruitment of people with disabilities in awareness activities and included questions on disabilities in their needs assessment surveys. This was a change from Ebola likely brought about by the establishment of a disability focal point within LRCS.

One NPHIL Director told me that, as a rule, they do not collect disability-disaggregated data but, as the programmes covered the whole country, they did not exclude anyone. However, without collecting this kind of data it is not possible for organisations to know conclusively that their response actually did ‘reach everyone’, a presumption that was repeatedly disproven in my conversations with people with disabilities, particularly in the rural and remote areas.

Both people with disabilities and caregivers who were part of the photovoice project described the severe difficulties with service provision during the curfews. In discussion sessions people talked about how inconsiderate the national response was for caregivers, with no support or accounting for the additional time and difficulties they experienced trying to fit all their responsibilities into the time before the curfew began.

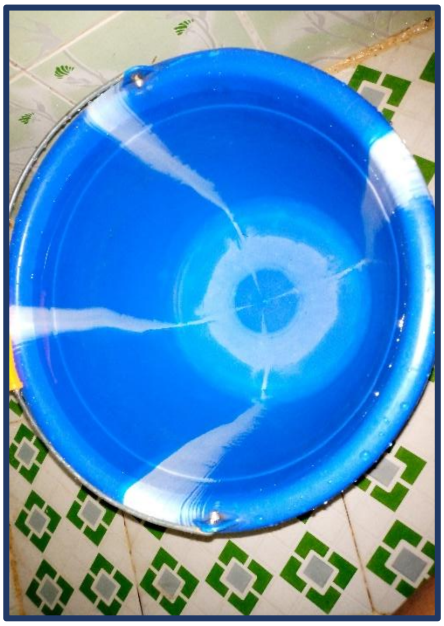

Photo 8

Our service providers are sometimes our children. During the Covid time, they work harder to go out to find food, to go out and look for water for us, so they were exposed to the Covid virus. The process of fetching water by service providers took more time because of social distancing at the pump and long line caused delay of our movements… My service provider was often not around during Covid. I had to take a bucket of hot water myself to the bathroom and it led me to have an accident. I fell with a bucket of hot water and was badly burned.

(female photovoice co-researcher with a physical impairment)

This simple but powerful image is used to highlight a range of impacts of COVID-19 that this co-researcher experienced due to the absence of her service providers during the curfew, which resulted in her being badly burned. In the discussion session about this image, she also shared a photo of herself covered in bandages taken shortly after her accident.

Others spoke about the challenge of movement as a person with a disability during the curfew, and the heightened demand for transport leaving the person with a disability at a disadvantage.

> *'just imagine people with disability and someone who is not disable, you two are fighting over a vehicle. The person who is not disable will definitely get in before you. So, it was very much challenging for me yeah. So normally for me what I used to do, I used to ride bike, motorbike and to do that now the bike, the price was very, very high… what will you do? You want to come home. You force to pay the 500LD because you want to come home on time, you don't want anybody beating you.' (28-year-old woman with a neurological impairment, Monrovia)*

She also highlighted the opportunistic inflation of prices during this time, a point which was also raised by photovoice co-researchers in discussions. As living with a disability in Liberia has been associated with a greater risk of living in multidimensional poverty (LISGIS, 2017), this is an unfair additional challenge.

However, there were examples of people with disabilities being prioritised, such as this OPD leader.

> *'people from the states send him [an acquaintance] money to buy some things to identify people with disability so since he knew me, he brought 10 bags, with buckets and some soap, chlorax and soap for my institution members' (52-year-old man with visual and physical impairments, Monrovia)*
>
> *'goodwill ambassadors came in with—they brought food, they supply food. One thing even though it came after the hour [late], but the stimulus package[120], it came too... during the Covid I must admit Liberians did well for disable in this country that on their part they did extremely well.' (32-year-old man with a visual impairment, Monrovia)*

This individual is a prominent member in the national disability community and, as such, speaks from a position of privilege. It is very likely that because he was a prominent member it was easier for him to access food and non-food items. The presumption that all Liberians with disabilities 'did extremely well' during the outbreak is demonstrably false. As has been presented extensively in this chapter, many people with disabilities, particularly in the rural and remote areas found COVID-19 extremely challenging.

This section has explored how disability shaped participants' experiences of the COVID-19 outbreak, particularly through social responses and structural exclusion. I now turn to examine how attitudes towards the health system influenced those experiences.

6.4.2. Attitudes towards 'formal' health

Despite Liberia's experience with Ebola and the increased focus on public health through the establishment of NPHIL, findings from a WHO Africa preparedness survey found that the country had allocated insufficient resources to address health emergencies such as the COVID-19 outbreak (Onyekuru *et al.*, 2023). Liberia did enjoy substantial post-Ebola investment (UN Liberia, 2020); however, in several interviews with a range of types of actor, people often told me that while many lessons had been learned from the Ebola experience, including the need to 'be prepared' for the next

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[120] This person was the only one I spoke to who mentioned the 'stimulus package'.

outbreak, this has been stymied by a lack of budgetary allocation or ring-fenced funding for preparedness or surveillance[121]. In the first months of the COVID-19 epidemic, Liberia had a very high COVID-19 case fatality rate (6.1%) compared with other Ebola-exposed countries (3.2% Sierra Leone, 0.6% Guinea; Impouma *et al.*, 2021). However, this may be less due to preparedness and more to do with Liberia (and Sierra Leone) instituting compulsory testing on all dead bodies. It is not clear whether all deaths of people who tested positive for the disease were attributed to COVID-19, which would likely substantially increase the rate. In addition, Liberia had the lowest testing rate which may have artificially inflated the fatality rate (45 tests per 10,000 population compared with 52 and 93 in Sierra Leone and Guinea respectively).

Attitudes to the formal health system during the COVID-19 epidemic were polarised. Some people with disabilities told me that they were not afraid of the idea of going to hospital during the outbreak at all, whereas others said that they were still extremely anxious. This was related in part to a legacy fear of Ebola, where hospitals were considered sites of infection or 'kidnap' (Shultz *et al.*, 2016; Mclean, 2024).

> *'I was not afraid [of the hospital], that time – particular time my stomach was hurting so I was force to go, so I was not afraid... if [I caught] Covid then they could treat me. That what I was thinking about.' (38-year-old man with a physical impairment, Foya district)*
>
> *'Covid, Ebola, everybody scare to carry their people to hospital. We say this is the same thing. Ebola came our people went to the hospital and they not come back, so the same when this [COVID-19] people go there they will not come back, so we keep to ourselves' (51-year-old man with diabetes and a physical impairment, Sinje district)*

Many of the health professionals I spoke to told me that demand for health services dropped dramatically during the 'hot' parts of the COVID-19 epidemic. This opinion is corroborated by an analysis of routine health data in 14 of Liberia's 15 counties, which found that in May 2020, outpatient attendance decreased by almost a third (32%;

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[121] This includes implementation of the 'integrated diseases surveillance and response' (IDSR). The IDSR guidelines were updated in 2021, and identify people with disabilities as a hard-to-reach population in risk communication (Ministry of Health and NPHIL, 2021). However, for the most part, the guidelines only mention disability in terms of its prevention.

Babalola *et al.*, 2022). This was due to fear of hospitals and health facilities during this time (McCollum *et al.*, 2022) and lack of trust in the health system (Alhassan *et al.*, 2023), but also lack of funds for supplies and paying health workers (Maxmen, 2020). Trust in the health system was hampered by the reallocation of health workers and resources to COVID-19 response activities, diminishing the provision of essential health services (UN Liberia, 2020; Alhassan *et al.*, 2023). Some believe that the lack of supplies for the health system resulted in more deaths from other factors (such as malaria or during childbirth) than due to COVID-19, a repeat from the Ebola epidemic (Maxmen, 2020).

Also worryingly, demand for vaccines (including routine vaccines for children) plummeted due to fears about the COVID-19 vaccine (Babalola *et al.*, 2022; Alhassan *et al.*, 2023). The Grand Cape Mount Chief Health Officer (CHO) told me that she was deeply concerned about this because catching up on the missed schedule was challenging, and without vaccination these illnesses have the potential to lead to disability or even death. In an interview in Sinje, a hospital's Officer in Charge reported that there had already been a measles outbreak which was caused or exacerbated by so many missed vaccinations affecting 'herd immunity'. The Lofa CHO said that at the start of the outbreak, resistance to the vaccine was so extreme that they had to temporarily suspend childhood vaccination programmes until more awareness had been given to communities.

Rather than a new photo, the image that this co-researcher wanted to share was taken before the project, but she felt that it represented her opinions about accessing health services. Her caption shows the dual fear that many experienced: that she was afraid her malaria would be misdiagnosed as COVID-19; or that she risked contracting the virus at the clinic. This co-researcher also quite clearly makes the connection between poverty, hygiene and disease, and supressed health seeking behaviour.

Photo 9

This is the clinic. I got sick with diarrhoea and vomiting because my living condition was not good. I encounter flies, but there was no money to buy fly spray, so the flies sit on my food and made me sick. When I went to the clinic, before the doctor put hand on me, they told me to pay finance. At that time, I was not having money...

In the Covid time I was sick with malaria, but I never showed at the clinic because I was afraid of the virus. And if I showed up people were going to say that I had covid because malaria has the same symptoms. I hide myself and called my doctor who treated me in my house until I get well. I even hide my children, who also got sick. I beg people to give me money to treat my children.

(female photovoice co-researcher with a physical impairment)

The international community, which had poured money into West Africa during the Ebola crisis, was nowhere to be seen during COVID-19. Because they were tackling the outbreak 'at home' (Richards, 2020a) and the global incidence of COVID-19 (compared to Ebola, which was only present in three countries), international organisations provided much less in the way of financial support, leading to a critical deficit in health supplies. This shortage was acknowledged by one person with disabilities I spoke to, although he attributed it to a different cause.

> *'The hospital was not really friendly because they themselves were being challenged. Things that was needed to treat people was lacking and what is true some partners were bringing some things but... then you find out most of the things brought to the hospital were taken [by doctors] to private clinics' (52-year-old man with visual and physical impairments, Monrovia)*

Whilst there may be some truth to his argument, this also shows the diminished trust that people with disabilities had in the health system during COVID-19 (Mclean, 2024).

‘local’ vs ‘Western’ treatments

> *‘sometime we used lime. The lime that used, we put it on our body. Anytime we going somewhere we have our lime in our pocket, sometime we rub it on our body’ (51-year-old man with diabetes and a physical impairment, Sinje district)*

In the absence of accessible health services or universal health coverage, people resort to informal or self-treatment of illness and minor ailments, including COVID-19 (Wilkinson *et al.*, 2020). Because COVID-19 was a novel virus with which Liberians did not have prior experience, treatments were sometimes taken from misinformation on the internet. Belief in non-biomedical prevention and treatment methods was widespread. An Ipsos survey conducted in Monrovia in the early months of the epidemic found that a majority (62%) believed at least one piece of misinformation about prevention and treatment of the virus (Ipsos, 2020). Other research found that a third of survey respondents believed that they could lower the risk of contracting COVID-19 by ‘eating ginger or garlic’ (Brown Wilson *et al.*, 2021).

People with disabilities I spoke to in all areas put faith in ‘non-official’ treatment.

> *‘I try my best by preventing myself from COVID-19 as we were told that ginger and lime was some of the prevention of COVID-19. So I used to buy the ginger grab it, squeeze it put enough of lime serve my children, buy the burning ointment [Deep Heat], always have grease with burning ointment in cold jacket for heat because we were told that COVID-19 can hurt people through cold so that awareness was already told’ (47-year-old woman with a physical impairment, Monrovia)*

The ‘awareness’ that this woman[122] identified – that the COVID-19 virus could be killed by covering yourself with quilts or coats to increase body heat – is a rumour that proliferated online at the start of the pandemic (WHO, 2020b). As with Ebola, people displayed ‘flexible’ approaches to health, with local and biomedical beliefs being held simultaneously. This person went on to tell me that she believes that COVID-19 was finished because of the comprehensive vaccination programme.

Others put their whole belief in ‘Western’ medicine and the formal health system.

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[122] Worryingly, this is the same woman who talked about ‘tips’ from indeterminant sources ‘going viral’

> *'For me I believe even though am not a medical practitioner, but I believe that Covid is a chronic infection or cold, so I think that for me personally I does whether doctor tell me… when am experiencing that heaviness when am breathing I can take my antibiotics… I don't have to get that chronic cough, I can just go and take my antibiotics for one week and stop it.' (39-year-old woman with a physical impairment, Monrovia)*

While this person is clearly educated and has medical understanding to a degree, it is concerning that she uses antibiotics for viruses. Overuse of antibiotics is one of the leading causes of increased resistance, which by some counts is one of the leading causes of death in Liberia (IHME/GRAM, 2023).

This section has discussed conceptualisations of 'local' and 'Western' treatments for COVID-19. One of the most high-profile examples of 'Western' biomedical interventions is of course the COVID-19 vaccine, which I will move on to now.

Vaccines[123]

The first COVID-19 vaccines arrived in Liberia in March 2021, three months after vaccines were first made available globally in December 2020 (UNICEF, 2021b). The vaccines were procured through the COVAX initiative, which aimed to redress inequities in global distribution (Gavi, 2020). By August, Liberia had received almost half a million doses[124] (UNICEF, 2021a). However, very few people in Liberia trusted the government to ensure that the COVID-19 vaccine was safe (Afrobarometer, 2021; Seydou, 2021). A research study conducted in Liberia found that vaccine hesitancy was most common in people living in urban areas and in people older than 55 (Sanvee-Blebo *et al.*, 2024). The most reported cause for hesitancy was the lack of sufficient information (84%) followed by concerns about the vaccine's safety (12%). Only 4% stated that conspiracy theories were the cause of their hesitancy to take the vaccine[125].

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[123] In 2021, the 'big three' vaccine companies (Pfizer, BioNTech and Moderna) made over $3.5 million profit *every hour* (Oxfam, 2021).

[124] A combination of AstraZeneca and Johnson and Johnson.

[125] It is not clear from the survey how the variable 'conspiracy' was constructed; the authors report that this proportion was ascertained through grouping 'common themes' but no more information is given including what kinds of conspiracies were believed.

Most people with disabilities I spoke to said that they had taken the vaccine. This, according to their narrative, was unusual, that conspiracies about the vaccine were rife, and most people did not accept it. This is at odds with official statistics for vaccine administration, which showed that the majority (and in some counties the vast majority) of people in Liberia had taken the vaccine (**Figure 11**; Africa CDC, 2023), which may show how the narratives around formal health differ from the reality of engagement with healthcare.

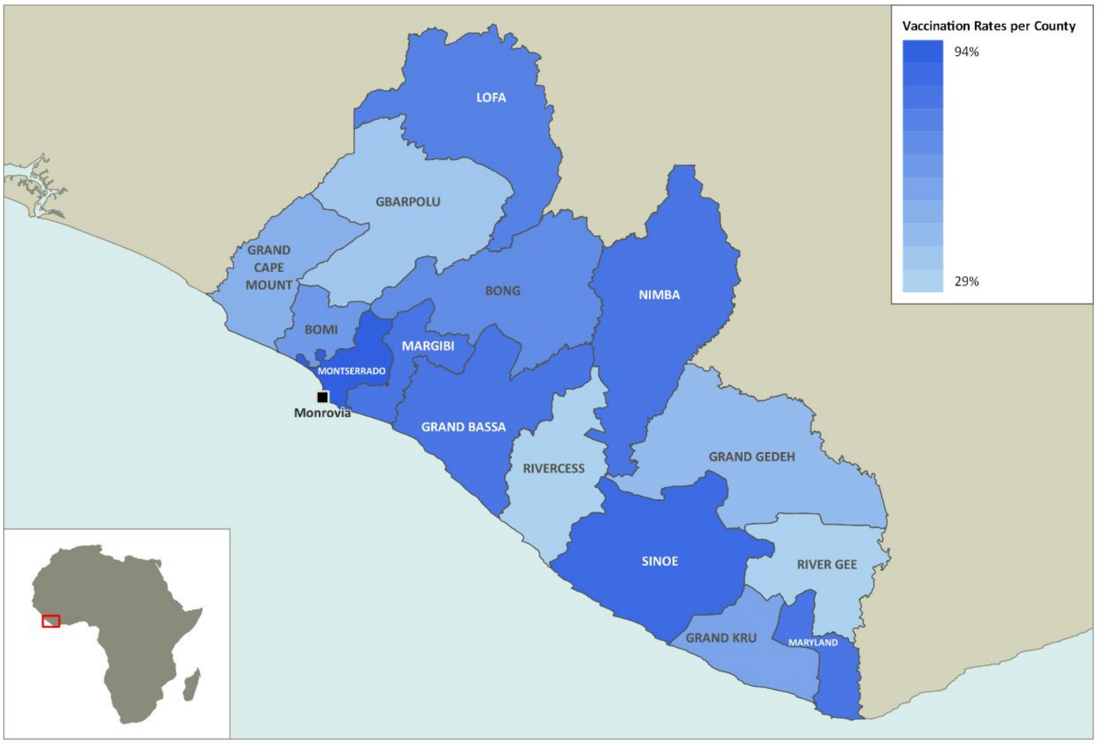

Figure 11 COVID-19 vaccine rates by county

Co-researchers in the photovoice project also talked about vaccines, including this person who worked as a health worker administering COVID-19 vaccinations to the general public.

Photo 10

I was informed that if I take the vaccine, it will be a good thing for me as a person with disability. I used the opportunity given to me to keep I and my family on the safe side of life, even though there were many challenges we faced as person with disability, but we took the courage believing that covid can be prevented by us also.

...for people with disabilities, the reaction to both the virus and the vaccine, many people had fear or trauma. There are people who refused to accept the vaccine at all... This problem exists because of fear and awareness was not made properly... Awareness should convince people beyond doubt of vaccine's safety. Not forcing but convincing

(male photovoice co-researcher with a physical impairment)

While the co-researcher chose to share this very effective photo, during the discussion session he disclosed that he had not actually taken the vaccine (despite the strident but apparently fictional caption). When he disclosed his vaccine status, he was angrily criticised by the other members of the group, all of whom had taken the vaccine and I had to intervene in a heated 'discussion'. The participant was aware of this hypocrisy, but he said that he was worried about the vaccine's safety, which is a common concern both in Liberia (Sanvee-Blebo *et al.*, 2024) and internationally (Sallam, 2021; Lazarus *et al.*, 2022; Wiysonge *et al.*, 2022). After discussing this with the co-researcher further, he told me that it was specifically the Astra-Zenica vaccine that he was concerned about. He did not doubt the vaccines efficacy, but he cited all the 'bad reactions' that people have (likely to be the extremely common side effects people felt the following day). He planned to take the Johnson & Johnson vaccine but hadn't as yet. Given that the co-researcher clearly has access to vaccines, this may suggest the (low) importance he places on personally being vaccinated.

Despite the apparent duplicity of his caption, it does accurately describe the feeling of control that the decision to take the vaccine provided, which I found in several of my conversations with other people with disabilities.

> *'I take my vaccine I, get my certificate in there for my vaccine. Everybody that in this village we went we took our vaccine because they told us that we should take it.' (51-year-old man with diabetes and a physical impairment, Sinje district)*

This community leader ensured that all his community members took the vaccine. He was one of the most hard-line protocol-enforcers of all the people with disabilities I spoke to, deeply believing the Western medicine paradigm. He was not alone in this, however.

> *'those who make the medicine, they tested it. If they could not know that this medicine was good, they could have not bring it to us' (38-year-old man with a physical impairment, Foya district)*

Yet, even when people with disabilities were willing to take the vaccine it was sometimes a challenge. Particularly in the rural and remote areas people said that they had missed out on COVID-19 vaccine drives because they couldn't get to the location or that it was not accessible. Others were still afraid of getting into packed taxis with strangers for fear of catching the disease.

> *No, I don't know that [they] were giving vaccine and again the movement was not like before now. Besides, I didn't want to get in [a] car, I was afraid (41-year-old woman with a physical impairment, Voinjama district)*

Some people took the vaccine for non-health reasons. In Liberia, like many places, in order to be able to cross borders you have your 'vaccine card' to evidence your status.

> *'I actually took the vaccine to facilitate easy travel because [if[I have opportunity that can spark up to travel I don't want to be embarrassed… So, in spite of all what was said about the Covid vaccine I said inasmuch as other have taken it, I will take it so that I will be able to travel freely (68-year-old man with a psychosocial impairment, Monrovia)*

While almost everyone I spoke to had taken the vaccine this was by no means universal. One person saw the side-effects her father experienced and refused the vaccine. She recognises that this has stymied her potential.

> *I didn't take it because I was afraid, because of the way I saw my father was sick at that time, and for me I don't like sickness, I am scared of sickness so I did not take it. But I am planning to take it because they said that, before you travel out of Liberia, you have to take the Covid vaccine and get your paper before you travel so I have to take it, I have to take it. (28-year-old woman with a neurological impairment, Monrovia)*

This theme has discussed how people with disabilities conceptualised their own health and disability during the COVID-19 outbreak. My final theme is a grouping of opinions of people with disabilities and the somewhat inevitable comparisons they made between COVID-19 and Ebola.

6.5. Opinions and comparisons

People with disabilities I spoke to were very opinionated about a range of topics during our conversations, and these opinions have been grouped into four sub-themes: 'not again… it never ends', 'comparisons with Ebola', 'other places had it worse', and 'is COVID-19 finished?'. While many of the opinions emerged organically, people were also encouraged to reflect on how they believed COVID-19 compared to Ebola.

6.5.1. Not again… it never ends

After Ebola was declared over in May 2015, there was very little time for the country to recover. Several of the key informants I interviewed felt that the economic impact of Ebola would take years to fully recover from, and there wasn't sufficient time before COVID-19 arrived (Aggarwal *et al.*, 2022). This is crudely corroborated by data that show that from the start of Ebola and in the interim years before COVID-19 Liberia's per capita GDP shrank by 14% (Robinson, 2024). Others felt that Ebola showed how much the health system 'was exposed' to the threat of damaging epidemics, and that the health system wasn't sufficiently strengthened in the three years post-Ebola. However, while in the minority, a few argued that Liberia had 'bounced back' and made a full recovery before COVID-19 hit. This was likely a generalisation based on their own personal experience.

There was very much a feeling of 'not again', such a short time since Ebola was finished.

> *'I feel bad because that time, these two sicknesses are life threatening diseases, I feel very bad, I said wow another one again' (43-year-old man with a visual impairment, Foya district)*

> *‘They say another sickness they called it Coronavirus, so I started think again because the way people talking they say it more than Ebola then I say God Ebola came and killed people then another sickness coming again’ (42-year-old woman with a physical impairment, Monrovia)*

There was a definite sense of repetition in many interviews. People with disabilities who had experienced the civil wars in particular said that Liberia’s difficulties were relentless.

> *‘the way that I feel, three things or four things happen to us in Liberia. First thing it was war, the war came. We suffered in this particular war, we didn’t feel fine until the war finished when we were supposed to be happy now... then Ebola came, it carry us back again because our people died in many. After Ebola, we make a change, again Covid came in’ (51-year-old man with diabetes and a physical impairment, Sinje district)*
>
> *‘the war that we coming from, that the same thing here again’ (58-year-old man with a physical impairment, Sinje district)*

The fear caused by two successive epidemics left some fearful of (what they believe is) the inevitable next devastating disease outbreak.

> *‘COVID-19 come and killed the amount of people, maybe the new one it may do more than that. So I start to worry about myself and my people, I don’t feel good (57-year-old man with a physical impairment, Sinje district)*

That there were less than five years between the end of one outbreak logically led people to compare the two diseases. This is what I will turn to next.

6.5.2. Comparisons with Ebola

Understandably, people with disabilities I spoke with often made comparisons between the COVID-19 pandemic and the Ebola outbreak[126]. Skrip and colleagues (2024) suggest that comparisons between the Ebola and COVID-19 outbreaks were made in terms of perceived intensity of the disease, preparedness, and individual proximity to Ebola influencing behaviours. I have discussed the first two of these extensively above. However, interestingly I found less behaviour being influenced by Ebola proximity.

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[126] The comparison almost always emerged naturally, and I rarely had to encourage people.

Rather, almost everyone reported following the rules, whether they had close encounters with Ebola or not (section **0**).

Understandably, many people I spoke with felt that COVID-19 was not as bad as Ebola.

> *'the challenges were almost like Ebola but Ebola was little higher [worse] than COVID-19 in Liberia but during COVID-19 at least sometime we used to [go] around to get food' (47-year-old woman with a physical impairment, Monrovia)*

This was for a range of reasons, including that symptoms were perceived as less destructive, or low numbers of cases (compared to Ebola and to other countries). In addition, some people with disabilities' anxiety was tempered by their 'Ebola expertise'.

> *'So, from our experienced with Ebola, we started putting thing in place to avoid the spread of the virus country-wide, so I was not that afraid of the Covid as I was afraid with the Ebola virus.' (28-year-old woman with a neurological impairment, Monrovia)*

However, one person felt that COVID-19 was just as bad, if not worse than, Ebola.

> *'we come to COVID-19, you see Covid and Ebola, Ebola little bit better than Covid.*
>
> ***Ellie: Why?***
>
> *...in Liberia [Ebola] killed plenty people, it went to Guinea and Sierra Leone but it went to Nigeria but it was just like small small. In Liberia yes it killed many people but Covid, it affects the whole world... what make [me] say Ebola is little bit better because Ebola only sit in certain countries but Covid in America it killed so many thousands of people, in China, in Russia, everywhere' (51-year-old man with diabetes and a physical impairment, Sinje district)*

This person took a wider focus than many people with disabilities I spoke to. Most people's responses were shaped by their own personal experience of the disease and restrictions. Some spoke about the national impact, but this man was the only person who had a global perspective when considering the severity of the two outbreaks.

The comparisons that people with disabilities made sometimes organically flowed into their opinions about the impact of COVID-19 in other places, which is what I will turn to now.

6.5.3. Other places had it worse

Many people with disabilities I spoke to said that COVID-19 in Liberia wasn't bad compared with other countries. A lot of people got news from friends and relatives in America, or through international media outlets such as the BBC and CNN.

> *'my brothers go on air, they will see on the internet, they will see dead bodies. They will say brother come and see, when you see the numbers of human beings that died in China, these Chinese and also in Europe.' (43-year-old man with a visual impairment, Foya district)*

Some felt that COVID-19 was a 'white person's' disease, unlike Ebola which mainly affected black people.

> *'Ok, to our side the black, we experience the Ebola many blacks died and it got through our system, our resistant and the black people die and COVID-19 to the world – sorry – the white people die more than we the black people, especially Liberia but many people die with it.' (30-year-old man with a physical impairment, Foya district)*
>
> *'It was through the phone we saw it in one country where white people was dying and they were discussing about the sickness that is bad more than Ebola and it quick to transfer and then they show us how it can transfer and what is the preventive method for it and they show us all and we saw through the phone.' (33-year-old man with a physical impairment, Foya district)*

This response highlights the crucial role of media in shaping public understanding of COVID-19. During the Ebola outbreak, information was much more controlled and 'drip fed' to the population, primarily through traditional media, particularly radio. In contrast, while people with disabilities still relied on these sources during COVID-19, most also accessed information online, even before the virus reached Liberia. These new, unregulated channels have significant implications for risk communication in future epidemics.

Responders need to control the narrative from the outset. The oversaturation of the information ecosystem makes it difficult to filter accurate, critical messages (Jin *et al.*, 2024). The constant media influx shaped how people with disabilities experienced the outbreak and contributed to an 'infodemic' of misinformation (Horton, 2020b). Tackling misinformation requires a proactive approach well before a crisis emerges, ensuring all parts of the information ecosystem are effectively managed (Ishizumi *et al.*, 2024).

A fundamental element in countering misinformation is trust (Ishizumi *et al.*, 2024). However, as discussed in this and the previous chapter, trust in public institutions remains low – both among people with disabilities and the wider Liberian population (Afrobarometer, 2023)

6.5.4. Is COVID-19 finished?

> *'in my heart I feel Covid finish and by the grace of God I don't want Covid to come back again. I pray that it shouldn't come back here again.' (50-year-old woman with a physical impairment, Monrovia)*

My final question when talking to people about COVID-19 was always, 'Is covid finished?'. Responses were split about whether the outbreak was finished in Liberia. Some felt that because they were not hearing about cases anymore it was over.

> *'I can't hear about COVID-19, so I can't really hear about it-oh. The way it used to be on the radio, as soon you put the radio on, this time we can't hear it on radio now… Me, I believe in God that it finished-oh' (41-year-old woman with a physical impairment, Voinjama district)*

For others, they believed that COVID-19 finished when the restrictions were lifted.

> *'that's the time I knew that Covid was going small, small, because people, the time, people were no more restricted to time anymore. People were moving freely yeah, and at certain point in time now we just, people were going to church everybody started going to church people started touching each other, people started getting in car four, four, three, three yeah that's time I know that Covid finished' (28-year-old woman with a neurological impairment, Monrovia)*

Others felt that COVID-19 was not yet finished in Liberia, some of whom were resigned to the disease becoming endemic.

> *'COVID-19 will be between us like the same way we can experience Malaria, so it's not totally free in Liberia' (30-year-old woman with a physical impairment, Foya district [translated from Kissi])*

The Chief Medical Officer in Lofa told me that the outbreak was far from over, and that a handful of cases had been reported in the county in the preceding week[127] alone. Many people felt that the prevention hygiene was only needed in times of crisis, and now that people feel like it has passed, they are much more lackadaisical.

Others were concerned about a resurgence in COVID-19 caused by it being reintroduced from abroad.

> *'[COVID-19] is not finish because in as much it is happening in other countries and people travel and come back. So I will say no, is still around but it just that maybe we bless we are not experiencing it that much, but is still around. (69-year-old man with a physical impairment, Monrovia)*

Finally, one person said that she had relatively recent direct experience with COVID-19.

> *'it was [a] day in last year[128] I went at Redemption Hospital. I went to visit one of my friends that was admitted at the hospital. So when I got to Redemption, this ambulance came in from Sinje... there is a big belly [pregnant person] and they dressed her that kind of way and we were told not go near the ambulance, because they have center there [at] Redemption for Covid patients. So, they opened the gate and the ambulance drove in... so I know within myself that COVID-19 is not yet finished' (47-year-old woman with a physical impairment, Monrovia)*

6.6. Conclusion

This chapter has presented findings on how people with disabilities experienced the COVID-19 response. Cross-cutting the four themes that were generated through the thematic analysis are two important concepts. The first is that people's experience of the outbreak was 'flattened' compared with Ebola, which followed something of a chronological narrative. The second is that of 'Ebola expertise'. People universally said that because of their experience living through the Ebola outbreak, they 'knew what to do' to combat COVID-19. This impacted their behaviours across multiple themes. The next chapter will move on to analyse the data from this and the preceding chapter using the methodologies set out in **chapter four**.

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[127] This interview was conducted in March 2023

[128] The interview was conducted in March 2023

Chapter seven: analysis and discussion

7.1. Introduction

The preceding chapters presented first-hand accounts from people with disabilities, exploring their experiences during the Ebola and COVID-19 outbreaks. These chapters sought to foreground their voices and perspectives and situate their accounts within the broader structural conditions that shaped their experiences. Drawing on the theoretical frameworks of structural violence and social justice outlined in **chapter four**, this chapter presents a comparative analysis of participant experiences across the two outbreaks, with the aim of examining how exclusion is produced, maintained, and disrupted during public health crises. Structural violence offers a powerful analytical lens through which to understand 'why outbreaks become disasters' (Leach, 2015b, p. 817). At the same time, epidemics can act as revelatory moments that both expose and amplify structural violence, particularly in contexts where health systems are under-resourced and shaped by donor dependency.

This chapter is organised into numerous sections. The first builds upon Liberia's historical and geopolitical context to consider how global actors – through 'aid', policy, and programming – can either contribute to or alleviate the structural violence experienced by people with disabilities. The second section focuses on rurality, using Foya[129] as a case study to highlight how history, 'aid' and geography intersect with disability to exacerbate vulnerability during epidemics. The next section addresses ableism as both a cause and consequence of structural violence, highlighting how systemic inequities perpetuate and intensify discrimination and exclusion during times of crisis.

Following this, I examine the interconnections between poverty and suffering, and the ways in which these experiences are shaped by material deprivation and structural inequality. I then consider issues of trust, awareness, and 'compliance' – factors that emerged as deeply interdependent in shaping how people with disabilities responded to epidemic control measures and health messaging. The final sections reflect on learning

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[129] a very remote city in Lofa county on the border with Guinea and Sierra Leone (see **Figure 12**) and was the entry point of Ebola into Liberia

across epidemics, exploring how participants drew on their experiences during the Ebola outbreak to navigate the challenges of COVID-19. I conclude by examining how people with disabilities conceptualised their own health and how they engaged with or resisted the health system during both emergencies. I end the chapter by reflecting on some of the challenges and limitations I encountered conducting this research project.

7.2. Whose system, whose health? Structural violence in practice

Structural violence does not exist in a vacuum, nor is it ahistoric. Health in Liberia is deeply intertwined with its history. Deep disparities in health between Monrovia and the rest of the country can be traced back to its earliest settlement (Ciment, 2014), marked by the domination and repression of indigenous bodies well into the twentieth century (Green, 2022). This was further compounded by global structural violence, which deprioritised the health of indigenous peoples (Farmer, 2020). However, discussions around health systems and the West African Ebola outbreak often overlook the legacies of colonialism, predatory extraction, and profiteering, focusing instead on the impact of the civil wars in Liberia and Sierra Leone (Shoman, Karafillakis and Rawaf, 2017).

Structural violence has been described as ‘by far the most lethal form of violence’ (Lee, 2016, p. 110), and in Liberia, its contemporary forms are deeply rooted in historical processes. The post-war period saw the adoption of neoliberal reconstruction policies that deprioritised investment in public services, including health and education (Kieh, 2017). This approach not only worsened outcomes across the population but also created or intensified disabling conditions (Grech and Soldatic, 2015). In particular, chronic underinvestment in the health sector left the system under-resourced and ill-equipped to meet even basic needs. The resulting denial of care to poor and marginalised populations – including people with disabilities – constitutes a clear manifestation of structural violence (Szántó, 2020a).

7.2.1. Post-war reconstruction: rebuilding or reinforcing?

Post civil wars, Liberia was in desperate need of international support to rebuild its devastated infrastructure and institutions. This aid played a critical role in mitigating the structural violence of the devastation left by the war. With international support, Liberia started to recover from the huge fallout from the conflict, and the proportion of people living in extreme poverty (less than $2.15 per day) reduced from over half (53.3%) to a quarter (25.9%) in 2015[130] (Hasell et al., 2022). Unsurprisingly, post-Ebola poverty increased slightly to 27.6% in 2016. There are no data for pre- and post-COVID-19, but it is reasonable to assume that a similar pattern occurred.

In 2003, Liberia's national debt stood at 300% of its national income. Under President Ellen Johnson-Sirleaf's stewardship, the country was admitted into the Heavily Indebted Poor Countries (HIPC) initiative[131] in 2008 and went on to receive $4.6 billion in debt cancellation – over 90% of the country's total debt burden (World Bank, 2008). This provided a crucial reprieve from historic structural violence that had long constrained Liberia's economic recovery and limited the potential finances for the state to provide for its citizens. A key requirement for eligibility for the HIPC initiative is the development of a Poverty Reduction Strategy (PRS). Notably, Liberia's PRS included extensive references to disability inclusion and awareness, marking the first time disability had been a significant focus in national policy (Republic of Liberia, 2008).

The PRS evaluation report shows some impressive achievements around health. Most notably, that since 2005 the prevalence of malaria in children under five reduced from 66% to 25% in 2010[132], and that the 'basic package of health services' (BPHS)[133] was now offered in 80% of functional government health facilities (IMF, 2012). The distribution of these health facilities was not entirely even, however. 41% of households still remained without an accessible health facility, two-thirds of which (66%) were in rural areas (LISGIS, 2008). Out-of-pocket payments for health also remained high, with

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[130] Liberia does lag behind the global poverty trend which shows a steady decrease in absolute poverty from 37.9% in 1990 to 8.5% in 2024 (Hasell *et al.*, 2022).

[131] The HIPC initiative aims to relieve heavily indebted countries of unsustainable debt burdens, enabling them to redirect resources towards poverty reduction and sustainable development (IMF, 2023).

[132] This remarkable achievement cannot of course be attributed solely to the implementation of the PRS, as multiple NGOs and other organisations had central aims of reducing malaria in children. For example, the Global Fund has been active in Liberia since 2004.

[133] The BPHS covered maternal, newborn and child health; reproductive health; communicable diseases; mental health; and emergency care (Jarrah and Collins, 2009). The initiative was funded through a multilateral donor funded Health Sector Resource Pool, which was managed by the Ministry of Health and Social Welfare (Lee *et al.*, 2011).

households paying 35% of total health costs. This disproportionately impacted people living in poverty, with the poorest quintile paying up to 17% of annual incomes on healthcare (Lee *et al.*, 2011). Although there are no data specifically on disabled households' health expenditure, given people with disabilities' increased need for healthcare (Carew *et al.*, 2019), these out-of-pocket charges are likely to also have disproportionately impacted on their annual income.

However, despite these achievements, the debt-relief conditionalities attached to Liberia's post-war recovery required the adoption of a neoliberal austerity agenda. This substantially reduced investment in public services, such as health and education, and led many to ironically refer to the PRS as the 'poverty enhancement strategy' (Pailey, 2024). Some have argued that post-conflict Liberia became a 'vast experiment' in which donors and international organisations tested out techniques for state reconstruction (Jézéquel and Perreand, 2011). Donor priorities for reconstruction prioritised security and market-led reform over the rebuilding of public services, which had devastating consequences for the health system (Kieh, 2017). This created an enduring reliance on NGOs and faith-based organisations to deliver healthcare – a pattern that has persisted for decades.

7.2.2. The complexity of 'aid'

Development 'aid' can play a complex and sometimes contradictory role in relation to structural violence. On one hand, it has the potential to redress certain aspects of structural violence, rising to the challenge when the state is unable or fails to meet the basic needs of its population. In such cases, humanitarian and development actors may provide essential services and support that would otherwise be absent. However, without investing in the reconstruction or long-term strengthening of government and health systems, this relief is often temporary. Once donor funding ends or projects close, the conditions of structural violence – poverty, exclusion, and marginalisation – often resurface. In this way, development interventions may not eliminate structural violence but rather can obscure or delay its effects, masking the deeper systemic failures that produce and sustain inequality.

Liberia's extreme donor dependency was starkly visible during the Ebola outbreak when over 90% of healthcare services were still being delivered by NGOs (Ministry of Health, 2015). Rather than strengthening state capacity, international actors had often 'shored up' a fragile and under-resourced health system, as many were uninterested in the 'dull and vital chore of strengthening health systems' (Farmer, 2020, p. 422). Many health facilities lacked even basic supplies, and inadequate provision of PPE contributed to nosocomial transmission, further eroding trust. Among people with disabilities, many recounted avoiding public health services entirely during the Ebola outbreak due to fear of infection, being kidnapped and a general lack of confidence in the system's safety and competence. This distrust did not disappear with the end of the crisis. In fact, for many, it resurfaced during the COVID-19 pandemic, when reignited fears led people with disabilities to once again avoid the formal health system.

Very few of the people with disabilities I spoke to relied on government-run health services, citing poor staffing, frequent drug stockouts, and lack of accessible or responsive care. Instead, many sought support from NGO- or faith-based health facilities, such as the Ahmadiyya Hospital in Monrovia. Staff at several of these facilities – including the Foya Borma Hospital – emphasised that they remained dependent on international organisations for critical medical supplies and financial support. These findings underscore how post-war policies and donor strategies have contributed to a fragmented, inequitable health landscape, in which people with disabilities are often forced to navigate a patchwork of inconsistent and unreliable care, rather than a system designed to meet their rights and needs.

The downsizing of the public sector further entrenched Liberia's reliance on external actors. In the absence of strong state systems, NGOs and faith-based organisations stepped in to fill critical gaps – a dynamic that was clearly visible during the Ebola outbreak. However, these interventions are frequently short-term, fragmented, and donor-driven, with little focus on strengthening infrastructure or building sustainable government capacity. As a result, they tend to prioritise quick, measurable outcomes over long-term structural change. An exception to the short-term project cycles comes from China. The country has invested heavily in Liberia – very visible identifiers of this investment include the construction of a brand new large ministerial complex (which is not entirely accessible) and road construction, particularly between the major international airport and Monrovia. This forms part of China's 'Belt and Road' initiative[134] (BRI), which Liberia joined in 2019. China is heavily involved in extracting Liberia's plentiful national resources and in September 2024, the country announced its plan to invest $3 billion to construct an oil refinery in Buchanan county (Menjor, 2024). Given the recent cuts to UK Aid and USAID (and in recent years, France and Germany have also cut their 'aid' expenditure), China is going to become of increasing importance in the 'development' space, the long-term implications of which it is too soon to understand.

7.2.3. From the top?

Vertical programmes are widely used for single disease-specific control or eradication efforts. They have been successful, most notably in the eradication of smallpox in 1980, and are frequently applied to diseases such as HIV, polio, and malaria (Atun, Bennett and Duran, 2008). Donors often prefer them because they are discrete, have clear objectives, and deliver time-bound results. These programmes are also typically centrally managed, allowing for greater financial oversight and control (Cairncross, Periès and Cutts, 1997).

When most effective, vertical programmes complement existing health systems, filling gaps that general health services may struggle to address, particularly in low-resource settings (Atun, Bennett and Duran, 2008). By intersecting with and supporting local health infrastructure, they can enhance service delivery through specialised expertise, targeted funding, and streamlined logistics. Well-integrated vertical programmes can strengthen disease surveillance, expand treatment access, and bolster healthcare capacity. However, if implemented in isolation, they risk creating parallel structures that

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[134] The BRI was launched in 2013. The initiative is a massive infrastructure development programme currently spanning 68 countries. By some estimates China's total expenditure on the whole programme could exceed $8 trillion. However, critics of the BRI are concerned about the lack of transparency (the conditions of loans are not disclosed) and its potential threat to national sovereignty, leading some to accuse China of 'engaging in "debt-trap diplomacy"' (Wong, 2023).

divert resources, fragment care, and weaken long-term health system resilience (Hrynick, Ripoll Lorenzo and Carter, 2021).

In times of epidemic emergencies, programmes often need to be established rapidly to contain and control outbreaks. In these cases, vertical approaches are often deployed because programmes can be established rapidly (Atun, Bennett and Duran, 2008), and in such cases, to meet urgent staffing needs, personnel are often pulled from existing programmes. As discussed in **chapter five**, this was particularly evident during the Ebola outbreak, when such vertical programmes pulled health workers away from the state health infrastructure. While these programmes were important in curbing the spread of the epidemic and saving lives, Liberia's critical shortage of health professionals[135] meant that it was extremely vulnerable to significant human resource disruption, and this greatly exacerbated the deterioration of general health services and led to the closure of health facilities. This was one way in which humanitarian actors inadvertently contributed to structural violence during both epidemic responses.

The impact of these vertical programmes was felt by the people with disabilities I spoke to. Similar to previous research on this subject (Carew *et al.*, 2019; Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021), many of the people with disabilities I spoke to found it much more challenging to access routine health services during both outbreaks – particularly during Ebola. This deprioritising of healthcare over containment is a clear example of the 'control-over-care' paradigm (Farmer, 2020). While Farmer primarily discusses the lack of supportive care for Ebola patients [136], the concept of 'care' can be expanded to include the broader erosion of general healthcare due to epidemic control measures.

However, people with disabilities faced additional barriers to healthcare access due to strict, enforced COVID-19 lockdown and curfews. In both outbreaks, the state's capacity to provide healthcare to the population declined significantly, and the use of

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[135] In 2015, there were only 3.7 health professions per 10,000 people in Liberia (WHO, 2015c). WHO considers a density of less than 22.8/10,000 people to be critically low.

[136] For example, health workers were prohibited from administering IV fluids to Ebola patients due to concerns over needle-stick accidents (Farmer, 2020).

physical force to enforce containment measures further restricted access. These experiences weakened trust in both the government (further discussed in **section 7.6**) and in the formal health system. Health personnel I spoke with confirmed that healthcare demand and utilisation plummeted during both crises. This is in opposition to both the social model, as additional barriers were created to health access, but also the human rights model which argues that XXX

Given Liberia's relatively low (recorded) number of deaths due to COVID-19, some participants – particularly those in rural and remote areas – questioned whether the restrictions had been too stringent. Several people with disabilities described the COVID-19 period as more difficult than the Ebola outbreak due to the economic and social hardships it caused. More than one participant spoke of people with disabilities dying of starvation during lockdown, although these remained anecdotal and were never substantiated by concrete examples. The denial of food XXX is a direct violation of human rights and shows the sheer lack of consideration that the state gave to the welfare of people with disabilities during COVID-19, particularly in rural and remote areas.

It also shows a limitation of emergency responses. If top-down emergency response programmes are set up without local knowledge, it cannot address the ableism of general services, and can in fact reinforce existing structures. If programmes don't know where the people most in need are, how can they effectively reach them? Calling something a 'comprehensive' response that by default 'includes everyone' is not enough. .Without developing and following roadmaps and accountability mechanisms, the programme is doomed to fail in effectively meeting people's basic human rights and actually 'including' all members of high-risk and 'vulnerable' population, including last mile communities and in many cases people with disabilities.

At the same time, many participants attributed Liberia's relatively low COVID-19 case numbers to the lessons learned from Ebola and the early implementation of response measures (see **section 7.8**). Most people with disabilities said they had complied with infection prevention actions and were satisfied with the protective measures. These divergent experiences reflect the complexity of pandemic response: balancing the need to contain disease with the potentially severe social and economic impacts of public health restrictions. For people with disabilities, especially those living in poverty or isolation, the cost of containment was often high. Balancing the stringency of COVID-19 responses against the broader disease burden in countries like Liberia is a complex task – one that requires attention not only to epidemiological risk, but also to the cumulative impact of lockdowns, disrupted services, and food insecurity (Hrynick, Ripoll Lorenzo and Carter, 2021). Whether a less stringent approach would have produced better outcomes overall is difficult to say – but it is clear that such decisions must take into account the full range of impacts on marginalised populations, not only epidemiological ones.

Vertical programmes are expensive (Cairncross, Periès and Cutts, 1997) and, as Richards (2016, 2020a) argues, are often inefficient, particularly if they fail to build on local knowledge systems or support sustainable health system strengthening. A greater emphasis on bottom-up, community-led infection control (explored in the **'health from the bottom up'** section) could represent a more cost-effective and socially responsive use of donor funds. Moreover, people with disabilities are often still positioned as passive recipients rather than as partners or experts in their own lives. The human rights model has a central focus on XXX. As such, for international 'aid' to support social justice meaningfully, it must be led by those most affected – with people with disabilities actively shaping priorities, programmes, and policy. Structural violence cannot be dismantled from the outside alone – but well-aligned international support can help shift the balance, when it works in solidarity with local actors and centres the lived realities of marginalised communities.

7.2.4. International actors – not the bad guys

International organisations have played a crucial – and at times transformative – role in Liberia's recovery from conflict and health crises. While a good amount of critique has rightly focused on how 'aid' can entrench dependency or bypass state systems, it is important to recognise the ways in which international actors have also helped to (at least temporarily) alleviate the effects of structural violence. In contexts where state capacity is extremely limited, international organisations have often stepped in to fill critical service gaps, particularly in health, education, and disability support (Abramowitz, 2014b).

In the aftermath of the Ebola crisis, international actors also contributed to building systems that were more inclusive of people with disabilities, at least in principle. One example is development partners (including UNDP) providing funding and technical support for policies such as the National Action Plan for the Inclusion of Persons with Disabilities. Through this, international organisations aimed to support people with disabilities and OPDs to advocate more strongly in their claims for social justice. A second and central example is UNMIL's success in promoting the inclusion of disability within national policies and frameworks.

UNMIL's Human Rights Protection Division (HRPD)[137] was a key supporter of people with disabilities during its mission through its efforts to promote inclusion, including in the policy environment. For example, the HRPD's advocacy and technical assistance meant that disability issues were substantively incorporated into several critical policy documents in 2013: the Agenda for Transformation (2013a); Social Protection Policy (2013c); and the Human Rights Action Plan (2013b). These agendas and action plans have the potential to substantially reduce the structural violence of the state on people with disabilities through the implementation of rights-based poverty-reduction and social support structures.

International organisations played a key role in supporting the establishment of the National Public Health Institute of Liberia (NPHIL). Established in the wake of Ebola, NPHIL was created to strengthen disease surveillance, enhance epidemic preparedness and response, and improve overall public health outcomes in Liberia (Republic of Liberia, 2016c). Donors such as the US Centers for Disease Control, the World Bank and WHO have provided technical assistance, training, and funding to help operationalise NPHIL's mandate. These partnerships have supported Liberia's early warning systems, laboratory capacity, and risk communication – all critical to reducing

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[137] The HRPD was mandated to promote, protect, and monitor human rights across all fifteen counties in Liberia, with a focus on vulnerable groups such as women, children, displaced people, and people with disabilities. Working in collaboration with national institutions, civil society, and international partners, HRPD supported broader policy development to enable Liberia to meet its human rights obligations (UNMIL, 2015).

the structural violence of an ineffective health system, particularly during times of health crises.

Unfortunately, NPHIL does not yet collect disability-disaggregated data in its surveillance and response mechanisms. However, if future international support to further build national capacity for disease surveillance, epidemic preparedness, and response coordination is shaped by rights-based principles, this has great potential to improve outcomes for people with disabilities by creating more inclusive and accountable public health mechanisms.

AIFO has been one of the most consistent international actors working on disability inclusion in Liberia. Unlike many organisations that engage through short-term one-off interventions, AIFO has maintained a longstanding presence in the country, partnering closely with national structures such as the National Commission on Disabilities (NCD) and NUOD. Its work has included substantial long-term work building OPD capacity, seeking to support organisations in their claims for social justice, rather than merely treating its symptoms. AIFO's commitment to working through local institutions, rather than around them, reflects a more sustainable and justice-oriented model of development.

However, even where international involvement has been positive, it is often reactive and short-term – shaped by donor cycles and external priorities rather than local agendas. Despite good intentions, many programmes designed to address structural inequality remain tied to project funding and are rarely embedded in long-term system reform. This limits their transformative potential and can reproduce the very conditions of exclusion they seek to address. By focusing on alleviating immediate suffering without addressing its structural causes – such as poverty, exclusion, and state neglect – humanitarianism can become a form of containment rather than a means of transformation (Fassin, 2012b). In other words, without addressing the root causes of structural violence, humanitarianism only functions as temporary relief.

7.2.5. Structural violence and the power for good?

There are difficult and sometimes paradoxical questions around power and structural violence as they relate to disability inclusion in epidemic responses. In humanitarian situations, international organisations often arrive early and rapidly establish vertical programmes, setting the agenda for much of the initial response (see **section 7.2.3**). In such situations, these organisations wield a great deal of power and as discussed throughout much of the chapter, this often can produce and reproduce structural violence and deep inequality, as was certainly the case in Liberia during the Ebola epidemic.

However, if such organisations choose to embed disability inclusion as a core pillar of the response, they can compel their partners to adopt more inclusive practices. In theory this has the potential for immediate positive impacts for people with disabilities. Well-financed vertical programmes have the capacity to effect change at-scale, particularly in resource-constrained settings where a sustained lack of resourcing perpetuates the exclusion and inequalities experienced by people with disabilities.

However, as is highlighted in this chapter, without addressing entrenched institutional and individual ableism, these changes are likely to be short-lived. Once the emergency ends and international organisations leave, local organisations may well fall back to conceptions around the medical or charity models of disability, or to not considering disability at all.

This kind of positive and inclusive agenda-setting does have precedent. For example, UK Development's Disability Inclusion Strategy 2022-2030 – which is underpinned by the human rights model of disability – has a central goal of ensuring that all UK Development-funded humanitarian programmes are 'fully disability inclusive' and 'where opportunities arise' will include OPDs in efforts to reform humanitarian systems (FCDO, 2022). It is too early to tell the extent to which this ambitious goal will be achieved, particularly with the rather vague plan for involving OPDs.

7.2.6.The UNMIL effect

As discussed in **chapter 2**, UNMIL was a key actor in postwar reconstruction until it completed drawdown in 2018. UNMIL's core mandate was to monitor the peace process, provide protection and support to various UN, humanitarian and human rights activities, and assist in security reform (UNMIL, 2018b). UN Missions tread a fine line to maintain neutrality in challenging contexts. Peacekeeping guidelines state that

Missions' role is to provide 'a secure and stable environment within which humanitarian actors may carry out their activities' (United Nations, 2008, p. 30), rather than providing health activities themselves, as this can be perceived to undermine their neutrality. However, this line is easily blurred by contextual need and suffering. In Liberia, UNMIL often did, in fact, provide medical assistance to the local population, and by so doing, critics argue that this simultaneously bolstered the health system by providing essential services but also meant that there was less impetus for the government to provide the services itself (Davies and Rushton, 2015). This therefore both masked existing governmental structural violence and inadvertently enabled it to be maintained. This is a perennial difficulty with 'development' activities, as is their temporary nature.

One of the less visible legacies of international intervention in Liberia lies in its economic footprint. Alongside peacekeeping and governance reform, UNMIL's presence significantly shaped the national economy, giving rise to what has been termed a 'speculative economy' – a parallel system largely sustained by international spending[138] (Rouse, 2019). As (largely non-national) UNMIL employees were limited in where they could stay or socialise due to security concerns, this created an unsustainable spending 'bubble', and at the height of its mission, UNMIL contributed up to 11% of the national GDP (Thompson, 2018). Following UNMIL's departure, this 'speculative economy' collapsed and was found to be masking 'huge structural issues in Liberia's actual economy' (Rouse, 2019). The departure of so many international peacekeepers had the indirect impact of huge job losses for primarily unskilled Liberian workers (Beber *et al.*, 2019), the vast majority (90%) of whom were not able to find other employment (Rouse, 2019).

UNMIL's departure not only exposed how much the mission had been shoring up against structural violence, it also revealed a significant failure of government planning. The transition period was a missed opportunity to address longstanding inequities. Despite years of warning, government preparedness focused heavily on security, with far less attention paid to the 'civilian transition' – such as human rights, poverty

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[138] UNMIL's total 'local' expenditure was $551.8 million (7.4% of total UNMIL spending), but it is estimated that this had a cumulative local economic impact of $827.7 million (Thompson, 2018)

alleviation and human development (Forti and Connolly, 2018). This imbalance underscores the structural violence of state neglect and the lack of accountability, both of which had been masked by the temporary boost provided by the speculative economy.

This section has explored how global actors and structures shaped both the direct and indirect effects of the Ebola and COVID-19 outbreaks in Liberia. International involvement played a paradoxical role – alleviating some of the immediate impacts while also reinforcing or masking deeper systemic inequalities. The next section turns to rurality as a key driver of structural violence, using Foya as a case study to examine how historical marginalisation and national-level disparities compounded the challenges faced by people with disabilities during health emergencies.

7.3. Rurality and structural violence

One of the key findings from this research is that of the increasing urban/rural divide (see **chapter six**). This was not necessarily due to a diminished outbreak response in rural and remote areas, which tended to remain patchy, but rather of the improvement of access in Monrovia. There was a clear relative improvement in Monrovia (but by no means universal), as evidenced by many people with disabilities I spoke to in the capital. Rural and remote areas felt unserved and deprioritised, but despite this OPDs and certain NGOs (such as Plan Liberia in Lofa) distributed what materials they could. The leaving behind of rural and remote areas resulted in increasingly inequitable structural violence, marked by ‘the power to decide over the distribution of resources’ (Galtung, 1969, p. 171). Despite this, there is limited literature examining how structural violence disproportionately affects urban and rural areas, particularly in relation to people with disabilities. However, comparing the experiences of people with disabilities during the two outbreaks highlighted these disparities more clearly.

Roads can also be a key location of structural violence (Lee, 2022). In Liberia, the poor state of the roads, particularly in rural and remote areas, impairs the free movement of people, goods and medical supplies (Kieh, 2017) and indirectly can be a cause of disability (Muderedzi *et al.*, 2017), as it impedes social services and perpetuates poverty and limits the availability of health care.

NUOD itself contributed to the widening structural violence disparity between rural and remote areas. During COVID-19 it received comparatively more food and non-food items for distribution to its members than it had done during the Ebola outbreak. Due to a range of factors – the structural violence of the roads and NUOD's limited capacity to serve its members – the result was increased maldistribution: the more easily reached populations in Monrovia received the lion's share of the supplies, leaving people with disabilities in rural and remote areas such as Foya suffering. People with disabilities' claims for social justice for more equitable distribution of resources from both the state and from NUOD were predominantly not heard during either outbreak.

This section has explored rurality as a site of structural violence. I will now move on to discuss the case study of Foya, which is by far the most remote place I visited when conducting my interviews.

Figure 12 Foya from Monrovia

7.3.1. The case of Foya...

Ebola first entered Liberia through Foya, Lofa county – one of the country's most remote and historically marginalised areas (**Figure 12**). Neglected by the government and devastated by intense fighting during the civil wars, Foya served as a key entry point for multiple rebel factions, leading to widespread destruction, displacement, and long-term instability (Jézéquel and Perreand, 2011; Abramowitz, 2015). Many people with disabilities in Foya and Voinjama (the county capital) told me that '*Lofa has so many disables*.' Whether or not this is accurate[139] (and it may be, given physical violence clearly increases the risk of disability), this perception likely stems from the extreme violence the county experienced.

Towards the end of the war, combatants implemented 'scorched earth' tactics, deliberately destroying infrastructure and agriculture in anticipation of future aid and further entrenching hardship (Jézéquel and Perreand, 2011) – a grim illustration of perverse incentives embedded within humanitarian assistance (Wood and Sullivan, 2015). This strategy left areas such as Foya effectively unreachable and devoid of healthcare, creating what Farmer (2020) calls a 'clinical desert' – a vacuum in both care provision and disease surveillance caused by the absence of trained professionals and functioning facilities. In response, MSF–France constructed a hospital in Foya in 2003 to address the acute health needs of the population and returning refugees[140]. However, rather than engaging in health system reconstruction, which MSF viewed as 'premature' due to the high likelihood of renewed conflict, their approach focused on short-term 'substitution' of health services. While lifesaving, this model – characteristic of many humanitarian responses – provided a parallel system of care that bypassed state structures. Where international organisations take on services that should have been provided by the state masks or delays structural violence, it also situates individuals in precarity. Such substitution can inadvertently mask and delay the effect of structural violence as it undermines state incentives to invest in its own long-term and sustainable health infrastructure – a dynamic that became painfully visible during the Ebola outbreak when the fragility of the public system was laid bare.

The timing of humanitarian intervention is as much about when to leave as when to arrive. As Abramowitz (2015) argues, international actors assert sovereignty in the 'right to self-determination at the moment of departure'. This is what Sirleaf and others would

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[139] Data on proportions of people with/without disabilities by county from the 2022 census are not yet available.

[140] Lofa had the largest number of refugees of any county – 65,000 (Reeve and Speare, 2010)

describe as structural violence (Wilkinson and Leach, 2015; Sirleaf, 2018; Farmer, 2020). MSF's withdrawal from Liberia in 2007 – giving the government just two months' notice – exemplifies this power dynamic. MSF's rationale was that they had fulfilled their mandate as a humanitarian organisation as they considered Liberia to have transitioned from crisis to stability. However, their abrupt exit caused a crisis in health, particularly in Lofa, where services had remained heavily reliant on international organisations (Abramowitz, 2016).

The Liberian government's post-conflict National Health Policy (2007) had a core focus on decentralisation, but implementation was patchy. County health teams remained under-resourced, poorly trained, and lacked the capacity for effective disease surveillance – a situation that would unfortunately persist up to the Ebola outbreak (Abramowitz, 2016). Because MSF had not supported systems strengthening, and without a transition plan in place, the organisation's withdrawal created an immediate health provision vacuum[141]. The 'black hole' MSF left behind caused the remaining health services to be overwhelmed, exacerbating vulnerabilities and paving the way for the rapid spread of Ebola when it arrived in the region (Abramowitz, 2015; Benton and Dionne, 2015; Sirleaf, 2018).

Post-conflict, the government instituted integrated disease surveillance and response (IDSR) in 2004. The IDSR aimed to have a streamlined approach to disease surveillance and outbreak reporting from communities up to the national health service. However, up until the Ebola outbreak, implementation was hindered due to limited human resource and infrastructure capacity, weak surveillance and reporting mechanisms which did not involve communities, and donor-driven, single-disease vertical programming. There was often only one employee per county with responsibility for implementing the IDSR, severely constraining the effectiveness of the system.

The power imbalance between international actors and local governance was mirrored in the experiences of people with disabilities. Many felt humanitarian organisations

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[141] It also caused a domino effect, leading to the closure of more than 30 World Vision-operated clinics in Monrovia less than two months later (Sirleaf, 2018).

‘landed’[142] on them during Ebola, bringing aid on their own terms while failing to engage with community members or consider their long-term needs. At the same time, the Liberian state – previously absent in service provision – became autocratic, violently enforcing restrictions without providing essential support (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021). The state again turned violent during the COVID-19 lockdowns and stay-in-place measures, and people told me of other people with disabilities who had died of starvation during this time.

Structural violence and misrecognition resulted not only in an overall lack of capacity to meet the needs of people with disabilities but also in their explicit exclusion. In Foya, key governance structures – including the district commissioner and paramount chief – stated plainly that they were unable to provide supplies for people with disabilities during the COVID-19 outbreak. This was not framed as a temporary shortfall but as a matter of systemic omission. In the face of severe resource constraints, people with disabilities were consistently de-prioritised, remaining at the bottom of the list of ‘vulnerable’ groups considered for aid and support.

Such decisions reflect more than operational limitations; they expose entrenched patterns of misrecognition and maldistribution that underpin structural and social injustice. As Fraser argues, social justice depends not only on the equitable distribution of resources but also on the full recognition of individuals and groups as equal participants in social life. In Foya, the exclusion of people with disabilities from emergency resource allocation denied them both material support and symbolic acknowledgment. Their needs were not only unmet, but their very presence was rendered invisible within systems that failed to recognise them as legitimate and equal claimants of support. This denial of recognition, alongside economic deprivation, exemplifies how structural violence is reproduced during crises – reinforcing the very inequalities that emergency responses should be working to dismantle.

7.4. Invisible and overlooked…

Ableism is a complex issue that operates at multiple levels (see **chapter four**). It ‘valorises’ ability whilst simultaneously marginalising disability and casting it as an

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[142] Metaphorically but almost literally in one case (see **chapter five**)

undesirable state of being (Campbell, 2009). This constitutes social injustice, where misrecognition positions people with disabilities as inferior, and exclusion prevents the achievement of 'parity of participation.' It is also an example of structural violence as it fosters an environment which divides a population as 'superior' and 'inferior' (Lee, 2022).

The 'invisibility' of people with disabilities is a frequent consequence of ableism (Nario-Redmond, 2019) and one which was evident during both outbreak responses. People with disabilities were deprioritised to the point of becoming effectively invisible. The example of the inaccessible WFP food trucks underscores this issue (**chapter five**). In addition to physically inaccessible locations, where disability was clearly not a factor in the decision-making, procedural restrictions such as prohibiting the use of proxies to collect food supplies also hindered access. While this was intended to ensure equitable distribution, it was rooted in the ableist assumption that everyone had the capacity to wait in line. As a consequence, those not 'able' are not in the line and remain invisible. Although OPDs were eventually able to successfully advocate for the changing of locations, this was a reactive measure rather than a proactive solution and likely did little to challenge the systemic ableism embedded in the response.

This invisibility also perpetuates the structural violence experienced by people with disabilities – a 'chicken and egg' cycle, where structural violence fosters invisibility, and this invisibility, in turn, allows structural violence to persist unchallenged. Without visibility, people with disabilities are excluded from decision-making processes and overlooked in planning, leading to policies and practices that fail to consider their needs, further perpetuating the cycle. Individual efforts to address ableism, such as the NUOD county coordinator who forced herself into IMS meetings, can go some way to redress social injustice on a limited basis. However, individual efforts, even when successful, only serve to bring into focus the systemic structural violence that they are trying to combat.

Ableism at the policy level also rendered people with disabilities invisible. The significant majority of relevant mainstream policies, strategies and action plans only mentioned disability in passing, and often at the end of a 'vulnerable' list (out of 40 that I reviewed[143], all bar eight mentioned the word ‘disability’ fewer than 10 times, and do not refer to the UNCRPD or rights-based approaches). In instances where disability was not framed in terms of vulnerability, it was often cited as a justification for exclusion (including within the Constitution), for example, as a reason for individuals to be relieved of political position or for being fired for gross misconduct. The misrecognition of disability being equated with inability and incapacity highlights an insidious structural violence.

The systematic de-prioritisation of disability was also evident during the COVID-19 pandemic. Several people with disabilities I spoke to in Monrovia (who seemed to be more politically engaged) criticised the government for failing to uphold its commitments under the UNCRPD, particularly in relation to the implementation of Article 11 (situations of risk and emergencies)[144]. Indeed, disability is either not mentioned or only in passing in all the government’s COVID-19 response and recovery plans. At the district level, the exclusion was even more pronounced, with members of local governance structures admitting they had deliberately excluded people with disabilities during the COVID-19 response, as they were not viewed as a priority group for (very limited) resource allocation. In addition, ableism was also reported in the organisations implementing the response. One head of an OPD told me that despite repeated applications by people with disabilities, not a single person was hired by MSF in Foya district.

The ableist rhetoric of ‘including everyone’ paradoxically renders people with disabilities invisible. While intended to ensure universal inclusion based on need, this narrative was particularly insidious especially (but not exclusively) within government organisations, where it superficially promoted inclusivity while failing to address the specific needs and rights of people with disabilities. This 'blanket' one-size-fits-all response likely contributed to people with disabilities, particularly during Ebola, perceiving the

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[143] See **appendix six** for a full list

[144] That States Parties will take ‘all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters’ (United Nations, 2006)

emergency responses as monolithic – making little distinction between government and international responders – and from which they were systematically excluded. As a result, they were denied access to relief efforts that benefited the wider population, further widening the gap between people with disabilities and non-disabled people.

Some national government agencies, like the National Disaster Management Agency (NDMA), did talk to me using disability rights language and had clearly met with the NCD post-Ebola. However, talking the talk of rights has not yet resulted in greater inclusion in disaster response strategies. Drafts of updated pandemic and Ebola plans that were shared with me only mention disability three times and two times, respectively, and again only at the end of a 'vulnerable' list. No specific provisions are made, and no specific strategies for reaching them. This is a missed opportunity to redress social injustices related to maldistribution and misrecognition.

7.5. On poverty and suffering

The widespread and grinding poverty experienced by many of the people with disabilities I spoke to was one of the clearest manifestations of structural violence. Poverty, a complex and multifaceted issue, severely constrains agency through the maldistribution of resources, perpetuating cycles of marginalisation and inequality (Rylko-Bauer and Farmer, 2016). This entrenches social injustice and leads to 'social suffering' – the collective and individual pain that arises when social structures and institutional failures intersect with illness, exclusion, and deprivation (Singer, Erickson and Abadía-Barrero, 2022).

As Kleinman (1997) argues, 'social suffering' is not only about material deprivation but also about how systemic injustice becomes embedded in the fabric of everyday life, blurring the boundaries between political violence, economic precarity, and personal pain. Similarly, Das (2006) highlights how violence is often inscribed into the ordinary, becoming part of the everyday practices and relationships that structure people's lives. For many people with disabilities, extreme poverty shaped every interaction with systems of health, education, and social support. It diminished expectations, curtailed opportunities, and rendered rights increasingly abstract. In this way, poverty functioned not simply as background context but as an active and enduring form of structural violence – both shaped by and shaping the broader political and economic conditions in which people with disabilities are routinely marginalised (Farmer, 2005) and through which suffering within social institutions becomes normalised (Kleinman, 1997).

These dynamics were evident in the context of both epidemic responses, where poverty and structural exclusion intersected to shape how people with disabilities experienced both risk and response. For many, navigating public health systems during Ebola and COVID-19 was not only logistically difficult but emotionally fraught – marked by a longstanding mistrust of institutions that had consistently failed to meet their needs. As Das (2006) observes, the state is often most visible in moments of crisis, but for marginalised populations, this visibility can be marked by abandonment or harm rather than care. Epidemic response strategies – often framed as neutral or technical – were, in fact, deeply political, shaped by the same systems that had long rendered people with disabilities invisible. Kleinman's (1997) reminder that health interventions must contend with the lived realities of suffering is crucial here: when epidemic responses failed to account for people's socioeconomic position, communicative needs, or embodied experiences of marginalisation, they not only missed the mark but actively reinforced inequality.

Public health measures, particularly in their more punitive forms, often amplified the structural violence already shaping people's lives. Curfews, lockdowns, and mobility restrictions had vastly different implications for people with disabilities living in poverty than for those with access to private care, information, and resources. A significant consequence of enduring such pervasive structural violence is the inability to 'look up'. When basic survival (such as finding the next meal) becomes the central preoccupation, the capacity to advocate for systemic social justice is severely diminished (Rylko-Bauer and Farmer, 2016). Many people with disabilities expressed deep resignation and exhaustion from constantly navigating the socioeconomic forces shaping their lives. This resignation underscores how structural violence operates not only through material deprivation but also by fostering a sense of powerlessness, further entrenching marginalisation.

Both outbreaks were deeply entangled with poverty, which significantly influenced transmission and impact. During the Ebola outbreak, impoverished communities faced substantially higher infection rates than those in better socioeconomic conditions (Fallah *et al.*, 2015)[145]. The COVID-19 pandemic further exacerbated poverty in Liberia, increasing hardship and intensifying existing vulnerabilities (Robinson, 2024). While poverty is pervasive in Liberia (LISGIS, 2017), disability interacts dynamically with these factors, both amplifying multidimensional poverty and being further shaped by the socioeconomic inequalities exacerbated by such outbreaks. People with disabilities had a differential risk of infection of both Ebola and COVID-19. Some of this is due to people with disabilities having higher risks of multidimensional poverty; others are due to reliance on others for support or a lack of accessible health information (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021). Some people with disabilities had an inequitable risk of infection due to their impairment type. For example, people with visual impairments told me about being grabbed by strangers, and I was also told of inaccessible toilets for people with physical impairments who, in order to use the facilities, had to make contact with surfaces including the floor, which is of course deeply unsanitary. The fear of contracting either disease meant that these individuals isolated themselves, in one case dropping out of university entirely.

Structural violence has also been argued to be a cause of disability in itself (Lee, 2022). If multidimensional poverty both produces and is produced by disability (Groce *et al.*, 2011; Banks, Kuper and Polack, 2017), then the state's inability, or in some cases unwillingness, to provide essential services constitutes an additional layer of structural violence. In contexts where multidimensional poverty is entrenched and extremely pervasive – as is the case with much of Liberia – impairment is a product of preventable harm. For people with disabilities in Liberia, this convergence of state neglect and systemic inequality not only limits opportunity, it actively reproduces disability and marginalisation across generations.

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[145] This research was undertaken in urban/peri-urban settings: Monrovia and Montserrado county. It is not possible to directly extrapolate these findings to rural and remote areas as the infection pathway is likely to be different in areas of lower population density.

7.6. Complexities of trust and rumour

Rumours and misinformation were rife among people with disabilities in both outbreaks. They were a way in which the people with disabilities I spoke to attempted, through the construction of their own narratives, to regain agency and control in their lives. In an environment of severe mistrust in the state and exclusion from its epidemic response, constructing counternarratives might be seen as understandable. Conspiracy theories can be a symptom of structural violence (Szántó, 2019) and, in a historical paradigm of oppression and absenteeism, have been described as acts of resistance against the 'coloniality of power' (Richardson, 2019, p. 104). In Liberia, such mistrust resulted in outbreaks of physical violence in West Point in Monrovia, as well as Womey[146] in Guinea. The attack was labelled a 'massacre' by the media, and while fear was often cited as a contributing factor to the killings (CNN, 2014), the historic oppression and violence directed at the region (Farmer, 2020), and the ongoing impact of predatory extractive industries (Leach, 2015b), were universally overlooked.

People need to trust both the message and the messenger. Many of the people with disabilities I spoke to expressed deep distrust in government. This aligns with the opinions of most Liberians, who overall have very little trust in government with almost two-thirds of people believe that most or all of the president's office (including the president himself[147]) are corrupt, and almost everyone (85.9%) thinks corruption is getting worse (Afrobarometer, 2023). There was limited rebuilding of trust between the two outbreaks, which is a reflection of the persistent structural violence of the state.

Some research with individuals and civil society in informal settlements in Freetown found that rumours and misinformation were much less rife during COVID-19, arguing that their experiences during Ebola made the messages more trustworthy and underscored the urgency of responding to the crisis (Diko *et al.*, 2024). This was not the case with the people with disabilities I spoke to. Many told me, particularly in remote areas, that their and others' belief in rumours was the same during COVID-19, despite many people having direct and often devastating experiences with Ebola. The kinds of

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[146] In September 2014, an Ebola awareness team was attacked in Womey, a village in a remote part of Guinea. Eight people including health workers and journalists were killed (*Reuters*, 2014).

[147] At the time of survey George Weah was the Liberian president.

rumours that people believed were similar in both outbreaks, particularly the denial of the existence of the diseases and conspiracies about their origins. These rumours do not exist in a vacuum – social media influenced the adoption of beliefs. Conspiracy theories widely shared online found their way into the dialogue of the people with disabilities I spoke to, and these 'tips' were taken as valid and shared widely – 'going viral', as one person I spoke to rather appropriately described it. This potentially created a feedback loop of rumours and misinformation. While this happened much more frequently during the COVID-19 pandemic, some research in Sierra Leone also found that during Ebola misinformation from social media created distrust of awareness messages (Diko *et al.*, 2024).

The COVID-19 'infodemic' dramatically altered the health information landscape (Horton, 2020b; United Nations, 2020), both globally and in Liberia. During the Ebola outbreak, most people with disabilities told me they received information primarily through the radio – a finding consistent with pre-pandemic research (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021). By the time COVID-19 arrived, however, internet access – whether direct or through others – had grown significantly, exposing people to a much wider and largely unregulated flow of information. People with disabilities frequently mentioned encountering misinformation online and from abroad. This raises important questions about whose knowledge is seen as credible and points to a complex interplay between global power, digital access, and trust, where international narratives may be perceived as more legitimate than 'official' health messaging – despite often being inaccurate or misleading.

7.6.1.'Eating the money'?

Low trust for many of the people with disabilities I spoke to was an outcome of longstanding social injustice – the outcome of a long history of corruption, marginalisation, and a litany of broken promises. The widespread belief that people in authority 'eat the money' reflects lived experiences of a state that was perceived to prioritise self-enrichment over the wellbeing of its citizens (Shepler, 2017). Within this context, the proliferation of rumours and conspiracy theories during both the Ebola and COVID-19 outbreaks is not particularly surprising. Seen through the lens of social justice, belief in conspiracy theories (no matter their origin) can be understood as a form of epistemic resistance (Medina, 2013) and a strategy for (re)asserting agency and reclaiming narrative control in the face of misrecognition and exclusion. The circulation of counternarratives, including conspiracy theories, can, therefore, be interpreted as attempts to reclaim epistemic agency and control in the face of systemic misrecognition.

Systemic corruption exacerbates existing structural violence as it directly siphons money from already limited funds. Liberia's history has been one of unending corruption up until almost the present time. Presidents Sirleaf and Weah were both accused of corruption (Tran, 2012; Giahyue, 2023)[148] and it is only the most recent administration that has started to take concrete actions to combat corruption. In March 2025, sitting President Joseph Boakai 'suspended more than 450 top government officials for failing to declare their assets to the anti-corruption agency' (Rukanga, 2025). Whether these actions will result in prosecution or be effective in curbing corruption it is too soon to tell.

Corruption impairs trust and also exacerbates maldistributive social injustice, deepening poverty – the structural violence of which has direct and damaging effects on people with disabilities (as was discussed in **section 7.5**). Trust also affects 'compliance.

7.7. What is 'compliance'?

Structural violence shaped the ability of people with disabilities to 'comply' with epidemic response measures in multiple, intersecting ways. While public health restrictions were framed as necessary to curb disease transmission, they often failed to account for the lived realities of those already structurally excluded from fulfilling their basic needs. People with disabilities described the lockdowns and curfews imposed during both Ebola and COVID-19 as forcing them into a state of enforced 'sitting down'[149], which they found extremely difficult (if even possible) to navigate without

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[148] In 2023, Liberia ranked 135 out of 180 countries on the Transparency Perceptions Index, scoring just 27/100 (Transparency International, 2025).

[149] As mentioned in **chapter five**, 'sitting down' means inactivity, but it can be a loaded pejorative term also meaning laziness, idleness or unemployment.

breaking the rules. For people with disabilities, who may find it challenging to mobilise within a short time frame or who rely on care from others, ‘compliance’ with restrictions often meant going without. Poverty has been reported to be a mediator with ‘compliance’ in urban Ghana and South Africa (Durizzo *et al.*, 2021).

This was not simply a matter of personal hardship. The inability to ‘comply’ was shaped by years of systemic neglect, from the chronic underinvestment in health systems tied to neoliberal reform and aid conditionalities, to the physical inaccessibility of services due to weak infrastructure, itself a legacy of protracted conflict. Poor road networks, a lack of inclusive transport, and inaccessible facilities disproportionately affected people with disabilities, whose needs were rarely considered in emergency planning. These barriers were compounded by ableist social norms that prioritised ‘ablebodiedness’ and making disability ‘invisible’, thereby positioning people with disabilities as less ‘worthy’ of health services even in non-crisis times.

This also speaks to how structural violence operated not only through *absence* (the lack of infrastructure, services or general inclusion) but also through *presence* (of coercive [violent] enforcement, inflexible systems, and social blame). Many people with disabilities reported being on the receiving end of threats or physical violence when perceived as breaking curfew, even if seeking essentials or support. The very design of the epidemic response thus punished those least able to ‘comply’. In this way, structural violence was not just a backdrop to the response – it was embedded in its logic, its delivery, and its consequences.

The challenges of ‘compliance’ were particularly acute for caregivers, many of whom disclosed behaviours that placed them at greater risk. The structural violence that caregivers experienced during ‘peacetime’ was compounded by the structural violence of the response restrictions. Time was a major issue during both responses. Their caregiving responsibilities often increased due to movement and time restrictions, as they had to meet both their own and their families’ needs while continuing to provide for the person they supported. Caregivers were forced to do their responsibilities under huge pressure and the threat of physical violence and often at high risk to themselves. The caregivers and service providers I spoke to were acutely aware that they were engaging in risky behaviours but felt they had little choice given the absence of state support for themselves or those in their care. The inflexibility of the response, which had a distinct lack of consideration or support, was one of the ways that it most was structurally violent to citizens.

Low levels of trust were found to reduce people's 'compliance' with COVID-19 restrictive measures in 18 African countries[150] (Mazive *et al.*, 2021). This echoes the findings from similar research conducted in Liberia during the Ebola crisis (Blair, Morse and Tsai, 2017). However, care should be taken not to draw a direct causal link between mistrust and the spread of disease (whether it be Ebola, COVID-19 or something else; Richardson, 2019; Richardson, McGinnis and Frankfurter, 2019). This was frequently unproblematically reported in the 'Western' media and fed into dehumanising narratives of 'backwardness' and Africa as a 'diseased, monolithic place' (Benton and Dionne, 2015; Dionne and Seay, 2015; Fairhead, 2016). However, such interpretations clearly oversimplify complex realities and overlook the deeper roots of structural violence – including the legacies of (quasi)colonialism, conflict, and predatory extraction – that continue to shape public perception and engagement with health interventions (Richardson, McGinnis and Frankfurter, 2019).

Many people with disabilities I spoke to told me that they had been 'compliant' with COVID-19 restrictions, but that 'compliance' overall was lower than during the Ebola outbreak. This can be attributed to 'outbreak fatigue' – a reluctance to adhere to measures that once again negatively impacted their lives, especially so soon after their suffering during Ebola. COVID-19 was also widely perceived as being 'less severe' than Ebola, and people often felt that the strictness of the restrictions were overkill. This finding contrasts with other research in Sierra Leone which found a high level of compliance during COVID-19 due to recollections of the severity of Ebola (Diko *et al.*, 2024; Mclean, 2024). However, despite the increased hardship caused by the COVID-19 response, most of the people with disabilities I spoke to still complied with the restrictions as much as they were able.

In addition, 'noncompliance' should not necessarily be taken to be 'resistance' (Wilkinson and Fairhead, 2017). Poverty was found to reduce the effect of COVID-19

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[150] Liberia was not one of the focus countries.

restriction measures (Durizzo *et al.*, 2021; Mazive *et al.*, 2021), which was a key factor that forced people with disabilities to be ‘noncompliant’. Stay at home measures such as the curfews were key locations of ‘noncompliance’ for people with disabilities in the face of unacceptable levels of food insecurity. People told me that they had to work their farms or hustle for money, and of the extreme case of the woman forced to resort to sex work. None of these cases should be considered as ‘resistance’, which implies deliberate (rather than necessitated) disengagement with, or actions directly in opposition to, the epidemic response restrictions. ‘Compliance’ with public health measures required active investment, often in direct conflict with other urgent priorities. Like many Liberians, some people with disabilities said that survival took precedence over risk mitigation. For example, the need for food outweighed concerns about contracting the disease, which, given people with disabilities’ fear of Ebola – and to a lesser extent COVID-19, particularly in the opening stages – is no small thing.

As mentioned, for the most part, the people with disabilities I spoke to (whether they believed the messages or not) said that they had ‘complied’ with the health restrictions to the best of their ability during both Ebola and COVID-19. However, the reasons behind this perceived ‘noncompliance’ or even behind ‘compliance’ have been less widely discussed (Abramowitz, 2017; Abramowitz *et al.*, 2017). For those people with disabilities who complied with the preventative measures, this was often because they believed in their effectiveness, but equally often, this was due to their fear of the potential violent repercussions for perceived ‘noncompliance’. By contrast, for those people with disabilities who actively rejected the restrictions this was because they did not believe that the prevention measures were effective, they did not believe the government ‘narrative’ of the origins of the outbreak, or they felt that ‘compliance’ would adversely affect their lives to an extent that they found to be unacceptable. This latter example includes the man with disabilities who fled Monrovia as self-preservation of his mental health after he had witnessed dead bodies being transported by truck.

7.8. Social and individual Ebola learning

Everyone I spoke to without exception said that they had learned from Ebola and put this knowledge into practice during COVID-19. This included the people with disabilities I spoke to, but also representatives of various organisations. This knowledge was empowering. Anthropologist Paul Richards introduces the concept of a ‘people’s science’ of Ebola, arguing that communities in Sierra Leone possessed the knowledge and expertise to combat the disease with minimal international intervention (Richards, 2016), but that it took ‘patience, respectful dialogue and learning amongst both villagers and health workers to develop aligned understandings of infection risk’ (Leach, 2020, para. 5).

Interestingly, the people with disabilities I spoke to felt specifically empowered by their experiences during the Ebola outbreak when dealing with COVID-19 (which has been documented elsewhere; Mclean, 2024), although this was not the first time that self-quarantine and isolation had been used by communities in West Africa as infectious disease control. Richards (2020b) highlights community responses to smallpox and ‘goat plague’[151] in West Africa, and a disabled community leader I interviewed in Grand Cape Mount talked at length about how his village had dealt with multiple cholera outbreaks. Independently implemented infection control took the form of enforced isolation, amendment to bylaws (including initially proscribing hunting and selling bushmeat), and punitive fines for people perceived as not complying.

However, the people with disabilities I spoke to attribute the confidence in responding to COVID-19 to the external health interventions of Ebola, rather than seeing it as an evolution of their own infectious disease knowledge. This perspective may be partly shaped by the ‘Ebola exceptionalism’ propagated by national and international responses (Richardson *et al.*, 2016), which often downplayed local knowledge during the outbreak, instead favouring a purely biomedical paradigm. This created a narrative that positioned international actors as the primary authorities, undermining the legitimacy of local expertise.

During a ‘knowledge-sharing’ event in September 2024, where I presented findings from my research[152], I posed questions on this topic to attendees. This sparked an interesting

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[151] An extremely contagious disease affecting goats and other small ruminants, which spreads rapidly if not contained and has a high animal mortality rate. Immediate quarantine is critical (FAO, 2025).

[152] See **appendix seven** for the findings booklet I shared with attendees (I’m quite proud of it!) and **appendix eight** for a summary of the visit.

discussion, with the primary feedback being that while participants were already familiar with managing infectious diseases (including haemorrhagic fevers), they perceived Ebola as an unfamiliar threat requiring formal education on prevention and control. They attributed this to a lack of confidence in applying their existing knowledge to what they saw as a ‘new’ disease. Interestingly, they went on to suggest that their confidence in handling COVID-19 stemmed from the disease’s own ‘newness’, not its similarity – because it was also a ‘new’ disease, they felt better equipped to respond. This familiarity with navigating uncertainty enabled them to transfer their knowledge of Ebola prevention to the COVID-19 outbreak.

People with disabilities’ experience with Ebola also indirectly affected their experience of state structural violence. Many people with disabilities told me that, where possible, they ‘prepped’ for COVID-19, thus decreasing their reliance on the state. There was widespread mistrust of the government’s capacity to respond effectively to the disease. This came from a recognition of the structural violence that they had been subject to during Ebola. People tried to anticipate and ameliorate the structural violence of lack of provision, such as understanding that insufficient IPC materials were likely to be made available. This prepping operated at both individual and community levels.

Development agencies and donors did apply lessons from the Ebola outbreak, demonstrating greater flexibility during COVID-19, thereby allowing NGOs on the ground to respond more swiftly. However, as many people told me, familiar patterns from the Ebola crisis re-emerged: donors and NGOs withdrew from Liberia at the onset of the COVID-19 outbreak (some never returning), which significantly limited the overall response. In these instances, NGOs exercised their sovereignty, asserting their right to determine the timing of their withdrawal (Abramowitz, 2015). Yet, this autonomy also exemplifies structural violence by the global community against Liberia – the power to dictate when and how to intervene (or not) remains firmly in the hands of external actors (Sirleaf, 2018).

7.8.1. The violence of language

Language was a key vehicle for violence throughout both outbreaks. It was used not only to describe the experiences of people with disabilities, but also as a means of marginalisation, dehumanisation, and control. Ableist language is a structural mechanism that sustains exclusion and causes status harm. Deficit-based or infantilising terms reinforce the notion that disability is inherently undesirable, shaping social attitudes. Such language contributes directly to misrecognition (Fraser, 2005, 2009) – the denial of equal social status and dignity – which in turn justifies and perpetuates the marginalisation of people with disabilities in both policy and practice, therefore enacting cultural violence (Galtung, 1990).

People with disabilities spoke of being subjected to demeaning treatment, particularly by police and other authorities. Pejorative terms like ‘cripple’ reflected entrenched hierarchies that positioned people with disabilities as inferior or undeserving. These words were not merely offensive; they actively contributed to structural exclusion. At the same time, people with disabilities also employed the language of violence to describe their own experiences. One participant described the COVID-19 lockdown as being a form of ‘incarceration’ – signalling not just restriction but a deeper loss of agency and autonomy – while another said they felt ‘hunted’ when they were perceived to be ‘noncompliant’ during the Ebola crisis. These metaphors were not exaggerated; they were grounded in lived experience and underscore how ableism operates both discursively and materially, with language used to both describe and enact structural violence.

7.9. Conceptualising health

The ways in which people with disabilities conceptualised their own impairment may have affected their reception of ‘biomedical’ explanations for the outbreaks’ causes and response activities. People with disabilities may have been more receptive to biomedical explanations for diseases as the medical model of disability is still very much in evidence in Liberia (many people spoke of their desire to be ‘cured’ of their disability).

The structural violence of the medical model in Liberia is insidious. People with disabilities’ desire for ‘cures’ leads to an uninterrogated desire for a health system that does not fit the needs of people. However, due to this structural violence of the insufficient health system, many were resigned to the state of the general health system and were not optimistic about their chances. This resignation also resulted in people seeking 'cures' outside of formal healthcare. Many people with disabilities told me that as children, their families had taken them to priests, imams or healers, hospitals and spiritual leaders in search of 'cures' for their disability. Their disability was sometimes blamed on witchcraft, curses or dragons. For many people, the biomedical paradigm was just one part of their health 'toolkit'.

The wider population mistrusted health professionals during both outbreaks. However, this was not the case for the people with disabilities I spoke to, many of whom expressed trust for health workers, even when mistrusting formal health infrastructure (fearing nosocomial transmission). Yet, people with disabilities (possibly rightly) did not have high expectations from the public health system. Where they could they accessed private healthcare (Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021). Particularly during Ebola, people with disabilities avoided the health system altogether where possible. Many people with disabilities resorted to self-treatment rather than accessing formal healthcare. However, even during 'peacetime', people with disabilities' capacity to access formal healthcare is often reduced due to unaffordable out-of-pocket costs (Carew *et al.*, 2019).

7.9.1. 'Flattening the curve', flattening the timeline

One way in which learning from Ebola shaped responses to COVID-19 was by 'flattening' the COVID-19 timeline. During the Ebola epidemic, people with disabilities initially lost agency but eventually regained it, following an observable 'narrative arc'. In contrast, during COVID-19, this pattern did not re-emerge. Instead, people with disabilities acted early, seeking to pre-empt structural violence rather than simply endure it. Their efforts reflected a refusal to be written out of crisis response once again and an insistence on shaping outcomes, not merely surviving them.

Participants described a range of actions, including advocacy, public awareness, proactive compliance, and peer mobilisation. These were not just practical responses; they were a way of asserting and maintaining agency. Even under the strict and violent enforcement of 'stay at home' measures, they were able to maintain a sense of agency and influence over their circumstances. Seen through a social justice lens, these acts challenged the structural conditions that routinely deny people with disabilities the opportunity to achieve ‘parity of participation’ (Fraser, 2005). This also can be seen as people with disabilities disrupting the narrative of passive vulnerability and creating their own space for recognition, one of the core dimensions of justice.

Another way this timeline was ‘flattened’ was through the vastly increased and more immediate access to information. Unlike during the Ebola outbreak, where media consumption was largely confined to traditional sources, predominantly radio, and messaging evolved over time, COVID-19 saw a rapid and fragmented flow of content (even at a not insubstantial cost). People with disabilities described receiving updates through WhatsApp, relatives abroad, and social media, often before any official guidance was issued from Capitol Hill[153]. While this increased access enabled quicker dissemination of health messaging, it also raised concerns about misinformation, confusion, and information overload. This shift raises concerns for future epidemic responses, as the rapid expansion of access to ‘information’ (both reliable and misleading) has the potential to undermine efforts to contain disease outbreaks. An effective response must not only disseminate accurate information but also actively shape the narrative; otherwise, misinformation and denial will persist, jeopardising public health efforts.

7.9.2. Health from the bottom up

Shaping the epidemic narrative, however, cannot only be a top-down exercise. Bottom-up strategies for risk communication are essential to ensure that health messaging resonates with people’s lived realities. When people feel that their knowledge is recognised and that information flows both ways, they are more likely to engage meaningfully with public health measures (Hrynick, 2020). These strategies include working with community- and traditional leaders, OPDs and faith-based organisations to co-create and share accessible, relevant messages. Engaging people with disabilities as communicators and educators can further enhance trust and relevance. By engaging civil society at the grassroots level, knowledge and information can move horizontally –

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[153] seat of the Executive Mansion and the Liberian Senate.

shared among different OPDs and people with disabilities in different areas – and vertically, reaching decision-makers and shaping the response itself.

Anthropologists advised that contrary to conventional ('Western') wisdom, communities were willing to change their behaviours – particularly around funerals[154] and burials – if they deemed it 'reasonable and implementable in the context of [their]… daily lives' (Abramowitz, 2017, p. 425). Communities were often already implementing their own quarantines when people potentially had Ebola, and such individual and community learning should be capitalised upon. When communities were enabled to actively contribute to the response (such as being trained to conduct safe burials), 'compliance' increased substantially (Richards, 2016). Drawing on existing knowledge systems and social ties allows information to flow through channels that are already trusted rather than imposed.

Two-way communication must also be prioritised. When communities are treated as knowledge-holders rather than passive recipients, public health communication becomes a collaborative and dynamic process – one that can better respond to fears, adapt to misinformation, and strengthen both trust and compliance (Gillespie *et al.*, 2016; Abramowitz *et al.*, 2017). Therefore, the role of OPDs and civil society should go beyond simply acting as an information channel. Bottom-up health responses must foster bidirectional knowledge sharing, where information flows both to and from OPDs/communities. This approach has the potential to be not only more effective but also more efficient – both financially and logistically – than traditional top-down programmes, which are often very expensive (Richards, 2020b). Bottom-up responses would also reduce maldistribution as resources could be better targeted at the people with disabilities who need them the most, avoiding to the greatest extent possible, resource duplication or missing out the person.

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[154] As anthropologists Paul Richards (2016), Melissa Leach (2016), and others argue (Fairhead, 2014; Moran, 2017; Farmer, 2020), labelling one group's funeral traditions as 'backward' is a highly relativist perspective. It fails to acknowledge and critically examine our own normative cultural practices surrounding death and mourning.

There is a plethora of guidelines, policy briefs, position papers, and research findings on how to include people with disabilities in humanitarian responses, including epidemic and health emergencies. Genuine inclusion doesn’t require reinventing the wheel. However, making these plans and approaches appropriate for people with disabilities, specifically in Liberia, is key to ensure acceptance and uptake. Bottom-up approaches allow health messages to be contextualised as needed, ensuring they are acceptable and accessible to the widest range of people. This is particularly crucial for people with disabilities – the example of the people with hearing impairments not knowing about the COVID-19 curfew could have been avoided had the disability community been actively involved in bottom-up health responses as this situation would have been identified and information made accessible at a much earlier stage in the outbreak.

Grassroots initiatives alone are not enough to eliminate social injustices in epidemic responses; however – representation matters. The inclusion of people with disabilities at all levels of decision-making is essential. A case in point is the Grand Cape Mount NUOD county coordinator, who was eventually able to report on the situation of people with disabilities during both outbreaks to the county-level outbreak ‘task force’ meetings. Such representation must be built into response systems from the outset.

7.9.3. Vaccines

Understanding how people respond to vaccines requires more than a focus on individual choices or knowledge gaps. Vaccine decisions are shaped by context – including histories of exclusion, relationships with health systems, and broader power dynamics. Anthropologists caution against the presumption of homogeneity in people’s vaccine opinions – including both fears and desires – as such assumptions risk flattening the complex social, cultural, and political contexts that shape individual decision-making. Vaccine acceptance or hesitancy is not simply a matter of personal belief or lack of information, but is embedded in wider histories of power, trust, and inequality. As Leach and colleagues (2022) argue, failing to attend to these ‘societal and wider political understandings’ obscures how experiences of marginalisation, past abuses, and perceived injustices influence responses to vaccination campaigns.

In the wake of historic vaccine suspicion and the increasing prominence of the global antivaxx movement (Lee *et al.*, 2022; Carpiano *et al.*, 2023), the uptake of COVID-19 vaccines in Liberia was surprisingly high (WHO, 2025). Historically, West Africa has had a fraught relationship with vaccines. Medical colonialism prioritised control over caregiving (Green, 2022), including attempts to conduct forced vaccinations and performing thousands of blood tests without any kind of informed consent (Farmer, 2020).

Almost all the people with disabilities I spoke to told me that they had taken the vaccine. However, many of them said that this was unusual. This contradicts official statistics – WHO reported that by the end of 2022, Liberia had successfully vaccinated 81% of its population (WHO, 2025) – and is an interesting frequently repeated narrative. This speaks to the mistrust that many felt towards the formal health response, and feelings of regaining control in the choice to take the vaccine (or not). Even if people lied to me about their vaccine status, in their choice of lying to me they controlled the narrative, which is also regaining control. Another factor may also be that most of the people with disabilities who participated in my research (particularly those in Monrovia) tended to have higher levels of education than average, which is associated with greater health literacy (Meherali, Punjani and Mevawala, 2020). That said, many people I spoke to had little or no education, and the majority of these people with disabilities also reported that they had taken the vaccine.

Another concerning finding was that mistrust during the COVID-19 pandemic extended beyond the vaccine and appeared to undermine confidence in routine childhood immunisations, which are usually not contentious. According to the County Health Officer in Grand Cape Mount – who likely had access to full vaccination data – uptake of routine immunisations dropped significantly at the peak of the outbreak, although it gradually rebounded once the crisis subsided. She blamed this on the COVID-19 vaccine hesitancy. However, missed vaccinations may have serious and long-lasting consequences, particularly for children who aged out of the immunisation window. In January 2022, Liberia experienced a major measles outbreak, with reported cases continuing for nearly a year. A total of 8,127 cases were recorded, with children accounting for nearly 60%. All 84 reported deaths were in children under the age of 15, with 93% occurring in those under five (Shobayo *et al.*, 2024). Vaccine coverage was dangerously low at just 44%. Especially in children, measles can cause permanent and life-altering impairments – including blindness, brain damage, and hearing loss – making these immunisation gaps a serious public health concern.

This section has explored how people with disabilities in Liberia conceptualised health and responded to epidemic threats across two outbreaks. It examined how desires for 'cures' were shaped by structural violence, as well as the role of information and communication on health, highlighting the importance of trusted, community-led approaches in building engagement and countering misinformation. Finally, it reflected on vaccine decision-making as a site of both agency and mistrust, shaped by histories of exclusion and ongoing inequality.

7.10. Models of disability: negotiating coexistence

The findings discussed in this thesis reveal that both people with disabilities and local and national stakeholders in Liberia employ a pluralistic and sometimes contradictory engagement with the various models of disability. Particularly in Monrovia, many people with disabilities often invoked the language of the human rights model – in many cases referring specifically to the UNCRPD and the lack of implementation of Article 11 (risk and humanitarian emergencies) during the epidemics. In these cases, many people with disabilities I spoke to were very politically engaged and were critical of the state for failing to hold up their obligations, particularly around exclusionary programmes and practices rooted in ableism, although mostly people did not directly use the term.

Although rights-based discourse was much less common in rural and remote areas, it was still present, particularly those in the leadership or senior positions of OPDs, although the language of the social model was much more common. While Monrovia is not an accessible environment, particularly for people with physical or visual impairments, rural and remote areas tended to be even more hostile for people with disabilities. Therefore, it was understandable that under conditions of extreme poverty and suffering – a consequence of pervasive structural violence – social model discourse was much more prevalent than that of rights. Very few people with disabilities in rural and remote areas who were not involved in OPDs used rights-based language or advocated for policy implementation.

The charity and medical models of disability are still deeply embedded, however. This was frequently in relation to the interactions that people with disabilities had with others, but the models were also evident in internalised self-perceptions. Several people with disabilities became emotional when telling me that they wanted to be cured, feeling burdensome if they were not able to contribute financially and faced exclusion because of their disability. These narratives of seeking cure and internalised pity were shaped by extreme poverty and suffering under structurally violent conditions.

The charity model sometimes surfaced in interpersonal encounters during the outbreaks. This included through the ableist presumption of need, such as a person with a visual impairment who was shoved across a busy road during the COVID-19 outbreak by a stranger 'trying to help'. which both put him at risk and also impacted on his psychological wellbeing through the fear of being infected. However, during the outbreaks, the perception of 'charity' became more complex. As lives were upended and livelihoods collapsed, sinking many people into precarity, people described the gratitude of receiving aid (particularly during lockdowns), whereas prior to the outbreak they described the pride of economic independence. For others, being forced into situations of precarity and having to beg for food and money – literally charity – was deeply shameful.

The responses themselves were overwhelmingly biomedical with a very narrow focus on disease prevention and control. There was little to no attention paid to the social model of disability: food distribution sites were inaccessible; televised briefings had no sign language interpreter; and restrictions around proxies for aid excluding many from desperately needed supplies. All this meant that people with disabilities remained uninformed, hidden or in some cases literally starving. This sidelining of social model reproduced structural violence, as the biomedicalisation of the response shaped who was seen and who was supported. It actively deepened existing inequalities by making it challenging – if at all possible – for people with disabilities to comply with the epidemic response measures.

The human rights model has received some recognition in policy discourse, particularly during the time when UNMIL's Human Rights Division was supporting the disability task force. However, implementation remains patchy. In addition, some policies that remain on the statues continue to use overtly medicalised and pity-based conceptions of disability – including within the Constitution. This signals a lack of political will to translate rights – which are enshrined in the UNCRPD – into meaningful change. All this illustrates how structural violence operates at the highest level, both in the lack of enforcing these rights-based policies, but also in the persistent and pernicious embedding of the charity and medical models.

Strikingly – and worryingly – no models of disability were in evidence in Liberia's Ebola or COVID-19 response plans at all. There were no indications that policymakers drew on any disability model in the design of response strategies and roadmaps. This gap points to the systemic marginalisation of people with disabilities during the design of such plans, and that their inclusion in the response is an afterthought. This brings into focus how much the human rights model remains aspirational in public health emergency planning, and that without addressing the pervasive structural violence and ableist structures, it will remain just that.

These findings show how the experience of disability is complex and was often drawn from multiple models simultaneously. They emphasise the importance of nuance when exploring how these models function in practice. The next section outlines how this research responds to that need and its contribution to scholarship on the disability models

7.10.1. Adding nuance to the models of disability

This thesis contributes to the literature on the models of disability by providing empirical evidence on how they operate in two public health emergency situations in a low resource setting. Findings show that it is not sufficient to presume a linear, discrete and chronological evolution of the models, each of which overwriting the last. Instead they show that all models coexist in a contested space where they interact in dynamic and complex ways. This thesis contributes to the literature by evidencing how people with disabilities continually negotiate these models, which are performed differently depending on the situation, need, or encounter.

A further contribution that this thesis makes to the literature is its use of structural violence. Despite its relevance, this framework has received limited attention in disability scholarship (Muderedzi *et al.*, 2017; Dean *et al.*, 2022; Wickenden, 2024). This thesis shows the nuanced ways with which different models of disability produce, reinforce or mediate structural violence during epidemic crises, and shows how they impact differently depending on whether perpetuated by state or by non-state actors. It also illustrates how people with disabilities actively negotiate structural violence, themselves drawing on and shifting between the different disability models as they navigate public health emergencies and humanitarian responses.

7.11. Strengths and achievements

I am proud of what I was able to achieve in undertaking this research – both in terms of the insights it generated and the work I did with the people with disabilities who I spoke to. I was able to collect really rich and evocative information from so many people who were really committed to sharing their experiences and opinions. My photovoice co-researchers were without exception extremely engaged and enthusiastic. I was astounded by the quality of the photos[155] and their group analysis.

Using structural violence as an analysis tool worked very well in this project. Its focus on inequalities, systemic exclusions and historical factors enabled an in-depth analysis of how harm and marginalisation is embedded within social and institutional systems in Liberia as well as within epidemic responses. It also uncovered the ways in which power operates within or over these systems, shaping the lives of people with disabilities.

One of the moments that I am most proud of is the ‘knowledge sharing’ event. This multi-stakeholder meeting was attended by the disability community, government representatives, UN agencies, Red Cross, as well as local and international NGOs, civil society, and importantly the research participants themselves. It was an opportunity to validate the results, but it served as a collaborative space for co-producing recommendations, which helped to ensure they were contextually appropriate and promoted ownership. This event was a real highlight for me.

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[155] See **appendix five**.

7.12. Challenges and limitations

While my research has many strengths, several limitations must nonetheless be acknowledged. First, although participants with disabilities generously shared their time, stories, and reflections with me, I was not able to explore their full life histories to the extent I had originally hoped. Time constraints meant that my analysis focused primarily on their experiences of the Ebola and COVID-19 outbreaks rather than tracing their lives more fully.

While the photovoice component of the study added richness and depth, it was not as co-produced as it ideally could have been. In principle, photovoice projects should be driven by co-researchers who actively shape the project from the planning stages. In practice (as is the case with many photovoice projects), I entered the research with pre-determined questions that drove the project. Although I tried to leave space for flexibility and participant-led exploration, I had to ensure that the topics aligned with my research objectives. This tension between methodological ideals and practical constraints is one that many participatory studies face.

Another limitation relates to the scope of the participant group. My research focused exclusively on people with disabilities, and therefore, I cannot make direct comparisons with the experiences of non-disabled people beyond what was shared anecdotally by participants. However, this focus was a deliberate decision. My aim was to centre the voices and experiences of people with disabilities whose perspectives are frequently overlooked in policy and academia.

Finally, this research does not explore the experiences of people with disabilities living in areas that were relatively unaffected by Ebola. This, too, was an intentional choice. Outside of the initial lockdown period, people living in these areas were largely spared the more intense restrictions that characterised the outbreak response in heavily affected counties. Focusing on areas with significant exposure to the epidemic allowed for a deeper analysis of how exclusion and structural violence operated in moments of heightened crisis – a focus that aligned with the central aims of the research.

While no study is without its limitations, these do not undermine the value or relevance of this research. Rather, they reflect the realities of conducting ethical, inclusive, and responsive research in complex and sometimes unpredictable environments.

7.13. Conclusion

This penultimate chapter has examined how people with disabilities experienced the Ebola and COVID-19 outbreaks in Liberia, drawing on their accounts to analyse the intersecting forces of structural violence and social injustice. Through the lens of these frameworks, the chapter has explored how historical legacies, global power dynamics, rural marginalisation, systemic ableism, and entrenched poverty shaped people's lives and constrained people with disabilities' access to health, protection, and participation. These challenges were not simply by-products of crisis but expressions of longstanding inequalities and state neglect – at times exacerbated by the very systems designed to provide relief.

Yet this analysis also highlighted how people with disabilities navigated, resisted, and at times even reshaped the responses to both outbreaks. Their stories reveal not only how exclusion operates but also what inclusive change could look like. As the thesis now turns to its final chapter, it returns to reflect on what must be done to move from exclusion to equity – and from structural violence to structural justice.

Chapter eight: conclusions

8.1. Introduction

This concluding chapter draws together the threads of the thesis and offers some final reflections. I begin by restating the research questions and summarising the key arguments from each of the seven preceding chapters. I then outline the contributions that my research makes to the literature on disability and disease outbreaks, before presenting several insights that emerged from the analysis. The chapter goes on to offer a set of recommendations for more disability-inclusive emergency response systems. I conclude with suggestions for future research and a brief reflection on my personal and professional journey through this project, before offering some final thoughts to close the thesis.

8.2. Research questions

My research had two overarching questions.

- How have people with disabilities in Liberia experienced recent epidemic responses and public health measures, and to what extent have they been included?
- What approaches can enable people with disabilities to participate in and lead inclusive systemic change?

8.3. Chapter summaries

Before moving on to the contributions and conclusions of this thesis, I want to take a moment to briefly revisit the chapters that led up to this point. Each one has built on the last to explore different aspects of the research and together helped shape the analysis.

The **first chapter** set the scene for the rest of the thesis. The introduction set out the rationale, research questions, and structure of the thesis. It gave a broad overview of Liberia and outlined the study's focus on the experiences of people with disabilities during the Ebola and COVID-19 outbreaks.

The **second chapter** offered a historical overview of Liberia, grounded in the belief that the past profoundly shapes present-day realities. Within the limits of the word count, it traced in as much detail as possible the key events from Liberia's early settlement through to the COVID-19 pandemic, highlighting how legacies of conflict, inequality, and international intervention have shaped the country's political, social, and institutional landscape. This historical context is essential to understanding the contemporary dynamics of health, disability, and structural violence explored throughout the thesis.

Chapter three was a scoping review in which I reviewed the limited literature on the intersections of disability and epidemic response in West Africa, with a particular focus on the Ebola and COVID-19 outbreaks. It revealed substantial gaps in both empirical data and theoretical engagement with disability within the context of public health emergencies. Despite this scarcity, several recurring themes emerged: disruption to health and education services, the impact on mental health and food security, and the persistent lack of participation by people with disabilities in emergency planning and response. The literature frequently overlooked the heterogeneity of disability and reinforced the urgency of centring the perspectives and experiences of people with disabilities in future research and policy.

Chapter four outlined the methodological approach and methods used in this research, including life history interviews, photovoice, and key informant interviews. Informed by the lenses of structural violence and social justice, these methods were selected to centre the lived experiences of people with disabilities and critically examine their interactions with – and positioning within – health emergency responses. I also reflected on how my own experiences, including a period of illness during fieldwork, shaped the research process and relationships with colleagues. Throughout, the chapter emphasised the importance of reflexivity and inclusive, participant-led approaches to knowledge production.

Chapter five presented the first set of findings from my research, focusing on participants' experiences of the Ebola outbreak. Through thematic analysis, I identified four key themes: 'the response is not responsive'; 'enforced inactivity in the Ebola time'; 'strategies for regaining agency'; and 'free at last?'. The analysis revealed a broadly chronological narrative in how people with disabilities experienced the outbreak. Initially, their agency was severely restricted by the nature of the response, particularly the enforcement of movement restrictions. Over time, however, participants developed individual and collective strategies to navigate these constraints and gradually reclaim a sense of autonomy. By the end of the outbreak, many described having regained their agency, albeit in a changed social and political context. The chapter also explored the proliferation of rumours and conspiracy theories, which served as both a coping mechanism and a means of critiquing the state and international response.

Chapter six examined the experiences of people with disabilities during the COVID-19 outbreak, drawing on interview data and insights from the photovoice project. Four key themes emerged: 'same difficulties, different disease'; 'Ebola gave us expertise'; 'health and disability during COVID-19'; and 'opinions and comparisons'. Unlike the Ebola chapter, these themes did not follow a clear chronological arc but instead reflected a more fragmented and layered set of experiences. Crucially, the chapter demonstrated how many participants drew on lessons from the Ebola outbreak, applying this knowledge in ways that fostered a sense of preparedness, agency, and resilience. At the same time, it underscored widening disparities between urban and rural or remote areas, where improvements in access to food, essential supplies and timely information in the former were not mirrored in the latter. Overall, the findings point to both continuity and change in how people with disabilities experienced and navigated public health crises.

In chapters five and six, I presented participants' narratives of the Ebola and COVID-19 outbreaks. In **chapter seven** I utilised the frameworks of structural violence and social justice to analyse how exclusion, inequality, and resilience shaped people's experiences across both crises. I examined how global and local systems – including donor dependency, rural-urban divides, ableist assumptions, and community learning – influenced people's exposure to risk, trust and resistance.

And so, we arrive at **chapter eight**. This concluding chapter brings together what I understand to be the key insights from the preceding chapters and offers some closing reflections. This chapter draws together the core arguments of the thesis, grounded in the lived experiences of people with disabilities during the Ebola and COVID-19 outbreaks in Liberia.

I will now move on to the contributions that my research can make to the current scholarship in this area.

8.4. Contribution to the literature

There is a small but growing body of literature that explores successive disease outbreaks in West Africa, often comparing the social and institutional responses to Ebola and COVID-19 (Onyekuru *et al.*, 2023; Diko *et al.*, 2024; Mclean, 2024). This literature reflects a broader recognition of the need to understand how previous experiences of public health emergencies shape current responses. However, this comparative work remains limited in scope and geography and rarely centres the experiences of people with disabilities.

Similarly, there is a modest body of work examining the role of structural violence in shaping the course and impact of disease outbreaks in West Africa. Much of this literature focuses on the Ebola crisis and includes contributions by scholars such as Wilkinson and Leach (2015), Bardosh et al. (2016), Hirschfeld (2017), Sirleaf (2018), and Farmer (2020). These works have been critical in shifting attention from individual behaviours to the wider systems that produce vulnerability. However, disability is rarely addressed within this framework. Even in the extensive writings of Paul Farmer, whose work inspired much of the current thinking on structural violence and health – and whose approach was a central foundation for my thesis – disability is strikingly absent (Farmer, 2004, 2005, 2009a), for example, mentioned only briefly in relation to post-Ebola syndrome (Farmer, 2020). Where disability is included in research on structural violence, it is often treated as a side note, with limited engagement in terms of analytical depth or political urgency.

It is striking how little literature explicitly examines the intersection of disability and structural violence, particularly in low- and middle-income countries (Muderedzi *et al.*, 2017). This gap is especially evident in the West African context, where histories of conflict, poverty, and health system fragility make such analysis urgently necessary. A notable exception is Dean et al. (2022), who explore the syndemic interactions of neglected tropical diseases, mental distress, and disability in Liberia using a structural violence framework. Another contribution is Szántó (2020b), who examines structural violence and disability in Sierra Leone. However, beyond these studies, disability is often either overlooked or treated in isolation from the broader political and economic structures that shape exclusion. This absence reflects a broader failure within global health and development literature to meaningfully engage with disability as a site of structural injustice.

Other studies have explored disability and Ebola in Liberia (Carew *et al.*, 2019; Kett, Cole, Beato, Carew, Ngafuan, Sekou Konneh, *et al.*, 2021), while COVID-19 and disability are addressed in a few emerging studies, including Chowdhury et al. (2022) which explores the experience of people with disabilities during COVID-19 in Liberia (and Bangladesh)s. There is also very limited literature that uses photovoice with people with disabilities in West Africa (Chowdhury *et al.*, 2022; Naami, 2022). Despite these contributions, no study to date has brought these various elements together into a single analysis.

This thesis, therefore, makes an original contribution by drawing together multiple underexplored dimensions into a single study. Its focus on two public health emergencies, a structurally marginalised population, and an analytical lens that foregrounds systems, power, and exclusion is, to my knowledge, the first study to do so in the Liberian context. My research also draws on qualitative and participatory methodologies – including photovoice and life-history interviews – to centre the voices and agency of people with disabilities. In doing so, it goes beyond documenting experiences to critically examine the ways that exclusion is produced and sustained across time and crises. This research not only fills an empirical gap in the literature on disability and epidemic response in Liberia, but also advances conversations about structural violence, systemic exclusion and possibilities for inclusive change.

8.5. Insights and conclusions

Having summarised the preceding chapters and discussed this thesis' contributions to the literature on disability and epidemic response, I now turn to the key insights that emerged from the research. These draw together findings on how people with disabilities navigated crisis, exclusion, and resilience and aim to identify possible routes toward more inclusive and equitable emergency response in future outbreaks.

8.5.1. Exclusion in health emergencies is rooted in structures

The exclusion of people with disabilities in health emergencies is embedded in longstanding institutional practices and social norms. This systemic neglect was evident in Liberia's epidemic responses, where people with disabilities were routinely left out of planning processes, data collection, and the distribution of lifesaving resources. Their absence from preparedness and response actions was not the result of individual oversight, but rather a reflection of structural failings that render disability invisible or unimportant in the eyes of the state and humanitarian actors. This invisibility is particularly harmful during emergencies, when access to information, food, healthcare, and protection becomes a matter of survival.

What this research reveals is that exclusion is not simply a product of physical or informational inaccessibility, but of deeper systemic patterns that deprioritise the rights and needs of people with disabilities. Exclusion during emergencies is an extension of the social and political marginalisation that many participants experienced in everyday life. Their insights point to the urgent need for systemic reform, including investment in disability-inclusive data collection, preparedness planning, and inclusive social protection systems. Without addressing these root causes, emergency responses will continue to replicate and widen the inequalities they purport to address.

8.5.2. Health emergencies magnify ableism

Epidemics cause and amplify ableism. During both Ebola and COVID-19, ableist assumptions were evident in the failure to consider the specific needs of people with disabilities in public health messaging, service provision, and containment measures. Blanket policies that assumed everyone could queue for food, access health centres, or comply with lockdowns ignored the reality of disabled lives. Participants shared stories of being denied services, poorly treated by health professionals or outright ignored by those tasked with delivering emergency aid. These experiences reveal how health emergencies become spotlights where societal attitudes towards disability are made painfully visible.

The normalisation of ableism in crisis contexts reflects broader cultural and institutional structures that assign lesser value to disabled lives. In the most extreme cases, people with disabilities' lives were deemed expendable through the denial of lifesaving supplies – a direct result of social and political practices that failed to see them as full and valuable members of society. This not only exacerbates harm during health emergencies but also contributes to long-term exclusion. As future public health crises are inevitable, there is a critical need to dismantle these ableist structures and ensure that emergency preparedness strategies recognise people with disabilities as equal stakeholders in health and social systems.

8.5.3. People with disabilities have resilience and agency

Despite the enormous challenges they faced, people with disabilities in Liberia were not passive during Ebola and COVID-19. Many took swift and deliberate actions to protect themselves and their communities, stepping in where the state or humanitarian actors failed. These strategies ranged from distributing infection prevention messages and materials, to engaging in community education, and OPDs negotiating to ensure inclusion in aid distributions. Such examples challenge dominant narratives that frame people with disabilities as dependent or helpless in crisis situations.

This research highlights how agency must be recognised and supported, not just celebrated after the fact. Participants' actions were not only pragmatic responses to exclusion but also acts of resilience despite systems that had failed them. Ensuring that people with disabilities are meaningfully included in emergency planning means listening to and learning from these experiences. Supporting their agency requires resourcing local OPDs, amplifying advocacy, and challenging the structures that routinely disempower them.

8.5.4. Emergency responses reproducing exclusions

The design and implementation of vertical programmes often failed to meaningfully engage with people with disabilities. They reported often not receiving supplies, being excluded from decision-making and were rarely consulted about their needs. Their marginalisation was compounded by logistical and infrastructural limitations that donor programmes did little to address. As a result, people with disabilities found themselves outside the margins of response. This bred frustration and mistrust, which ultimately may compound the pervasive poverty that people with disabilities experience (Kett *et al.*, forthcoming) and reinforce the very exclusion that such programmes are designed to challenge. For donor-led responses to truly promote equity, they must centre the voices and needs of marginalised populations, invest in inclusive systems, and move beyond the short-termism commonly found in humanitarian interventions and dovetailing with ‘development’ initiatives to ensure a continuation of post-emergency recovery and inclusion (Howe, 2019).

8.5.5. Trust is structural as well as personal

Trust is not simply a matter of communication or persuasion; it is steeped in history and embedded in structures. For people with disabilities in Liberia, mistrust in the state and in humanitarian actors was shaped by long histories of exclusion, neglect, and litanies of broken promises. Many participants described feeling that they had been repeatedly overlooked, not only during crises but in ‘peacetime’ as well. This persistent structural violence eroded their confidence in those implementing the response. As a result, public health messaging was met with scepticism, and adherence to guidelines was filtered through (and sometimes despite) individual and collective experiences of marginalisation. Rebuilding trust requires both systemic change and long-term investment. It means listening to those who have been marginalised and valuing their knowledge, perspectives, and priorities, and resourcing OPDs and people to play meaningful roles.

8.5.6. Learning from one crisis does not guarantee change

One of the most sobering findings of this study is that despite the extensive experience of Ebola, many of the same mistakes were repeated during the COVID-19 response. People with disabilities were again excluded from planning processes, again left out of communication and resource distribution, and again faced the consequences of inaccessible and ableist systems. This points to a critical failure in institutional learning. This was ‘not all institutions’, as some had put in place data collection mechanisms and focal points directly as a result of their experience during Ebola, but more learning needs to be made in order to create the systemic change needed.

People with disabilities, however, often did learn. Many drew directly on their experiences during Ebola to inform their responses to COVID-19. They prepped where they could, mobilised their communities, and advocated for themselves more forcefully. However, without systemic change, such grassroots learning can only go so far. For future health emergencies to be truly inclusive, learning must be embedded at every level – from national health strategies to the policies of international donors down to local health and governance structures – with people with disabilities at the centre of that process.

8.5.7. Yet, change is possible – and is already happening

Systems are not fixed, and positive change can and is being made. Despite the numerous challenges highlighted throughout this research, there were also encouraging signs of progress. Several government and institutional actors demonstrated a growing awareness of disability rights, and a few institutions began to integrate disability more meaningfully into their programmes. Some people described an increased agility of donors to pivot to COVID-19 responses (including in disability NGOs), others pointed to the (eventual) increased accessible health messaging for people with hearing impairments, and some OPDs were consulted at national and local levels – even if this was often only occasional. These examples, while limited, show that change is not only possible but already underway in some quarters. Achieving more equitable outcomes for people with disabilities will require not just more change but faster and more consistent change – driven by the leadership of people with disabilities themselves and supported by inclusive institutions that uphold their rights.

8.6. Recommendations

Building on these conclusions, this research offers useful insights for shaping future emergency responses in Liberia, with potential relevance for other low-income or crisis-affected contexts. The following recommendations aim to support more inclusive emergency responses, and to enable people with disabilities to participate in and lead these efforts.

8.6.1. Resource and strengthen OPDs

OPDs are essential to creating inclusive emergency responses, yet they are often under-resourced, lack capacity and are excluded from decision-making structures, particularly at the county and district levels. This research found that OPDs were frequently engaged in awareness-raising but rarely involved in shaping policy or implementation. To enable meaningful participation, OPDs need sustained support to strengthen institutional capacity and facilitate their inclusion in planning and coordination mechanisms. With adequate resourcing, OPDs can play a central role in preparedness, response, and recovery – and in holding these systems accountable.

8.6.2. Recognising people with disabilities as knowledge-holders

People with disabilities bring essential knowledge, insight, and lived experience to emergency response and recovery efforts, yet this expertise is rarely recognised. As this research has shown, people with disabilities are not passive recipients of assistance but active navigators of systemic barriers and contributors to community resilience. Their perspectives are vital to understanding what works – and what does not – in public health crises. Participatory research approaches, such as (but not limited to) photovoice, should be used consistently to enable people with disabilities to co-produce knowledge as researchers and experts in their own experience. Their contributions can shape decision-making and drive systemic change at every level, from local preparedness to national coordination.

8.6.3. Accessible information and two-way knowledge sharing

Access to timely, accurate information is a fundamental right and a cornerstone of effective emergency response. During both Ebola and COVID-19, many people with disabilities were excluded from vital health messaging due to inaccessible formats or geographic isolation. Inclusive communication strategies must be designed to meet the diverse needs and circumstances of people with disabilities. Equally important is the need for meaningful knowledge-sharing. Responses in both outbreaks were marked by missed opportunities to learn from communities. Local knowledge and community-led strategies were often siloed or overlooked. Future responses must establish both horizontal (between and within communities) and vertical (local to decision-maker) channels for sharing inclusive practices and lived expertise. Building on local knowledge can not only strengthen emergency responses but also increase the resilience of communities between crises.

8.6.4. Investing in inclusive preparedness, not just response

Exclusion during crises is a symptom of failures during ‘peacetime’. Building inclusive emergency systems must begin well before an emergency hits, through disability-inclusive disaster risk reduction, planning, and investment in infrastructure that enables inclusive response systems. People with disabilities and their organisations must be supported to participate meaningfully in this work. Inclusion cannot be an afterthought or confined to consultation. It must be embedded into the design of emergency systems – from national preparedness frameworks to local coordination mechanisms – and backed by adequate funding specifically allocated for accessibility and inclusion. Crucially, insights from people with disabilities must be able to shape policy and planning – not only because this is a rights issue, but because it strengthens the overall effectiveness and equity of public health responses.

8.6.5. Challenging ableism through policy and practice

Ableism was a structural barrier that cut across every layer of the epidemic responses, ranging from inaccessible distribution systems and discriminatory practices to policy frameworks that rendered disability invisible. It operated through everyday assumptions and discourses about ability: who is seen as capable, self-sufficient, or worthy of inclusion. These assumptions shaped how decisions were made, who was prioritised in resource-limited settings, and whose needs were overlooked. The systemic devaluation of disabled lives influenced not only service delivery but also the broader culture of emergency response, where inclusion was often seen as optional or secondary. Tackling ableism requires moving beyond rhetorical commitments to genuine rights-based, disability-inclusive approaches that actively challenge these embedded norms. This includes aligning with the UNCRPD, embedding accountability and participation mechanisms, and promoting inclusive practices across all sectors and levels of response.

8.6.6. Increasing the evidence base

Data are essential for equitable planning, yet it remains one of the most underdeveloped aspects of disability-inclusive emergency response. Needs assessments must collect, analyse, and apply disability-disaggregated data to understand who is most affected, where support is needed, and how to avoid reinforcing existing exclusions. This includes making full use of existing datasets, as well as employing validated tools such as the Washington Group questions (Washington Group on Disability Statistics, 2020a) in national surveys to ensure that data are comparable and actionable. People with disabilities should also be involved as data collectors and analysts – their participation can challenge assumptions about ability and expertise. Disability inclusion must be embedded across all monitoring and evaluation frameworks, with clear indicators and accountability mechanisms to track whether interventions are reaching those most in need. Without robust, inclusive data systems, emergency responses will continue to overlook and underserve people with disabilities.

Building on these recommendations, I will conclude by suggesting areas for future research. Further work is needed to support people with disabilities and OPDs to advocate for, and participate meaningfully in, disability-inclusive emergency preparedness and response efforts.

8.7. Future research

Conducting this project has revealed several interesting directions for future research. One particularly important avenue lies in further examining how structural violence manifests in the lives of people with disabilities in Liberia. While this thesis has begun to explore this intersection, especially in the context of epidemic responses, there is significant scope for a deeper investigation into how social, economic, and institutional structures produce and sustain exclusion. Future research could trace these dynamics across various sectors, including education, livelihoods, and political participation to build a more comprehensive understanding of systemic inequalities.

Another promising line of enquiry involves exploring the implications of the humanitarian–development–peacebuilding nexus for people with disabilities. Increasingly referred to as the ‘triple nexus’, this approach seeks to integrate humanitarian aid, long-term development, and peacebuilding efforts, particularly in fragile and conflict-affected settings. However, little is known about how this framework addresses – or fails to address – the rights and needs of people with disabilities. A critical examination of the tensions of integrating disability within ‘triple nexus’ programming could reveal important gaps in inclusion and highlight opportunities for more inclusive approaches to crisis response and recovery.

Comparative research across different countries and contexts would also offer valuable insights. As demonstrated throughout this study, people with disabilities’ experiences of epidemic responses are shaped by national histories, political systems, and social norms. Further similar research in other settings – for example, with people affected by Ebola in DRC or by outbreaks of other infectious diseases – would offer more nuanced, context-specific understandings of exclusion and resilience. Such comparisons could also contribute to the development of more globally informed, yet locally grounded, disability-inclusive health strategies.

Finally, this research raises important questions about how structural violence operates differently across geographic and spatial lines, particularly between urban and rural or remote communities. Although not the primary focus of this study, initial findings suggest that place-based factors significantly influence the depth and experience of structural violence, and how urban-based interventions can maintain or even increase structural violence in rural and remote areas. Further research is needed to explore how geography mediates the impacts of structural violence on people with disabilities and how responses can be tailored to reflect these differences.

8.8. Reflections

This research project has been such a journey for me, professionally and personally. I am definitely not the same person I was when I started my PhD three years ago! Conducting this research has challenged me intellectually and emotionally, and it has solidified my commitment to centring the voices of people with disabilities as active participants and co-researchers. I feel privileged to have worked with colleagues and participants to understand people with disabilities' lives and experiences during two very challenging and traumatic times. The stories that they shared with me will stay with me for the rest of my life.

There were definite bumps along the road (how appropriate for Liberia!), such as project partners who had wildly different expectations of what they had agreed to do, or misunderstandings about how my disability needs to be supported. Being hospitalised with shingles was an unexpected challenge, but it wasn't as bad as it might have been (the timing could not have been better!).

However, this journey has also broadened my understanding of what it means to do ethical, inclusive research – not only in terms of data collection, but in how we show up for people, listen and hold space for the complexities of their lives. Research is never just about the production of knowledge, and the responsibility of truly representing people's stories – especially those that speak to deep trauma or injustice – is not one I have taken lightly.

As I complete this thesis, I carry with me a firm belief that inclusive and participatory research is not only possible but essential. My hope is that the insights shared here contribute (even in a small way) to creating spaces where people with disabilities are not merely heard, but are recognised as leaders, experts, and agents of change.

8.9. Final conclusions

In closing, this research has aimed to centre the lived realities of people with disabilities during two public health emergencies in Liberia, revealing how deeply embedded systems of inequality continue to shape their experiences. These accounts highlight the ongoing impacts of structural violence, while also challenging assumptions of passivity or dependency. Participants spoke not only of being marginalised, but of finding ways to act, adapt, and advocate. Their insights show that people with disabilities are already engaged in response and recovery efforts, even when these contributions remain undervalued or overlooked.

Although the challenges are substantial, this research also points to possibilities for change. The knowledge and resilience within disabled communities offer a foundation upon which more inclusive systems can be built. Efforts are already underway, but these must be supported, amplified, and resourced. For future emergency responses to be genuinely inclusive, people with disabilities must not only be seen – they must be enabled to lead.

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Appendix one: photovoice training plan

	Activity	**Description**
Photovoice training		
Day 1 *Consent forms signed*	Welcome and introduction to the project	▪ Overview of the project and how they will be involved ▪ Training plan
	Group agreement	▪ Group agreement set by the participants
	What is photovoice?	▪ What is participatory research? ▪ Aims of participatory photography ▪ What is photovoice?
	Break	
	Visual literacy	▪ What is visual literacy? ▪ Photo dialogue (*how* images communicate and *what* they communicate) ▪ Suggestions of visual literacy – post-its ▪ Exercise (using stock photos)
Day 2 *Print outs of model release forms*	Recap	
	Taking photos ethically	▪ Why might photography be unethical? ▪ What are release forms?
	Using cameras/techniques	▪ *Hand out cameras* ▪ How to operate camera ▪ Setting up photos – tips ▪ 4 Fs (framing, focus, follow through, flash) ▪ Be creative!
	Break	Having a go with the camera – any questions
	Camera exercises	▪ Camera exercises
<u>Homework</u>	Keep/change exercise	Participants take 3 photos of things they value and 3 they want to change to discuss as a group

Day 3	Recap	
	Thematic photos presentation/discussion	- Group feedback and discussion (revisit visual literacy)
	Group analysis outline	- How to do group analysis - Analysis techniques – SHOWED, identify-contextualise-codify, similarity/difference - Analysis exercise (using homework photos)
Homework	Working to a theme	Participants will be given a broad theme and asked to take photos to the theme, choosing 1 or 2 to discuss with the group
Day 4	Recap	
	Captioning	- Introduction to captioning - What makes a good caption? - Different captioning techniques – 6-questions, photo narrative, talk it out, free association - Revisit visual literacy - Exercise – captioning stock photos
	Break	
	Captioning exercises	- Using homework photos – small groups
	Caption presentation	- Presenting to group for feedback, discussion
	Reflections and feedback	- What went well in the training, or could have been better - Anything you feel you don't know? - Next steps
End of training		
Homework	Photos on an initial theme	As with the previous homework, participants will take photos on a theme and select 1 or 2 to discuss
Weekly analysis discussions		
Day 5-9	Welcome and reflections	- How was taking photos of the theme? Challenges?

	Group analysis and discussion	▪ SHOWED ▪ Similarity/difference
	Captioning selected photos	▪ Small groups ▪ Revisit visual literacy/captioning techniques
	Group identify next theme	▪ Building upon previous theme or new area of focus
Homework day 5-9	Photos on agreed themes	As before
Day 10 *Photo release forms signed*	Welcome and reflections	▪ As before
	Group analysis and discussion	▪ As before
	Captioning selected photos	▪ As before
	Final photo/caption selection and group exhibition	▪ Participants choose two of their photos/captions to be part of the final exhibition ▪ Print out and display photos and captions
	End of project celebration	▪ Refreshments and cake

Appendix two: key informant interview guides

KII – organisations of people with disabilities, civil society

Name:

Role:

Where do you work/what is your role?

How long have you been in your current position?

(if less than 7 years) what was your role during the Ebola outbreak?

Please tell me about your current work (*prompts:* day-to-day activities, how many people do you manage, who do you work with to fulfil your duties?)

How were you involved in the COVID-19 response? What did this entail?

Who else did you work with (govt, INGOs, UN, civil society etc)? How did you work with them? What was that experience like?

How did the COVID-19 restrict your work activities if at all?

What specific populations were considered in the COVID-19 response? Why were they considered?

To what extent were people with disabilities considered?

What populations do you think were missed out/most badly impacted?

What role did civil society play in the COVID-19 response? (*prompt:* consultation, planning, implementation, evaluation?)

What long-term impact has COVID-19 had on your work?

What long-term impact has COVID-19 had on Liberia?

Now thinking back to the Ebola time –how were you involved with the Ebola response? (if no) what were you doing during the Ebola time?

Who else did you work with (govt, INGOs, UN, civil society etc)? How did you work with them? What was that experience like?

How did the Ebola restrictions affect your work?

What specific populations were considered? Why were they considered?

To what extent were people with disabilities considered?

What populations do you think were missed out/most badly impacted?

What role did civil society play in the Ebola response? (*prompt:* consultation, planning, implementation, evaluation?)

How did this change in the COVID-19 response? (*prompt*: better, worse, activities)

To what extent do you think Liberia has recovered from Ebola? Why do you say that?

How were the responses to COVID-19 and Ebola similar or different? Why do you say that?

What if any lessons were learned from Ebola for COVID-19? What should have been learned?

How affected has Liberia as a whole been by COVID-19?

What should be learned for the next epidemic?

Anything else to add?

Who else do you think I should be speaking to?

Thank you for your time.

KII – community leaders

Name:

Role:

What is your role?

How long have you been in your current position?

(if less than 7 years) what was your role during the Ebola outbreak?

Please tell me about your community (*prompts:* number of community members, groups, assets, support)

Please tell me about your current duties (*prompts:* day-to-day activities, who do you work with to fulfil your duties?)

How were you involved in the COVID-19 response? What did this entail?

Who else did you work with (govt, INGOs, UN, health workers etc)? How did you work with them? What was that experience like?

How did the COVID-19 restrict your community if at all?

What specific populations were considered in the COVID-19 response? Why were they considered? What populations do you think were missed out/most badly impacted? (*prompt:* govt considered, community considered, people with disabilities?)

What role did civil society play in the COVID-19 response? (*prompt:* organisations of people with disabilities?)

What long-term impact has COVID-19 had on your work?

What long-term impact has COVID-19 had on your community?

What long-term impact has COVID-19 had on Liberia?

Now thinking back to the Ebola time –how were you involved with the Ebola response?

(if no) what were you doing during the Ebola time?

Who else did you work with (govt, INGOs, UN, health workers etc)? How did you work with them? What was that experience like?

How did the Ebola restrictions affect your community?

What specific populations were considered in the Ebola response? Why were they considered? What populations do you think were missed out/most badly impacted? (*prompt:* govt considered, community considered, people with disabilities?)

What role did civil society play in the Ebola response? (*prompt:* organisations of people with disabilities?)

To what extent do you think your community has recovered from Ebola? Why do you say that?

To what extent do you think Liberia has recovered from Ebola? Why do you say that?

How were the responses to COVID-19 and Ebola similar or different? Why do you say that?

What if any lessons were learned from Ebola for COVID-19? What should have been learned?

How affected has Liberia as a whole been by COVID-19?

What should be learned for the next epidemic?

Anything else to add?

Who else do you think I should be speaking to?

Thank you for your time.

KII – policymakers, health and development practitioners

Name:

Role:

Where do you work/what is your role?

How long have you been in your current position?

(if less than 7 years) what was your role during the Ebola outbreak?

Please tell me about your current work (*prompts:* day-to-day activities, how many people do you manage, who do you work with to fulfil your duties?)

How were you involved in the COVID-19 response? What did this entail?

Who else did you work with (govt, INGOs, UN etc)? How did you work with them? What was that experience like?

How did the COVID-19 restrict your work activities if at all?

What specific populations were considered in the COVID-19 response? Why were they considered? What populations do you think were missed out/most badly impacted? (*prompt:* people with disabilities?)

What role did civil society play in the COVID-19 response? (*prompt:* organisations of people with disabilities?)

What long-term impact has COVID-19 had on your work?

What long-term impact has COVID-19 had on Liberia?

Now thinking back to the Ebola time –how were you involved with the Ebola response?

(if no) what were you doing during the Ebola time?

Who else did you work with (govt, INGOs, UN etc)? How did you work with them? What was that experience like?

How did the Ebola restrictions affect your work?

What specific populations were considered? Why were they considered? What populations do you think were missed out/most badly impacted? (*prompt:* people with disabilities?)

What role did civil society play in the Ebola response? (*prompt:* organisations of people with disabilities?)

To what extent do you think Liberia has recovered from Ebola? Why do you say that?

How were the responses to COVID-19 and Ebola similar or different? Why do you say that?

What if any lessons were learned from Ebola for COVID-19? What should have been learned?

How affected has Liberia as a whole been by COVID-19?

What should be learned for the next epidemic?

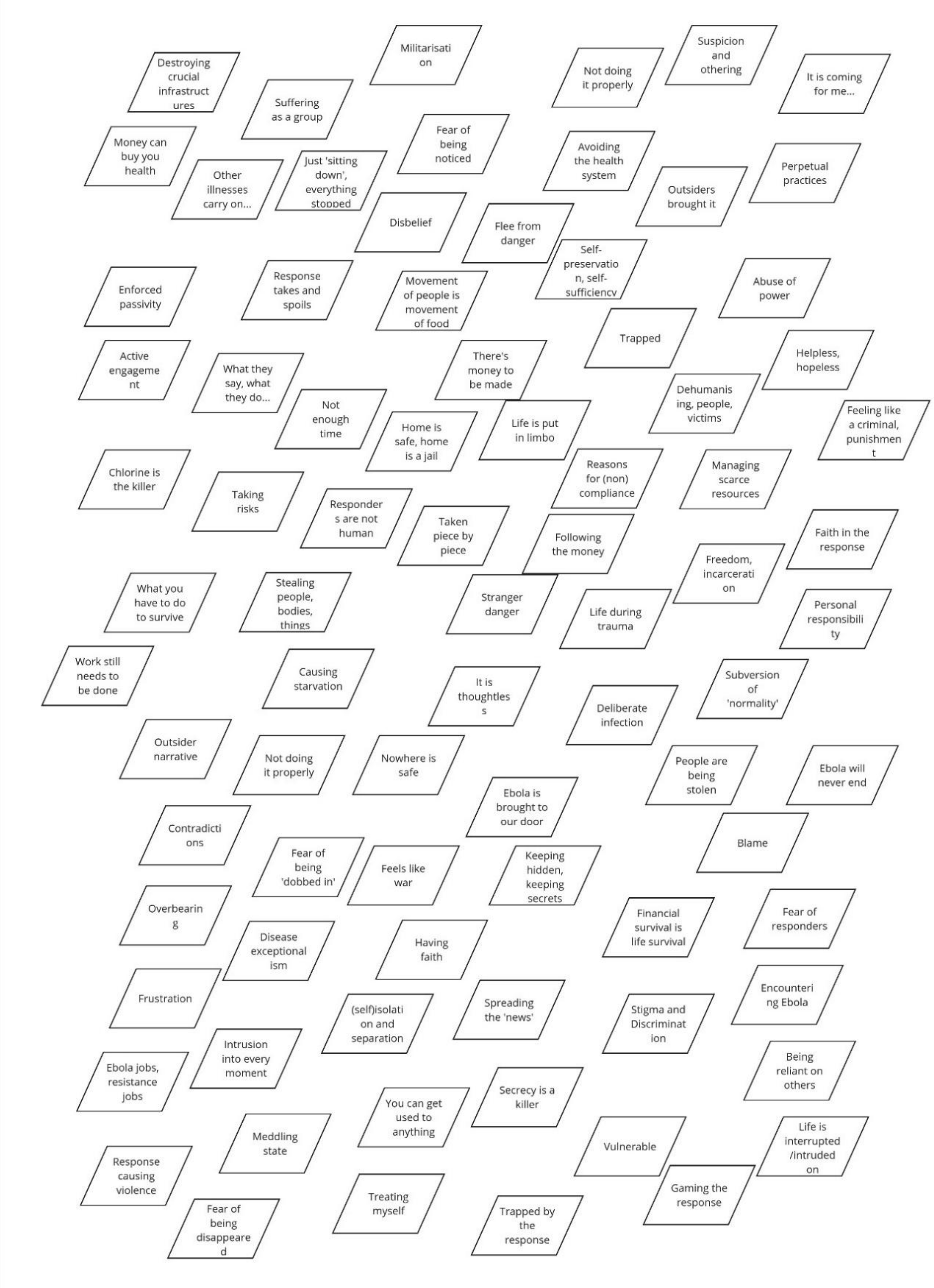
Anything else to add?

Who else do you think I should be speaking to?

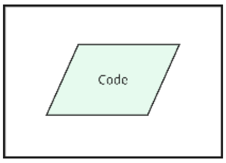
Thank you for your time.

Appendix three Ebola codes and themes

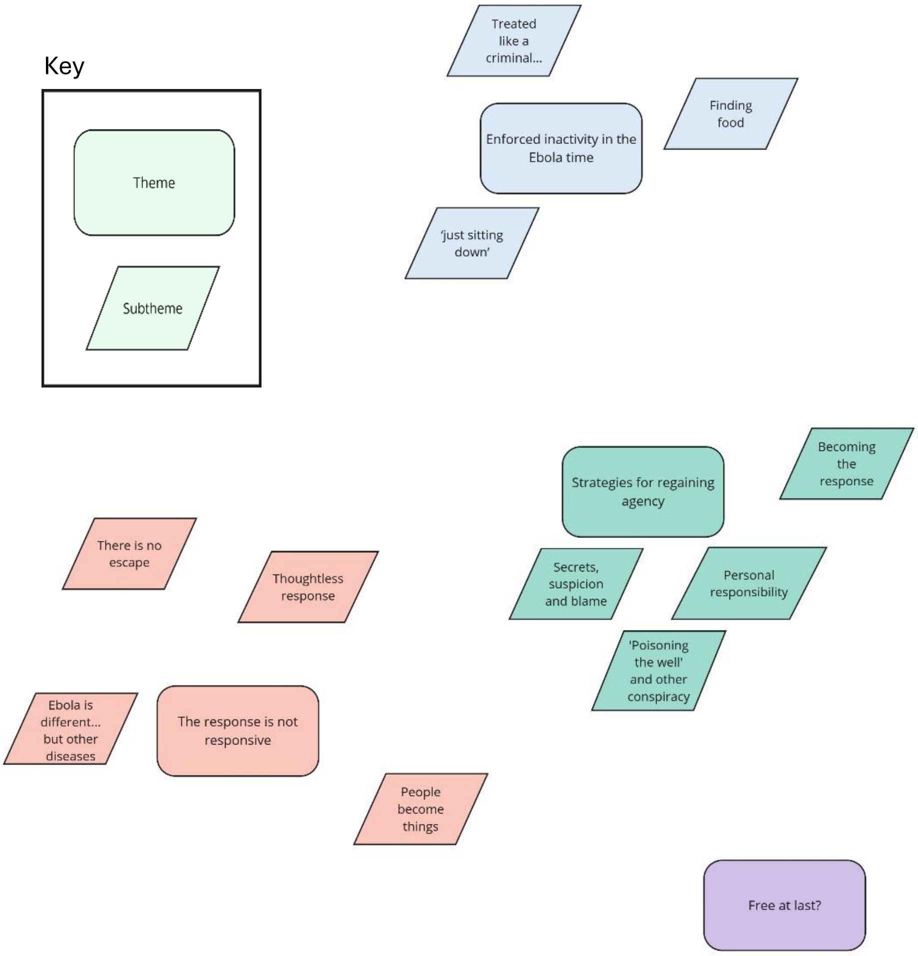
Initial codes



Key

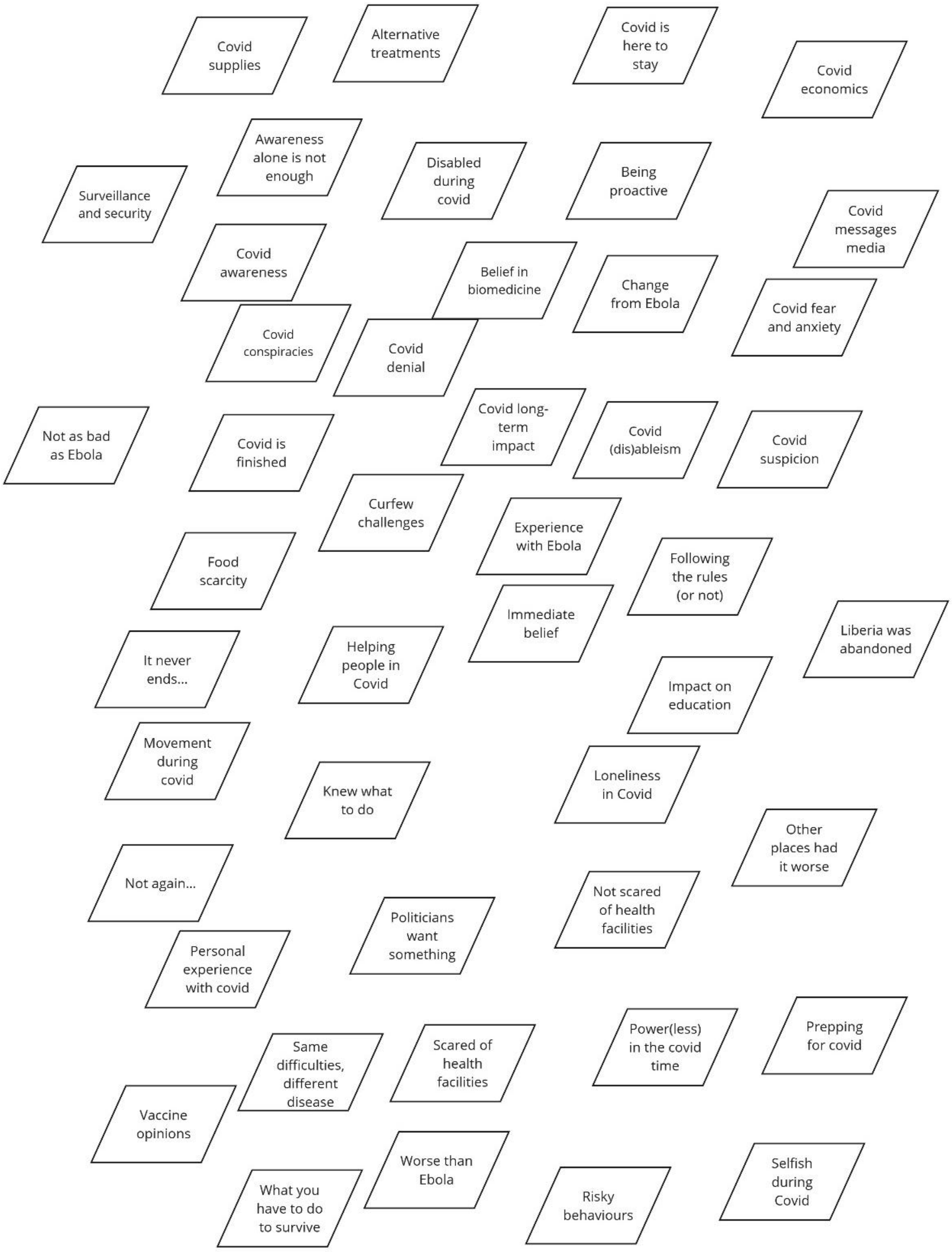


Final themes



Appendix four COVID-19 codes and themes

Initial codes



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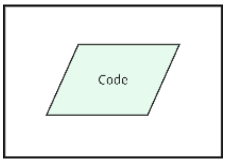
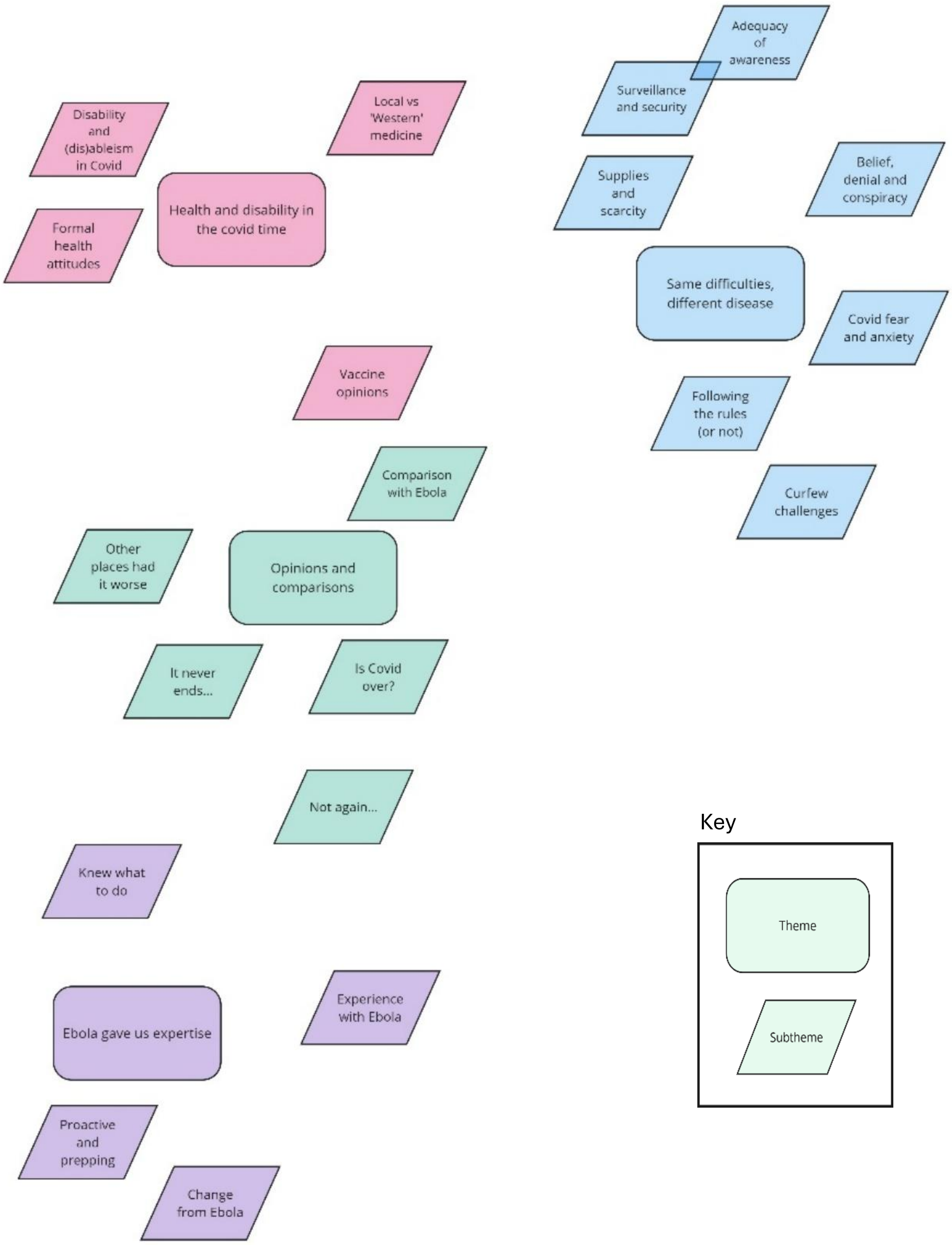


Final themes



Appendix five: photovoice photos

Women with disabilities

The first time I went to this building I went there to receive money from Western Union, but when I went there were so many steps to climb, and persons living with disabilities it can give you hard time, it is challenging for us. There is no flat area for the wheelchair user to climb. It is not accessible for a person with a disability. I was afraid when I saw the steps to the building.

The second time, I was forced to go there because my friend came down with covid and was in the clinic. Her parents were not around, so I was the person to go in and out. I talked to the nurses and the doctor asking about her health. Every time they would tell me she's improving, and she was eventually sent home.

I told the owner of the building that it is fine and beautiful, but in the sight of a person living with a disability it is not good because there is no accessibility for us. For us living with a disability there is a slogan: Nothing About Us without Us. So, in this light we are appealing to the national government, civil society groups, NGOs to please carry out awareness that if you want to put any structure down, the area should be flat for persons with disabilities, especially wheelchair users.

Fatuma Roberts

I face the challenge of drawing of water from this well.

For a person with a physical disability this well is not accessible and is dangerous. It would be easy to lose your balance and fall into the well. Fetching water is also challenging, as the wells are often far from people's homes and water needs to be carried over long distances, which is especially difficult for people with physical disabilities. During COVID-19, fetching water often became even more difficult. The lines for wells were very long due to the social distancing requirements, and it took a long time to draw water.

I recommend that water and sewer pump should be placed in my community. As a result, I won't have to face the challenge of drawing water again. I am kindly calling on to the community leaders, government officials, and well-wishers to help me achieve this.

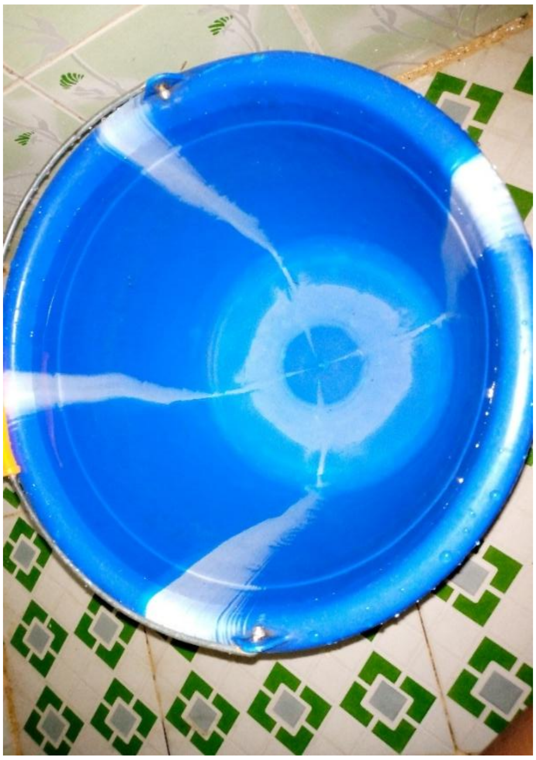
Evelyn Quire

Since I became disabled, I've been faced with a lot of challenges and one of which is my movement(mobility). Getting from one place to another is very challenging for me. Accessing a motorcycle or tricycle many times to go places is sometimes risky as person with disabilities in Liberia.

I am a single mother. It is my responsibility to take care of my child who lost her father as well as myself. It is not an easy thing for me as person with disability, sending child to school, paying rent, feeding, cooking, washing clothes, cleaning up the house, and at the same time moving around on a daily basis on a motorbike just to give I and my child a better life. It's hard for me as a disable women. Right now, I want to go to college but I don't have the support. I am calling on the government and others international partners to please help our disability community with scholarship, jobs, empowerment because disability is not inability.

I am also calling on all citizens of this nation to please stop the discrimination and see us like you because being a disability it's doesn't mean you are inability.

Jochebad Morweh



Water is life and is needed for survival for all human beings.

Our service providers are sometimes our children. During the covid time, they work harder to go out to find food, to go out and look for water for us, so they were exposed to the covid virus. The process of fetching water by service providers took more time because of social distancing at the pump and long line caused delay of our movements.

My service provider was often not around during covid. I had to take a bucket of hot water myself to the bathroom and it led me to have an accident. I fell with a bucket of hot water and was badly burned.

People with disabilities live in poverty and don't have access to education, employment, or safe drinking water. Therefore, I am requesting government and international organisations to please provide free housing units that have water supply, for persons with disabilities and their service providers.

Leona Hansay

As a physically challenged person, safe, accessible and secured transportation is one challenge faced by me on a daily basis. Many times, I will fall from my chair while getting on a vehicle because of the operator's impatience to wait until I get in or there's no one to assist me get on board or the vehicle is packed to an inconvenient place which gives me so much difficulties to access a vehicle.

Some challenges in getting a secured and accessible transportation entails me waiting in the sun, rain and cold for hours. I feel embarrassed as person with disabilities (female), being lifted by people from my chair to assist me get into a vehicle even though I got no choice.

It saddens me seeing people who are physically fit accessing a vehicle without facing problem as compare to me who struggle everyday and it's my wish that I could do same one day if and only if there is an enabling environment provided for people living with disabilities in Liberia. There is a need for the provision of disabled friendly vehicles for all persons with disabilities in our country to enable us have equal access to transportation.

Rose B. Dargbeh

This is my house that I am renting and it is in a swamp. There is no restroom. During the rainy season we put sand in bags and use them to stop the house from flooding. The water can overflow and enter the house and sometimes water snakes come. We have to put the mattress up to avoid the flood. The water can reach knee-height and sometimes my crutches sink ink the mud and can break.

Even to get fresh water it was very difficult. There is no pump in the community, so we use the rainwater to drink and cook, and we use chlorine to make it safe. It is very challenging. Sometimes I can't afford the rent and the landlord gives us notice to leave. If you want to rent in a decent area you have to pay a lot of money.

In the covid time we could not get out. There were no foods distribution, and I had to call my brother who could fetch food. Having enough money for rent was very difficult. It was very difficult, particularly for a person with a disability.

Is very challenging to live as a single woman with disability in Liberia to earn money to rent. I appeal to the government of Liberia, George Weah, President of the Republic of Liberia, and international donors and partners to please look at the challenges we face as persons with disabilities in Liberia in getting a place to live.

Rosetta L. Mensah

This is the clinic. I got sick with diarrhoea and vomiting because my living condition was not good. I encounter flies, but there was no money to buy fly spray, so the flies sit on my food and made me sick. When I went to the clinic, before the doctor put hand on me, they told me to pay finance. At that time, I was not having money, I got assistance with some but not all. After my treatment, I paid the last money.

In the covid time I was sick with malaria, but I never showed at the clinic because I was afraid of the virus. And if I showed up people were going to say that I had covid because malaria has the same symptoms. I hide myself and called my doctor who treated me in my house until I get well. I even hide my children, who also got sick. I beg people to give me money to treat my children.

For women with disability, there is no access for some of us. I don't have access to anything, everywhere I go I pay money, even to the hospital or clinic I pay money before getting my treatment. In each clinic or hospital whenever a disabled person enters, we should have free treatment. I am appealing to government and international organizations to provide free medical services for persons with disabilities and their service provider throughout Liberia. We should be given medical insurance card to have access to medical services.

Victoria G. Nyemah

The photo shows a school class learning together. It captures everything about people with disabilities. You can see the Deaf, you can see non-disabled and physically challenged people, you can see a sign language interpreter.

During COVID-19, the Deaf community was left of information that were given to the public, there was no information and there were no sign language interpreters. They were not informed. At least five Deaf people were beaten by our own police because the Deaf people did not get the information about the 3pm curfew and there was no one to inform them. After the beating, NUOD talked to police and held a workshop sensitising them to the situation of the Deaf community.

This photo captures everything about people with disabilities, showing we can be part of the society to make sure that if we are educated, we should be given opportunity to work and to achieve our goal as humans, not because we are disability people, we can do anything like others. Article 27 of the CRPD, people with disabilities have the right to work on an equal basis with others. Disability is not inability.

Soweo Z. Johnson

Men with disabilities

WHAT IS IN THE PHOTO: *I see a photo of three distinct personalities: Ex-President Ellen Johnson Sirleaf, Dr. Ben Harris, a Psychiatrist, and former First Lady Rosaline Carter, of USA. These people are champions of mental health.*

WHAT IS HAPPENING: *I see people discriminated and left in the corners of every street in Liberia. I hear the voices of thousands crying vehemently: “Get these people off the streets. Put them off sight to die slowly!” I taste the bitter longing of victims denied their rights to health and other services. I touch the world with the undeniable truth that mental health wellbeing and services are tremendously an asset and not liability. I feel the way to better achieve in our national agenda, is to all agree that there is no health without mental health.*

Persons with psychosocial disabilities were vulnerable during COVID. The attitude to mental health made them vulnerable, they were not attended to because of stigma: “We don’t have time for them today”. They go home and suffer in silence.

Mental health has been neglected in Universal Health Coverage. The whole world is advocating for mental health to be taken from under the rug and made a core component of health.

Bill S. Jallah

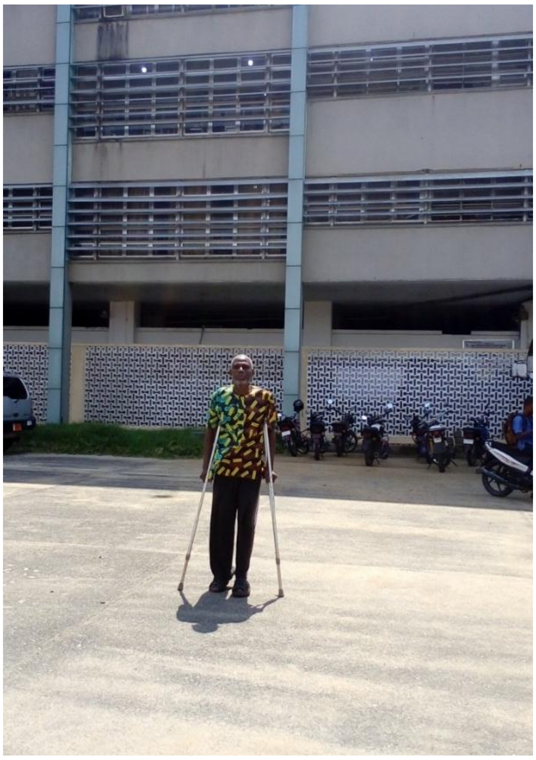
Help those who are losing their sight

This photo is of a lady that is losing her sight and needs help. Her problem started in 1996, she was injured during the war. All the hospitals told her the surgery could be done to restore her sight but out of Liberia. During COVID-19 she had many challenges. She couldn’t do anything because of the pandemic no one could come to her aid, she couldn’t see anything, her son passed off. She survived because friendly neighbors helped her and her church also. She is a person with a disability who doesn’t go on the street, and I helped where I could.

In Liberia people get ill because of poor health conditions. During the period of COVID-19, many Liberians, men, women and children faced with eye problems suffer medical problem because of the global pandemic. This pandemic brought a setback to the disabled community. People that face problems could have them solved but because the National hospital is not upgraded, they go visually impaired or they have to go abroad.

The Government of Liberia should upgrade the hospital and any disabled person, or who is going blind, should be treated free.

Diarran J.T. Appleton



Attention my dear audience. *I bring you greetings from the community of people with disabilities.*

My story: See a beautiful health center located in the city of Trougbo with vehicle and motorcycles park before it. And also, a physical disability elderly man with crutches under his arms standing alone sad, downhearted and frustrated.

Why: People are in the building with various types of disabilities who have been denied the right to health care. The doctor says that I should travel abroad for medical care. There is no sign language interpreter to interpret for the hard hearing disability person and there is no ramp for the wheelchair user to reach the doctor. And there is no medical facilities for total hip replacement.

What happens? Persons with disabilities do not assess full health care. They go home without health care. The persistent prolonged non-health care may result to another form of disability if not taking care of.

Why does this problem exist? The many stakeholders do not consider the population of include people with disabilities. Many stakeholders should take our inclusion into consideration.

David Hne Wallace, Sr

As a person with disability, it was important to take the vaccine to enable me to move about in the public that will not create a harm for me.

I was informed that if I take the vaccine, it will be a good thing for me as a person with disability. I used the opportunity given to me to keep I and my family on the safe side of life, even though there were many challenges we faced as person with disability. We took the courage believing that covid can be prevented by us also.

But for people with disabilities, the reaction to both the virus and the vaccine, many people had fear or trauma. There are people who refused to accept the vaccine at all, they thought it was not necessary, or that they will take the vaccine but not now.

This problem exists because of fear and awareness was not made properly. For people who are afraid to take the vaccine or refuse, WHO, government and humanitarians should make more awareness.

Awareness should convince people beyond doubt of vaccine's safety. Not forcing but convincing.

Ephraim Sebo

As covid hit Liberia in 2020, it became greatly worrying to Liberians, most especially persons with disabilities. I am visually impaired, and in this photo my colleague and I are sitting and we are discussing the best way we can address the challenge that people with disabilities are facing in lockdown.

The curfew meant highly restricted movement. Our members are sitting home, what can we do for them to eat? We decided on an SOS appeal on the radio. People came to help our members. But the most problematic thing is that all of our colleagues don't live together, so we decided to start doing distribution and awareness to our members.

We went to individual houses to give a bag of rice, soap bucket, sanitizer and lectured a bit. They said that before they had the bucket they didn't know anything about covid. We provided information, and a bucket and food so that they could stay home and stay safe until the lockdown lifted.

Government should implement Article 11 of the Convention on the Rights of Persons with Disabilities.

Lahai J. Gotolo

As a visually impaired person, I was always vulnerable due to the covid, because I don't know who is helping me and if they were free from covid. And everyone was thinking about their individual safety, and I also was thinking about the same, because covid was the biggest problem the world was faced with. We risk taking the virus home to our family. Family members can be harmed by the virus

The road in Monrovia is challenging, there are many drivers who don't recognize or consider the white cane. We need assistance to find our way out. We people with disabilities are vulnerable to people who help. We don't know if they have been victims of the virus or are free. Sometimes they don't ask you where to hold you to cross. They don't ask 'what can I do?' You want to give them the end of the cane, but they would grab your hand.

Government should ensure safety of all people with disabilities. A safety measure needs to be put in place with Article 11 of the Convention on the Rights of Persons with Disabilities. Every driver should take into consideration the white cane to give the pedestrian a way out.

Melvin L. Harding

In the photo I feel sad and frustrated and isolated.

In covid I was unemployed and the little work around I could not do. As a person who is physically challenged and as a tutor I could not find work due to the social distancing health protocol.

I was worried about my family, how they would survive in a situation like this. I woke up every morning wondering where to go, what to do. I was hopeless. I can hustle, but I'm not used to going into the street asking for help. I don't want to ask them. Who will be reasonable and understand? It is a desperate time.

Persons with disabilities went through difficulties as it relates to making earning money during the covid-19 because nothing doable could be found.

I urge government, NGOs, humanitarian organizations and others to have emergency budgets so that they can be able to quickly assist persons with disabilities because in most cases we are the most vulnerable.

Togar Bungar

I smell the atmosphere of future leaders fighting for a better living standard

I see self-esteem for the attainment of educational empowerment in action rather than waiting for national government to do everything

I taste the burning desire and ambition of children with Disabilities to become successful adults in society

I touch the emotions and aspirations of a challenging way of life, I feel that hope is alive which is far better than living without hope

I am a teacher at a school for the Deaf. During COVID-19 we were paralysed due to the lockdown. Widespread rumour of fear spread like wildfire. People were afraid to sit down together. It was very difficult. But the administration kept the school open in compliance with the MOE protocols, students wear nose masks, washing hands.

If we want the SDGs to be achieved, leaving out children with disabilities, especially Deaf children, out of the national development agenda, means they cannot be realised.

Sylvester Mombo

Caregivers

I am a service provider/caregiver at the National Union of Organizations of the Disabled. I took this picture in order to display what issues were unfolding during the COVID-19 period.

As part of my caregiving, I was a member of an awareness team carrying out both awareness and sensitization about health measures, some as you see it being displayed in this picture: wearing of masks, washing of hands constantly, and also the social distancing aspect of the protocol that were observed in my office and the community in which I live especially for children and persons with disabilities.

This is what I always do at my job sites always do for my bosses in my office. I extended in my community as a caregiver, especially those of them with visual impairment as well as the community dwellers.

I recommend that service providers be taken seriously and more professionally and that more support come to our organization so that we can develop a salary structure and get paid for the services we provide for what we love doing.

Evelyn N.W. Deh

A concerned and caring man

As he sits and smiles, he is thinking about how to express concern and care for the children, especially the Deaf children that he takes care of. Since his arrival from the Ivory Coast in 2004, he established the Monrovia School for the Deaf on the Smythe Road.

It has been a single-handed institution and only been supported by Mary's Meals and recently the Samaritan Purse family stepped in to help. Presently, there is an ongoing construction on the Robert Field Highway, but due to lack of financial support the construction work has ceased.

It is time to see the need and send assistances to this man who has over the years taken care of a lot of Liberian Deaf kids.

Hi is no other but Mr Emmanuel Jacobson.

I am a service provider at the Monrovia School for the Deaf. From the onset of the institution in 2004 I voluntarily served as an instructor for five years. Due to one or two obligations, I left and am back providing great humanitarian services to the institution, still under the leadership of Mr Jacobson.

Joshua S. Gargar

I see an environment that lacks sanitation

I feel the dirt under my feet

I smell the stink of stale waters, rotten food, used baby pampers, etc.

I taste the odour of uncleanliness

I hate the environment

I am a personal assistant and I go wherever my boss goes. We went to this place to solve a case about a disabled child who got burned by hot oil. This photo is of the surrounding of the mother's home. I had to help four visually impaired individuals, guide them to the home of the mother. It was a critical thing to do. I had to guide them through this environment without them getting messed up or falling into the water. It was risky for me and the others and we felt vulnerable being in such a place.

The environment needs to be thoroughly cleaned and the dump site relocated; the mother's home is on the dumpsite of the community.

Linda K. Hoff

As a caregiver, this is one of the things I do for the person I am giving care to, my oldest brother. I fetch water and the distance from my house to the pump is very long. I have to get to the pump early because the pump is in the school building. It is open at 5am, but close at 7am for the morning session. The school session starts at 8am and the school administration will not allow anybody coming in apart from the students.

Due to the covid time, the school was not in session at that time, but we still needed to fetch water. The pump was open at 7am it was closed by 3pm because of the lockdown, everyone should home at sharp 3.

I used to wake up every morning from my sleep to go and fetch water. It was a big challenge for me every morning. I also have to cook, go to the market, wash and do house cleaning.

My brother I am giving care to is older than me, but I am the oldest of my other siblings and because of that I am responsible for everything. I have been doing this for years. Sometimes I feel so tired, but I just have to do what I can do to satisfy my family as the oldest sister.

Naomi T. Togbah

Do not ill-treat people who are disabled because they are human like us.

Disabled people are able people therefore they should not be denied to work in any entity or government institution. People with disability need proper care during pandemic and epidemic. They should not be isolated because they need the help of their caregiver to take preventative measures.

This person is my neighbor, I have visited him for a year to help with his isolation. I sometimes share food. At times because of the condition of people they are isolated, we should take them as our friends and as human also.

Persons or people with disabilities have the right to proper healthcare. Different awareness should be made during pandemic and epidemics so that persons with disabilities will be aware of the danger of the virus or diseases. During lockdown government and other civil organisations should be able to provide for the needs of people with disabilities to avoid them coming in the street.

Do not disown or neglect your family members or relatives who are disabled because nobody asks or pray to be disabled. Let us accept all human not of their condition but what they can do.

Paul L.B Jackson

I see a woman who is physically challenged holding crutches to help her balance. She is standing at the doorway of her house in a beautiful African dress. She is strong, in a state of courage. She is not mocked by her disability, rather she has turned her disability into utility. It has become her momentum to push through in life.

This shows that being a disabled does not mean that you are a liability to society.

This is a woman I give care to. I go to her house every morning to do work that she is not able to do as a disabled person. I help her wash her clothes, take her children to school. During the lockdown I still went to her house, I had to watch the hours because everyone had to be home at 3pm sharp. I had to leave her place at 2.30.

Especially during the lockdown due to covid I felt for her and other disabled women because their lives was at risk. To go out to get food and other needs. I don't know who they are interacting with so their lives were at risk during covid and I felt for them.

The government should have provided food for them during the covid time.

Philipmena Philip

I am a caregiver to my mother and grandmother at home and I am also a student. I take care of them, make sure they eat well, take baths, do their laundry and all things involved in caregiving.

During the COVID-19 I was risking my life waking up early in the morning going to town to get goods to put in my shop. In that period, I was doing a business to help take care of my mother and my siblings. Sometimes I went to check on her and the kids. I was on 12th Street and she was in Duport. I had to rush back home because of the 3pm lockdown.

I took this photo to explain during the COVID-19 the Duport Road clinic played a major role in accepting and treating patients and telling patients what to do. We were lucky to have the Duport Road clinic in our environment. Wherein we as a caregiver we had place to take our families and loved ones for test and treatment.

As a caregiver you have to put these people in your shoes, take them as your family because it could be you, and not because you are getting paid as a health worker so you should treat the person anyhow.

Please treat people like yourself in your caregiving.

Sabah E. Roberts

As a caregiver, I help disabled persons in my community. I give people money, help them to buy medicines, I ask the community people to help me clean this road. They have to help every year.

This is the road leaving my community to get on the main street. The road is a hill and I help disabled persons get up the road. As a caregiver I find it difficult to help people with disability because during the raining season the road can change to drainage, the whole dyke erodes away. Every year we have to fill in the dyke. It is very difficult for a wheelchair user to ride or a visually impaired person to walk. During the covid, people were afraid to clean this road because they thought they could get covid from the dyke in the road. Because of that the community was dirty and mosquitos were plenty in the community, people came down with malaria plenty.

As a caregiver I am asking the government and NGOs to help improve the road system of our community. A good road that is clean would mean people with disabilities can move smoothly and make the community better.

Teta T. Sannoh

Appendix six: policies reviewed

#	Policy	# mentions
1	Liberia Multi-Sectoral Nutrition Costed Strategic Plan (LMNCSP)	0
2	Liberia's Revised Nationally Determined Contribution (NDC)	1
3	Liberia Economic Recovery Plan (LERP)	6
4	National Adaptation Plan (NAP) 2020 - 2030	0
5	National Nutrition Policy of 2019	2
6	Liberia National Drought Plan	0
7	Pro-Poor Agenda for Prosperity and Development (PAPD), July 2018 – June 2023	64
8	National Policy and Response Strategy on Climate Change	3
9	Liberian Agricultural Sector Investment Plan (LASIP II)	0
10	Joint National Action Plan for Health Security (NAPHS)	3
11	National Action Plan for Disaster Risk Reduction 2016-2021 (Revised)	1
12	Strategic Plan 2015 – 2018	2
13	National Human Rights Action Plan 2013-2018	32
14	National Social Protection Policy and Strategy	57
15	Land Rights Policy	0
16	Sector Investment Plan (SIP) for the Water, Sanitation and Hygiene (WASH) sector in Liberia (Summary Report)	0
17	National Disaster Management Policy 2012	9
18	National Disaster Response Plan	9
19	Climate Change Gender Action Plan (ccGAP)	5
20	Agenda For Transformation: Steps Toward Liberia RISING 2030	51
21	National Health and Social Welfare Policy and Plan, 2011-2021	4
22	Water Supply, Sanitation and Hygiene (WASH) Sector Strategic Plan for Liberia	14
23	National Gender Policy (Abridged version)	10
24	National Food Security and Nutrition Strategy	0

25	Poverty Reduction Strategy	40
26	National Health Policy – National Health Plan 2007 – 2011	2
27	National Environmental Policy 2002	0
28	National Non-Communicable Diseases Policy and Strategic Plan	7
29	COVID-19 Health Emergency Declaration	0
30	Public Health Law Title 33 Liberian Code of Laws Revised	3
31	Governance Manual of the One Health Coordination Platform	0
32	Food Law of Liberia of 2017	0
33	Equal Rights of the Customary Marriage Law of 1998	0
34	Children's Law of 2011	18
35	National Water, Sanitation & Hygiene Commission Act of 2012	0
36	Health Ministry Act	0
37	Education Reform Act	1
38	National Human Rights Action Plan (2019-2024)	47

Appendix seven: results booklet

National Commission on Disability

27 September 2024

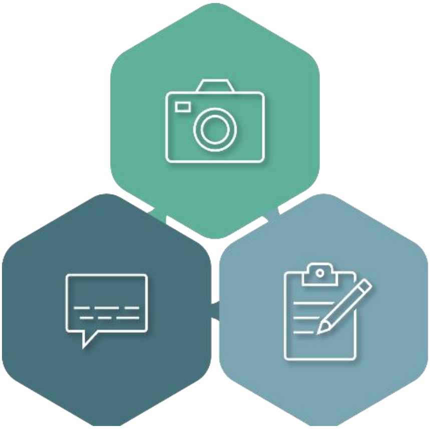
Comparing the experiences of people with disabilities during Ebola and COVID-19

Results from a doctoral research project

Ellie Cole, PhD researcher, UCL, London, UK

The project

- Builds on previous research (Prof Maria Kett, UCL)
- How people with disabilities experienced the COVID-19 and Ebola restrictions
- Three strands: photovoice, life histories, interviews
- 3 counties: Montserrado, Lofa and Grand Cape Mount
- In collaboration with the National Union of Organizations of the Disabled (NUOD) and the University of Liberia



Photovoice

Life histories

Interviews

‘included everyone’ vs ‘inclusion’

- Many organisations claimed they included everyone, but few explained how they specifically reached people with disabilities, and there was little extra support.
- Only a handful of organisations worked directly with disability groups like NUOD or other organisations of people with disabilities (OPDs).
- During Ebola, hardly any organisations collected disability-disaggregated data. A few did conduct disability-inclusive needs assessments during COVID-19.
- Pandemic response plans didn’t take people with disabilities into account. Governance structures sometimes actively excluded people with disabilities during COVID-19.
- People with disabilities were not recruited to the general response teams but were included in awareness-raising teams. However, their efforts were often limited to raising awareness only among other people with disabilities, not the wider population.
- Information was mostly ‘top-down’, with little knowledge-sharing, especially outside Monrovia.
- To address a lack of information in rural areas, some OPDs took it upon themselves to raise awareness, but this risked spreading false information.
- Many people with disabilities felt left out of the mainstream pandemic responses and relied on their own communities for support.
- Article 11 of the Convention on the Rights of Persons with Disabilities (risks and humanitarian emergencies) was not fully implemented during either outbreak

‘in Liberia people always put people with disabilities aside. So, in the disable community we always feel like a different country, so we always do things in our community, like [we are] a different community even though we are in Liberia… in the [general] community people don't give a person with disability responsibilities’

(woman with a neurological impairment,

Remote areas left behind

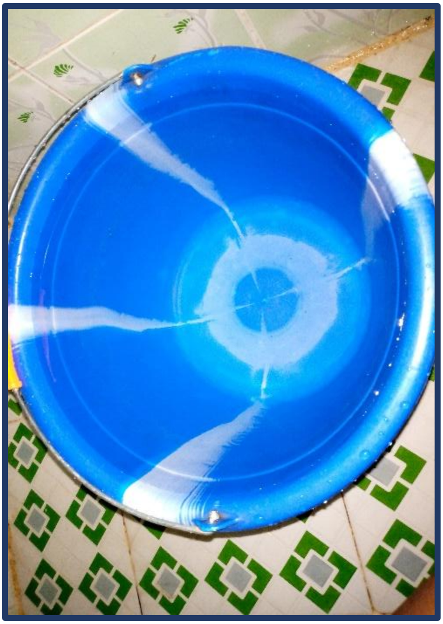
- During COVID-19, the gap between Monrovia and rural or remote areas widened. This wasn’t necessarily because things got worse in remote areas, but rather because Monrovia saw some improvements.
- During COVID-19, the government provided more food to NUOD for distribution to its members than they had during the Ebola outbreak. AIFO also offered more support during COVID-19. However, this extra food often didn’t reach people in remote areas.
- During COVID-19, finding food in Monrovia was easier for some people with disabilities. However, in remote areas, many found it even harder to access food than during the Ebola outbreak.
- Organisations representing people with disabilities in remote areas felt ‘abandoned’ and deprioritised.

‘no one catered to us… no one came’

(vice-chair of a rural OPD in Lofa)

Inflexible response

- During Ebola, the response was largely imposed on people with disabilities, with little consultation.
- Many people with disabilities felt trapped during the Ebola outbreak, receiving minimal support.
- The response overall was patchy in both outbreaks. People with disabilities usually received some infection prevention items, but not all. And some (particularly in rural and remote areas) received nothing.
- Food insecurity worsened in both outbreaks. In Ebola, food spoiled as people with disabilities couldn’t access farms. During COVID-19, there were some improvements in Monrovia, but remained scarce in remote areas.
- People with disabilities were excluded from decision-making about food and vaccine site locations, which were often inaccessible. Consultation with OPDs would have addressed this issue.
- During both outbreaks, people with disabilities and personal assistants struggled with restrictions, especially due to the extra time that was needed to complete daily tasks. Many criticised the government's lack of consideration.
- Curfews heightened isolation and left people vulnerable, as personal assistants couldn’t visit, leading to injuries.
- People with disabilities reported experiencing violence during both outbreaks, including from police and others.
- A positive development during COVID-19 was that, after strong advocacy, Sign Language Interpreters (SLIs) were included in public briefings.



Our service providers are sometimes our children. During the covid time, they work harder to go out to find food, to go out and look for water for us, so they were exposed to the covid virus...

My service provider was often not around during covid. I had to take a bucket of hot water myself to the bathroom and it led me to

...for people with disabilities, the reaction to both the virus and the vaccine, many people had fear or trauma... Awareness should convince people beyond doubt of vaccine's safety. Not forcing but convincing'

(male photovoice co-researcher with a physical impairment)

Learning from Ebola

- One of the most striking findings was how empowered people with disabilities felt to deal with COVID-19.
- When possible, people with disabilities took proactive steps during COVID-19 by gathering supplies they thought they would need during curfews and to treat COVID-19.
- However, many were unable to do this because it required unaffordable out-of-pocket payments.
- People with disabilities felt that 'other countries had it worse than Liberia', believing that the country's experience with Ebola gave them the knowledge needed to respond.
- OPDs acted more quickly during COVID-19, educating their members before 'official' awareness teams reached them.
- Despite the proactive efforts, Ebola left deep psychological scars, and many people with disabilities still did not have access to the psychosocial support they needed.

Trust and denial

- People with disabilities were very mistrustful during both outbreaks. At the start of both, many denied that the diseases were real or believed in rumours and conspiracies. Over time, most people changed their views.
- Trust played a big role in whether people followed health restrictions. People with disabilities were more likely to comply if they trusted the information and the giver.
- Misinformation was common, especially during COVID-19. People with disabilities often received information from unreliable sources on the internet or from relatives abroad.
- Nearly all people with disabilities involved in the project had taken the vaccine, but there was still a lot of mistrust.

Appendix eight: end of trip report

In September 2024, I spent three weeks in Liberia to share my research findings with a variety of stakeholders, particularly with the disability community. It is rare in research to have the opportunity to return findings to the communities that contributed to the project, so the IIV was hugely valuable to me. Additionally, the visit allowed me to hold a participatory workshop using my research findings as a foundation to develop future research initiatives and explore opportunities for collaboration.

▪ Meetings

Upon arriving in Monrovia, I had an initial meeting with the leadership of the National Union of Organisations of the Disabled (NUOD), my key project partner. NUOD, as the umbrella organisation for disability civil society in Liberia, plays a central role in advocating for disability rights. The meeting included the executive director and most of the executive board. I provided a summary of my findings and we discussed upcoming NUOD activities. The meeting was also an initial planning session for a participatory workshop and results-sharing event, with NUOD making valuable recommendations for additional invitees.

During my stay, I also met with a broad range of individuals, including:

- Executive director of the National Commission on Disability (NCD),
- Deputy minister and director for technical and vocational education and training (TVET),
- Assistant minister for administration at the Ministry of Youth and Sport,
- Health and development professionals,
- NGO country directors,
- Heads of disability organisations, and
- Academics from the University of Liberia.

At each meeting, I provided an overview of my research, discussed their organisation's role in disability, and explored potential future opportunities. For example, the deputy minister for TVET expressed interest in incorporating a disability module into the TVET training syllabus. We discussed how disability inclusion extends far beyond physical accessibility, noting that current training does not address disability issues. I recommended connecting with the disability community, including both NCD (the government arm) and NUOD (the umbrella civil society organisation).

▪ Participatory workshop

I organised and facilitated a half-day workshop with my photovoice co-researchers, who I had not seen in two years. Reconnecting with this group, who played a central role in my research, was a deeply meaningful experience.

During the workshop, I presented key findings for their feedback. While the co-researchers were familiar with their part of the project, they were keen to see how their work was integrated into the broader research. I also shared a draft of a findings brochure I was putting together for the results-sharing meeting. They gave some very helpful feedback that was incorporated into the final version.

Participatory research too often assumes needs and priorities without directly consulting the focus communities. To counter this, I facilitated a group exercise to identify participants' key needs, priorities, and successes. This exercise provided valuable insight, which will form the basis for a future research project. For me, this workshop was one of the most important moments in my visit.

photovoice co-researchers

Results-sharing meeting

On 29th September, I hosted a results-sharing meeting to present my findings as widely as possible. I extended invitations to as many stakeholders I could, including additional individuals recommended by my partner and colleagues.

I was delighted that around 30 people attended the meeting. Participants included:

- Deputy director at the Liberian Disaster Management Agency;
- Deputy minister for TVET;
- Representatives of the Ministry of Youth and Sport;
- Head of programmes at the Liberian Red Cross Society, and their disability-focal person;
- Representatives of UN agencies;
- Representatives of the NCD;
- Disability-focused and mainstream INGOs such as Plan Liberia, Associazione Italiana Amici di Raoul Follereau (an Italian disability NGO), International Rescue Committee;
- NUOD executive board and other members of disability civil society;
- The Disability Alliance (a group of international organisations with a focus on disability);
- Representatives of faith organisations; and
- Photovoice co-researchers.

Time	**Item**
10.00-10.05	▪ Welcome and opening prayer
10.05-10.15	▪ Introductions
10.15-10.30	▪ Overview of the research
10.30-11.15	▪ Key findings presentation and discussion
11.15-11.30	▪ Q&A
11.30-11.45	▪ Individual/institutional remarks
11.45-12.00	▪ Closing remarks, next steps and thanks

meeting agenda

During the meeting, I presented my findings by theme, seeking feedback and validation after each section. This interactive format worked well and led to lively discussions and provided valuable feedback that I am now incorporating into my thesis.

I gave a copy of my results brochure to all attendees, and I also exhibited the images and captions that were created during the photovoice component of my research.

photovoice photos

I also provided additional copies of the results brochure to my partner organisation and gave them the photovoice photos and captions. They were very enthusiastic about being able to use these results in their future advocacy.

Challenges

Unfortunately, my visit coincided with graduation/commencement week at the University of Liberia, which prevented me from meeting students and delivering a guest lecture as originally planned. However, I was able to meet with academics from the public health department to discuss my findings and share the results brochure. I also encouraged them to renew their links with the disability community to explore ways to integrate disability issues into their curriculum.

Opportunities

During my stay, the Director General of the Liberian Institute of Statistics and Geo-Information Services invited me to a send-off ceremony at City Hall. This event celebrated young people who were going to undertake postgraduate trainings abroad and was attended by academics and statisticians, government representatives (the vice president of Liberia was in attendance!) and other key stakeholders.

At the recommendation of the deputy minister for TVET, I also visited the Monrovia Vocational Training Center, Liberia's flagship TVET institution. The deputy minister was particularly proud of the centre's accessibility, and during my visit, I spoke with a representative about their disability-inclusive training programmes. I was also given a tour of the facilities, including the bathrooms – often a huge accessibility issue.

My meetings and the participatory workshop provided a strong foundation for future, genuinely participatory research. I am excited to develop this into a future research project that can hopefully be of best use by people with disabilities in Liberia. The visit also allowed me to reconnect with key partners and establish new relationships, which will be invaluable for future collaborations.