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The nexus between disability and urban informality: disabled voices from Eldoret's informal settlements

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Declaration

I hereby declare that the thesis, presented to the Department of Urban Studies and Planning at the University of Sheffield is solely my work, except for the work of others, which has been duly acknowledged.

No part of the work or in its entirety has been presented elsewhere for any other form of degree.

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Abstract

This thesis explores the nexus between disability and urban informality with a particular focus on how cultural, spatial and political characteristics shape the everyday lives of people with disabilities (PwDs) in informal settlements aiming to promote inclusive and contextually meaningful planning interventions. Arguably, there has been a limited scholarly focus on the voices of people with disabilities (PwDs) in informal settlements in secondary cities of the Global South including Eldoret. Yet, understanding their priorities is critical for broader and all-inclusive decision-making processes, as well as informing wider theories of disability which lack intellectual insights from the global South. This study contributes to that understanding from a disability lens through capturing the agency of PwDs and the structural forces that make it difficult for them and their families to have decent living conditions in urban informal settlements. The study draws on southern theory as the main theoretical underpinning with a specific focus on southern conceptualizations of disability and informal urbanism. Through a qualitative case-study approach, the study explores three informal settlements in Eldoret using interviews, observation, transect walks and document reviews.

The research finds that PwDs encounter varying socio-cultural realities, and are spatially affected by the material realities within informal spaces, as well as by urban governance responses. While considering how socio-cultural realities influence PwDs lives, the study discusses disability induced stigma, informal *chama* networks, care dynamics for the disabled and culture as being integral to shaping PwDs living informally in Eldoret. From a spatial and material perspective, the study highlights housing, water and sanitation services as fundamental to how PwDs experience life in informal settlements. The thesis also reveals how urban governance responses by state actors, non-state actors and traditional authorities play a key role towards the lived realities of PwDs in informal settlements. The thesis makes a key contribution to urban theoretical knowledge from the south within the context of informal settlements in secondary cities whose growth dynamics are different from the often-emphasized primate cities. Further, the study contributes to post-colonial debates within cities of the South and at the same time advances intersectionality as a way of understanding the diversity that exist among PwDs who live informally.

Dedication

To my late mother Joyce Chepkemai Mariech

&

Three daughters

Zolani, Rehema & Zariah

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Abbreviations and Acronyms

PWD: Person with Disability

UN DESA: United Nations Department of Economic and Social Affairs

CRPD: Convention on the Rights for Persons with Disabilities

DFID: Department for International Development

SC: Social constructivism

CR: Critical Realism

DPO: Disability People's Organization

NGO: Non-governmental Organization

ST: Southern Theory

WHO: World Health Organization

ICF: International Classification of Functioning Disability and Health

ICIDH: International Classification of Impairments Disability and Handicaps

DPM: Disability People Movement

UPIAS: Union of the Physically Impaired Against Segregation

CDS: Critical Disability Studies

CDT: Critical Disability Theory

PwA: People with Albinism

SMC: Small and Medium- sized City

KUB: Kenya Union of the Blind

KIHBS: Kenya Integrated Household Budget Survey

KNBS: Kenya National Bureau of Statistics

KNHRC: Kenya National Human Rights Commission

KENSUP: Kenya Slum Upgrading Project

APDK: Association for the Physically Disabled of Kenya

NCPwD: National Council for Persons with Disabilities

NACOSTI: National Commission for Science, Technology and Innovation

KIAG: Kenya Association of Investment Groups

ELDOWAS: Eldoret Water and Sanitation

NSA: Non-state actors

NKI: Nyumba Kumi Initiative

CCT: Conditional Cash transfer

Chapter One: Introduction

Research background and problem

Globally, it is estimated that one billion people live in urban informal settlements with a possibility of reaching three billion dwellers by 2050 (UN DESA, 2013). Similarly, existing data from the World Disability Report highlight that more than one billion people worldwide live with disability in one way or another with most cases, about 80%, being reported from the global South (Iriarte et al., 2015) and a majority of them not only left at the margins of cities in informal settlements but mostly living in poverty (Kabare, 2018). While this co-relation is a testimony of the significance between disability and poor urban spaces, at a more fundamental level Gleeson (1999) talks of the 'long disciplinary silence' within geography in relations to questions of disability and continues to speak about how geographers have been 'absent without leave' in the wider intellectual crusades that tend to campaign for issues around disabilities. He further alludes that without concrete theoretical and empirical work on disability the discipline will be impoverished and therefore there is a need to embrace it as a critical geographical dimension.

Since the onset of the new millennium, scholarship attending to the complex relation between geographies of disability have grown profoundly and have encouraged an exploration of socio-spatial realities which influence PwDs lived experiences (Power, 2001). However, the debates of how spaces relate to experiences of PwDs have originated predominantly from Anglophone countries and mostly highlight the heterogenous nature of physical and social conditions (ibid) while drawing on Anglophone spatial contexts in their analyses. Such debates often stack different disability notions together under the same 'rubric' meaning there is a risk of offering less regard to the specificities of being disabled (ibid:84). Some scholars have since called out research work that understate these differences in turn promoting the political urge and the need to develop inclusive concepts that reshape the various structural and spatial forces that destabilize PwD bodies and responses (ibid). This research interrogates the geographies of disability within contexts of heterogenous informal spaces of southern secondary cities which have largely been overlooked in disability studies. It uses nexus thinking¹ as an

¹ Nexus thinking as deployed in this thesis creates a framework to explore in-depth the disability-informality nexus (connection) to better understand the extant relationship of the two concepts. Nexus thinking as a conceptual framework has been deployed in this research with the understanding that it has mainly been used to explore debates around water-food-renewable energy needs but less in relation to socio-spatial areas including the connection between disability and informality as outlined throughout this research.

important conceptual link to better understand ideas from both informal and disability geographies.

Urban planning trajectories that are not specifically cognizant of disability issues such as housing needs can have devastating effects on PwDs (UN DESA, 2015) resulting in 'multiple forms of discrimination at home, in the community and society at large' (Runo, Mwai, & Onywere, 2019:1). This situation is exacerbated by a lack of inclusion in urban political decision-making processes. The link between disability and poverty in cities of the global South is 'virtually undisputed' (Cobley, 2012:372); a disabled person is likely to be poor and often experiences a lack of basic services such as water and sanitation and most importantly inadequate shelter as well as often experiencing food scarcity (Kabare, 2018). In a similar vein a poor person is most vulnerable to disabling conditions. 'A growing realization of this reality has drawn attention to the urgency of addressing disability issues, in order to meet global development targets, such as the Millennium Development Goals' (ibid:372), the Sustainable Development Goals (see UN, 2015), the New Urban Agenda (UN Habitat III, 2017) and the Convention on the Rights for Persons with Disabilities (see CRPD, 2006). Disability drives people into poverty via negative outcomes such as the failure to access meaningful employment and other relevant economic activities (ibid). Further synthesis of this reality is inevitable especially when it is related to the proliferation of informal settlements, a trend which has become synonymous to most cities worldwide (Kiddle, 2010), and has become a critical focus for urban theory (Roy, 2005). In other words, both disability and informality are strongly shaped by poverty since PwDs often live in urban informal places characterized by social and economic deprivations that hamper sustainable lives Empirical evidence has shown that most PwDs who reside in Kenyan cities live in informal settlements because on the one hand their poverty levels limit them to such areas and on the other hand high costs of services in various cities including Eldoret limit them at the margins of informality (Patrick et al, 2022). To decipher that reality the integration of geographies of disability to informal urbanism scholarship is key. However, such knowledge correlation lacks empirical investigation and has been broadly under-theorized within the context of planning strategies in the global South, a gap this study aims to bridge.

Just like other marginalized groups, the disabled experience wide-ranging forms of discrimination in cities especially those in the global South (UN Habitat III, 2017). They form the largest minority population in the world (UN, 2006). They have been

isolated, incarcerated, observed, written about, operated on, instructed, implanted, regulated, treated, institutionalized, and controlled to a degree probably unequal to that experienced by any other minority group (Davis, 1997:1)

Those who live in informal settlements and are disabled experience extended forms of exclusionary practices where they are exposed to often-harsh realities within the city landscapes. The UN Convention on the Rights for Persons with Disabilities (CRPD) was formed to address issues that affect PwDs. Although CRPD itself has achieved some significant milestones, more so at the international level (UNCRPD, 2006), more effort is needed towards redressing issues leading to the extended marginalization of the disabled in global South cities. In promoting this international and multisectoral endeavour, there have been insignificant efforts by states to develop strategies that are aimed at poverty reduction and socio-spatial integration (Calderon, 2008) which are supposedly meant to address lived experiences such as urban informal processes (Kiddle, 2010). Mitchell & Snyder (2016:489) while referring to Berlant (2007:754) work, highlight that PwDs and other similar minorities alike 'tend to live in greater proximity to ecological disaster and/or in conditions generating slow death' especially in informal urban landscapes. As argued by most disability geographers, these daily human experiences tend to be understood limitedly from the perspectives of the dominant able-bodied class while excluding competencies of PwD's whose bodies do not fully or in part conform to such built environments (Hall & Wilton, 2017). Poverty as revealed above makes the situation even more complex. At the same time ineffective housing policies of cities in the global South have precipitated the proliferation of informal settlements and housing programs targeting low-income residents are either not delivered or are unaffordable (Kiddle, 2010). Although there is a plethora of such pro-poor urban initiatives in the global South, they usually display a one-size fits² all situation where PwDs 'continue to face challenges and barriers that limit their enjoyment of their right to adequate housing' (Chenwi, 2021:321).

Housing as a critical component of cities shapes how other services are provided managed and distributed. Planning solutions to housing that focus their empirical studies in the East African region, generally reveal that the extensive commercialization of housing for low-income groups has led to significantly informalized housing supply systems (Huchzermeyer, 2007; Mwangi, 1997; Mwau et al., 2019, 2020; Rakodi, 1995). Previous research mainly focused on informal housing production in Nairobi. Huchzermeyer for instance, confers how 'large-scale private landlordism dominates low-income housing provision in Nairobi, with extreme residential densities in districts where rooming tenements reach seven floors above ground'(Huchzermeyer, 2007:714). In other words, growth patterns in most cities within the East African region have been extensively shaped by approaches which are market-led and

² 'One-size-fit all' implies to a notion where strategies or a policy does not take into account individual groups' needs and end up failing to achieve intended purpose.

profit-oriented, in turn leading to massive deficits in services because of a lack of what really constitutes the interests of the majority poor (Jones, 2017; Mwau et al, 2019). This trend is proving costly and results in deeply inflated housing costs that are untenable for the urban poor pushing them further into informal settlements commonly characterised by precarious housing (Kiddle, 2010). In the same breath, the increased proliferation of informal settlements in other Kenyan cities such as Eldoret (the focus of this thesis) implies that the conventional formal housing provision either by the state or private developers does not meet the demand for housing by the urban disabled poor. This is particularly the case in secondary cities which are often overlooked in research while emphases are put on larger primate cities. Yet, these smaller urban spaces possess unique housing trends that have exceptional effects on PwDs. The pervasiveness of such informal housing production, which is portrayed in a similar manifestation in other cities within the global South, is understood to stem from profoundly problematic housing systems that lead to uneven housing supplies as noted above. This in turn results in a complex system of housing provision that exists parallel to formal arrangements- 'the informal production of houses' in urban informal settlements (Walker, 2001:22). However, the fact that an informal system of housing provision co-exists with a formal system is not the problem per se, the main concern is the nature of the housing production and the resultant physical forms of the houses and the effect it has on disabled communities. As such, the often extremely low standards and norms of housing affect the sustainable urban livelihoods of the inhabitants. Arguably, research has depicted that flawed governance systems (through inept urban development planning) and intricate urban political interplays coupled with self-interested elitist groups lead to market-driven kinds of housing provision that are deliberately instigated for profits hence promoting urban inequality (Jones, 2017).

As pointed out by numerous studies (e.g Buckley, Kallergis, & Wainer, 2016; Huchzermeyer, 2009; Meth, 2019) the reality of the problem is beyond the physical manifestation of the built structures, whatever the source of housing provision, the inhabitants are exposed to other intricately connected socio-spatial realities. Broadly, the main focus often tends to be on housing as a siloed element rather than 'developing quality environments for low-income communities, supported by the necessary physical, social and environmental services' (Chenwi, 2021:324). Ideally, the urban environment should provide everybody including PwDs with the necessary fundamental services as an imperative (Hussain, 2017). Yet, in many countries, particularly in the global South, the needs of PwDs are often poorly considered in development practice (Iriarte et al., 2015). As noted above CRPD highlights wide-ranging issues that promote the rights of PwDs. Its principal emphasis is raising awareness in various societies about 'respect for the rights and dignity of persons with disabilities' (Lid, 2014:1344).

A significant focus of the convention relevant to this research is article 28, which stresses that state parties have to provide PwDs with an 'adequate standard of living and social protection' (CRPD, 2006:18), housing being a pivotal element within the article. CRDP formed a part of a paradigm shift (Lid, 2014) in the development of the 'disability rights movement' and disability studies which fanned various scholarship that strongly emphasizes 'social and political barriers faced by PwDs' (Hussain, 2017:45). A new planning doctrine which this research advances is to promote the often-denied urban privileges of the disabled in cities of the global South.

The CRDP as a framework for the universal rights of disabilities stresses that PwDs should be well integrated into society. As explicated in the next chapter, the 'social model' of disability, one of the most dominant ways of looking at the disabled, defines disability through various impairment barriers placed on PwDs. The barriers which include socio-economic and environmental dimensions are depicted in CRDPs 'clear emphasis on inclusion, participation and equality'(Cobley, 2012:372) however, the reality is that PwDs are not well integrated. Kenya a signatory to the Convention has fully committed to support the principles of the Convention 'based on the social model principles of removing societal barriers, protecting rights and promoting mainstream opportunities' (ibid:372). The National Survey for PwDs conducted in 2007 revealed that about 4.6% of the Kenyan population live with disabilities, albeit there is a possibility that many PwDs cases are unaccounted for in the country (Kabare, 2018). The inconsistencies in the prevalence of disability in African countries is attributable to factors such as proxy respondents, language barriers and cultural traditions which limit how people respond to survey questions (Chenwi, 2021). Despite the flaws, the survey in Kenya clearly shows that PwDs face severe challenges and often live in underprivileged spaces in informal settlements. Such spaces, which are highly attractive to the urban poor given their relative affordability, house up to 73% of urban population in most cities in sub-Saharan nations (Wekesa et al, 2011). This study examines the experiences of the disabled that define their day to day lives in the context of varying informal spaces within Eldoret to illustrate the significance of the nexus.

Non-contextual and generalised categories are often used to describe informal settlements as unplanned spaces thus failing to nuance the diversity of their materialities as well as the communities living within them (ibid). This reinforces the negative and stereotypical perception towards residents living therein further excluding them, as spaces where socially degrading activities such as crime and violence thrive (ibid). In other words, the diversity in such spaces is often overlooked and a stronger emphasis put on the physical transformation to achieve the often romanticised and ambitious city visions that are aimed at matching other global

conceptions which see informality as a 'problem to be fixed' (ibid:7). As a result, urban informality is often conceived as an homogenously dysfunctional process and set of spaces housing a homogenous population, often poorly accounted for in any meaningful ways. Therefore, this research meaningfully contributes to rethinking diversity in informal settlements through a focus on disability. Although there has been outstanding progress in research and policy initiatives on informal processes in cities of the global South (Mwau & Sverdlik, 2020; Walker, 2001:22), the variety of approaches have so far not fully addressed the topic of disability. If there are efforts, they have been partially initiated. Such an insight, where disability is not fully integrated within urban processes such as formalisation, upgrading or other related strategies in informal settlements, stands out as a strong motivation for this research. The study explores the various socio-spatial realities that shape the lives of PwDs in existing informal settlements in Eldoret and also critically examines the governance responses and challenges that disabled slum dwellers undergo so as to negotiate their day to day lives. Particular focus in this thesis is put on physically disabled individuals or caregivers of various PwDs as a marginalised constituency of people within the urban, who are experiencing discrimination, stigmatisation and exclusion because of deeply entrenched cultural beliefs such as disability being a symbol of misfortune and a caricature of bad omen (Mukoche et al., 2014).

While most cities in Kenya starting from Nairobi thrive economically, culturally and are politically vibrant, they are manifested by deep inequalities which stem from the country's colonial legacy and the intricate contemporary patterns of urban development which are exclusionary against the poor (Patrick et al, 2022). Given that Kenya's urban landscapes are tied to their rich colonial history, they are massively segregated, meaning urban development has over the years led to the rapid growth and proliferation of informal settlements which are predictably a refuge for the poor including the disabled (ibid). Also, PwDs are generally neglected from social processes and norms and tend to be abandoned by family. They often end up in the city peripheries if they manage to escape the often harsher and harmful cultural realities that are more prevalent in rural areas such as stigma associated with disability as punishment of sin (Baker and Imafidon, 2020). Although such realities in the urban are less detrimental given their often more progressive approach to diversity, the disabled in Kenyan cities are often negatively perceived thus excluding and denying them of their urban rights (Frediani & Monson, 2016). A study done in Kisumu city (3rd largest city in Kenya) by Frediani, & Monson (2016) highlight how PwDs are gravely deprived of their rights as enshrined in the governance frameworks; something which ought to be resolved prior to any planning interventions. They contend that PwDs are affected by the conditions of their low-income neighborhoods which are deprived of most services such as roads, housing, electricity, sewer,

water and sanitation. Similarly, Mwau et al (2020:72) note that low-income housing in most Kenyan cities is often inconsiderate to PwDs needs 'whose quality of life and dignity are especially imperilled by deficient water and sanitation'.

In order to have a nuanced understanding of the complex urban system, the lived experiences of various urban populations need to be explored and discerned. A lack of or partial approach to understanding the various urban experiences in informal settlements leads to poor policy intervention that is unable to offer long-term solutions. Urban communities who are most affected by ad hoc interventions are those who live in vulnerable situations where they encounter all manner of inequalities driven by poverty and exclusion. PwDs form one of the most underprivileged community groups in informal settlements who are usually situated at the heart of such prevailing conditions in cities in the global South. Their lived experiences are usually composed of intersecting social identities such as gender, age and ethnicity which can work to exacerbate the conditions they have to negotiate on a daily basis (see Rigon, 2022). Yet as noted by various scholars such complexity is not often taken into consideration in both knowledge production and implementation of policy strategies. This implicit gap in knowledge partly predates this study and forms a foundation to a new understanding of the concept of disability in relation to informality in Eldoret through an intersectional lens.

A southern secondary city perspective and the disability-informality nexus

While many scholars have emphasized the need for a southern urban theory as a way to better understand cities in the global South and ultimately leading to a surge of the same in the recent years, Parida and Agrawal (2022) specifically highlight that literature about southern cities do not portray the lived experiences within smaller to medium sized cities. More explicitly, disability debates around processes of urban informality in the smaller towns are often underexplored. Recently for instance, Patrick *et al's* (2022) work on inclusive infrastructures in Nairobi is an example of such intellectual biasness, whilst they raise pertinent issues around urban disability which resonates with this study, more research is needed on smaller urban spaces. These spaces are distinct from the other larger urban areas since they possess fewer resources, have different governance/political regimes and capacities, have smaller budgets, economies and tax bases, experience severe spatial challenges e.g inadequate water and have less diversity and cultural changes associated with metropolitan spaces (Veron, 2010). Critically, as compared to the more complex primary cities, these smaller towns are often less dense and are located next to rural/ agricultural areas and therefore make the transition of people to urban life easier through provision of employment and easy markets for goods and services (Tacoli and Agergaard, 2017). Moving on, existing scholarship emphasizes more the relationship between disability and other generalised concepts e.g poverty (Albert, 2004) and economic empowerment (Cobley, 2012) but there is

less evidence of a focus on the explicit relationship between disability and informal processes in small cities. This thesis therefore aims to bridge this glaring gap using the context of Eldoret a medium-sized city as a case study.

In global south contexts, experiences of disability have either been homogenised or generalised/simplified 'in line with the social model as one of disproportionate oppression, intensified by a homogenised 'third world' constructed as backward, undeveloped and often brutal towards its weaker members' (Grech, 2011: 89). Therefore, there is urgent need to listen to the voices of the disabled to deconstruct such extant perceptions. The significance of listening to such voices is inherent to the conceptual tenets of southern theory. Southern theoretical views reverberate with disability scholarship from the Global South as they tend to 'explain the dominance of perspectives from the metropole' (Meekosha, 2011: 677) thus opening up different ways of theorising socio-spatial dynamics in the urban such as the disability-informality nexus. Within such contexts, through southern theory we can understand

'how colonial projects were concerned with rearranging social relations – so that traditional ways of supporting impaired people would be undermined – the kinship, family and community systems' (Meekosha, 2011: 677).

Explicably, there exist a significant dearth in epistemologies that link disability studies and practice in the global South (Grech, 2009). According to Bezzina (2018) the support to PwDs by governance agencies in the region is usually framed using western models and conceptions with little consideration to local dynamics. She highlights a report by the DFID which speaks about how disability projects are undertaken where emphasis is put on promoting the social model of disability thus universalising a western conception. Further, the report stresses the need for a rights-based approach to sustainability yet, PwDs in the global South are often more concerned with survival as a reality. Whilst such imported concepts from the North are critical, more attention has to be paid to realities of culture, social dynamics, the politics and history which define disability in the urban South. As argued by Grech (2011: 87) 'the implications for disabled people remain confined to epistemological silence' meaning PwD voices stay unheard in decision-making processes. While such hegemony is not particular to disability, it reflects the on-going knowledge domination by western practices in the academy and in policy circles. This research therefore seeks to minimise that dominance by applying a southern theoretical perspectives for a nuanced understanding of the nexus between disability and informality.

Research objective and questions

This research brings to the fore the disability-informality nexus by examining PwDs lived realities in rapidly changing informal settlements in Eldoret, a fast-growing secondary city. Its aim is to establish how informality (re) shapes and (re) defines the lives of PwDs within informal settlements in Eldoret, Kenya through an understanding of their spatial conditions and their everyday way of life and the links to urban governance. To achieve this, the following questions guided the research:

1. How do sociocultural perceptions, norms and practices shape the everyday lives of PwDs in informal settlements?
2. How do PwDs adapt and negotiate the various spatial and material conditions within urban informal settlements?
3. How do urban governance structures shape and define PwDs everyday lives in informal settlements?

Methodological approach

Through a qualitative research approach, this study analyses empirical data from interviews, observations, transect walks/rides and document reviews to explore and understand the dynamics of disability and informality in the rapidly growing secondary city of Eldoret. The study combines social constructivism (SC) and critical realism (CR) as its guiding philosophical approach to gain a nuanced understanding of the geography of disability through an exposition of PwD's urban lived experiences within informal settlements. Since the research predominantly relied on the participants views of how they experience disability conditions and the reality about disability itself, both SC and CR were best suited as a two-pronged philosophical approach hence rendering a more holistic understand to disability-informality nexus.

Thesis outline

Broadly the thesis is categorized into two halves. The first half (chapter 2-4) provides the understanding of the ideas in this research using both theoretical and context background material to establish a framework to better analyse the empirical findings presented in the second half (Chapter 5-8). Chapter 2: Reviews relevant literature on disability and informality thus establishing a conceptual framework for the research. It establishes the importance of rethinking disability and informality using a southern lens. In particular the chapter situates an understanding within local dynamics of disability while at the same time underscoring the significance of western models which often tend to overlook existing realities in the global South. While aiming to understand disability more generally, the chapter first presents three

key models of disability (charity model, medical model and social model) that are relevant to the lived experience of the disabled in the global South. Addressing the gaps exhibited by these models, the chapter argues for southern theory as a framework to better understand realities of the disabled in the region. The chapter then goes ahead to nuance the disability-informality nexus using a southern theory lens with a specific focus on southern conceptualizations of disability and informal urbanism. Intersectionality, a vital concept building into this thesis, is discussed towards the end of the chapter and serves to nuance the connections between disability and informality enriching the nexus thinking approach.

Chapter 3: Presents a critical reflection on literature on how disability and informality in Eldoret is manifested. A contextual background of disability and informality cutting across the national scales down to the local setting of Eldoret is explored where emphasis is placed on the role of colonisation in shaping the disability-informality nexus. Importantly, the chapter explores a historical account of the disability-informality nexus and how the various governance regimes from the British rule to the current government treat PwDs and informality. While stressing Kenya's dark colonial past and its exclusionary legacy, the chapter fleshes out some of the subsequent more progressive but also problematic planning models and governance practices and how these shape PwDs in informal settlements.

Chapter 4: Details the methodological process adopted in this thesis. The rationale is provided here through an explanation of how PwD's lived experiences were explored and analysed. In describing how that process was undertaken, the chapter is divided into four main sections. The first section describes the research's philosophical position whereby social constructivism and critical realism are presented as a two-pronged paradigmatic approach towards understanding everyday lives of PwDs in informal settlements. It also reiterates the primary aim of the research and how the research questions connect with these philosophical positions. That is then followed by a description of how the research design was constructed and the basis that led to the adoption of a case-study approach. Moving on, the following section provides a description of the fieldwork process, the logic behind the selection of various research methods and how data was analysed through systematic coding and theming. Some of the research considerations like ethical issues and the researcher's positionality are also discussed thus legitimising the entire process. Importantly, the research contextual background is briefly discussed in the final section where the characteristics of the three case study sites are brought to light.

Chapter 5: This chapter sets the beginning of the study's empirical analysis by addressing the first research question. The chapter presents a critical discussion of various thematic findings that highlight 'social and cultural realities' of PwDs as they negotiate the often-harsh living

conditions in informal settlements which as it will be deliberated in the next chapter are in many cases characterized by insufficient services. The chapter is divided into two main sections. The first section examines the socio-structural elements in disability spaces beginning with stigma and discrimination as a fundamental issue which cuts across all social strata within disabled people's lives. Strategies to overcome these are then discussed beginning with informal social networks popularly known as *chamas* as a way to unite and build up ways of promoting themselves as disabled people. The other core arguments in this section focus on the geography of care in relation to disability within the milieu of informal settlements. The second half of the chapter highlights the cultural traditions tied to disability with religion and spirituality as key constructs which shape PwDs lived experience.

Chapter 6: This chapter explores and addresses the second question of the research. The chapter analyses housing, water and sanitation issues which as evidenced by the data were the key spatial components that shaped lives of PwDs in informal settlements. The first section which details the housing situation of PwDs in Eldoret, highlights three main housing typologies relative to the disabled, namely shared rental housing, caretaker/borrowed housing and owner-occupancy housing. Additionally, problems that arise due to housing are discussed, with key issues including tenure insecurity and evictions, size of houses, affordability and homelessness. The second section discusses water problems relative to disability where the core argument focuses on the available water infrastructures and the challenges to accessing water from a disability perspective. Finally, sanitation which was identified as another integral spatial component for PwDs is brought to the fore in the last section of this chapter. The key argument here being on sanitation facilities and the barriers to a healthier environment within informal settlements in the lives of PwDs. The barriers included access and distance to toilets, unclean facilities, cost implications and safety/privacy all which were fundamental for the disabled.

Chapter 7: This final empirical chapter focuses on urban governance responses to disability and how they shape lived realities for PwDs in informal settlements. The chapter responds to the third research question. Generally, the chapter offers a critical reflection on the existing relationships and attributes between the government, non-state actors and the disabled people in society. The chapter looks at three main responses as evidenced practices of urban governance within Eldoret town. The first set of responses are from state actors and how they impact on the disabled lives. While there are varying responses from the state which are not necessarily tailored for the disabled, the discussion herein exemplifies two such initiatives i.e the cash transfer program and the *kazi-mtaani* initiative. Notably, in as much as the *kazi-mtaani* initiative was established for all population groups in communities, it seemed to shape

the day-to-day lives of the disabled more than even other siloed state programs which are explicitly targeting PwDs. The other key governance structure discussed in the chapter is the role of non-state actors in Disability People's Organisations (DPO) on the one side and the influence of NGOs on the other side. The last structure of urban governance covered is the importance of traditional authorities to the disabled. The chapter also explores the barriers to efficient governance processes and how PwDs are affected. Three key issues are discussed: a lack political representation, mistrust and bureaucracy in service delivery and corruption practices within governance practices.

Chapter 8: This concluding chapter draws together the results of this study to answer the research questions. The principal arguments of the thesis are presented through a synopsis of the contributions of this research by bringing together the conceptual framework and the arguments emanating from the research inquiry. It also suggests a possible way forward for future strategic disability development in Kenya and makes recommendations for further research advancement that can improve service delivery. The chapter outlines the value of new knowledge presented in this study and its potential to influence theory and understandings of disability-informality nexus from within the context of a small city in the global South.

Chapter 2: Retracing disability and informality using a southern theoretical lens

This chapter provides a review and critical discussion of literature relating to the concepts of disability and informality thus forming the first part of the literature review. Following on the previous chapter which introduced the nexus between disability and informality, this chapter, unpacks the concepts that underpin the study through an extensive examination of various theoretical approaches to disability and informality as individual subjects or where the relationship is established even through partial linkages. In detail, the chapter argues that existing debates are not nuanced enough to delineate the complex relationship between disability and informality. Thus, a new way of understanding disability manifestation through their lived realities and the everyday politics to negotiate informal spaces presents a shift in how disability in Kenya and beyond can be perceived. Importantly, while there has been work on how disability is produced from the lenses of informality in the Global South, little attention has been rendered to how both intersect and interact via a nexus approach for instance. In building discussions around that nexus as a space to distil and listen to the disabled and subaltern voice, the chapter introduces southern theory (ST) as a productive conceptual and methodological approach that fosters both understandings of disability and informal urbanism. Drawing from key ST theorists such as Connell (2007) and Comaroff and Comaroff (2012), the chapter explores how disability is understood and problematized. While coining it as a remedial lens the chapter presents ST as a way to understand differently how disability is produced and manifested in the context of informal urban spaces in the global South. Southern disability perspectives and informal urbanism which form integral conceptual underpinnings of the southern city theory are parsed as possible avenues to provincialize local knowledge which in turn lead to possibilities of developing a disability-informality framework that is more suitable for non-western societies and contextually relevant for this research endeavor. To theoretically reinforce the same, the last section of the chapter briefly argues for an intersectional approach to the nexus furthering its understanding of the varied ways in which informality and disability are produced and experienced and extending the approach as a novel scholarship from the south.

Defining disability: interpreting and understanding the concept

The most universalized definition which has been widely adopted internationally was presented by the International Classification of Functioning Disability and Health, commonly known as ICF. While resembling the tenets of the social model as discussed later in this chapter, the ICF model defines disability as a result of a person's health condition interacting with the surrounding circumstances. The ICF model is a WHO framework which was endorsed in 2001 as a successor to the previous 1980 ICIDH conceptual framework whose intention

was measuring of disability conditions at various levels and was overly fixated to disability functioning and limitations thereof as the principal determinant for defining disability (Imrie, 2004). While contrasting the same, the revised framework is premised on the understanding that disability exists because of structural barriers that impede participation (WHO & World Bank, 2011). Debates which acknowledge ICF model demonstrate disability as a ‘complex dialectic of biological, psychological, cultural and socio-political factors’ (Shakespeare & Watson 2002:22) . The model as shown in fig 1 below is intended to standardize disability measurements and descriptions. The framework does not see disability to be an inherent feature, rather, it sees it arising from ‘activity limitation’ and restrictions from participation which happen in an unfriendly environment as defined by the background context (Mitra & Shakespeare 2019).

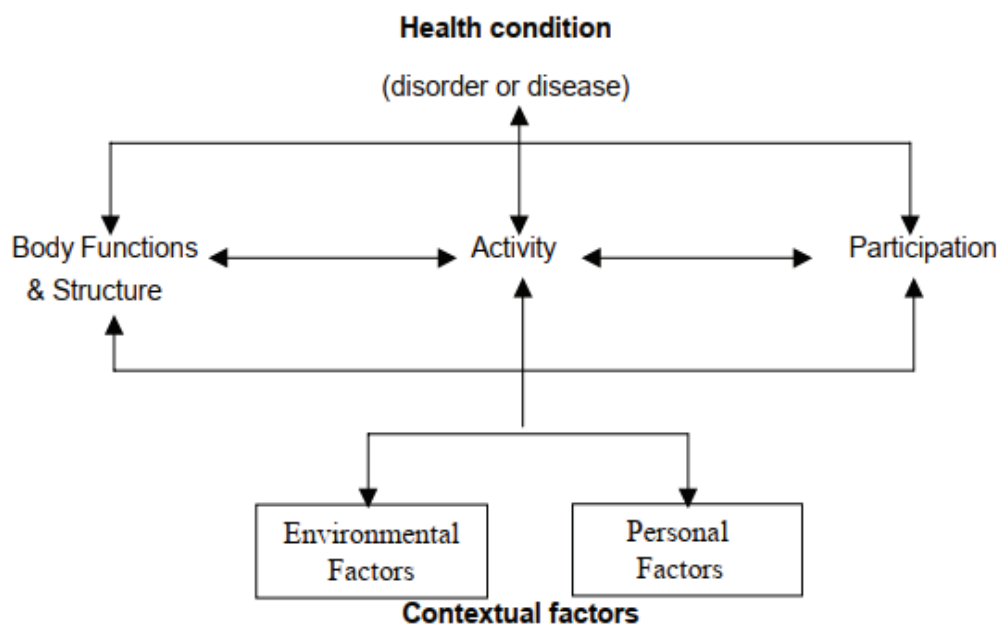


Figure 1: Showing the ICF Model (Source: WHO, 2002)

As the diagram demonstrates, the ICF model sees the concept of disability as an interaction between the health conditions of an individual with the contextual characteristics that define a place. Health condition describes diseases for instance both congenital and acquired while contextual factors represent the prevailing environmental circumstances such as social dynamics, built environment, culture, geography etc and personal attributes such as age, ethnicity, gender etc. In the diagram there are three levels of disability and functioning, first is within the actual body part of a person (anatomy), second is within the whole person in activities such as bathing, eating and third is about participating in situations that involve

human interaction. In other words, there are three distinct hierarchies that shape disability and functioning -the body level, the whole person and at the society's level.

Although the ICF model has been immense in shaping the global disability agenda, critics believe that in its current structure it is less likely to enrich the lived experiences of PwDs (Oliver, Sapey & Thomas 2006). As this research demonstrates in later sections of this chapter, this is particularly relevant for cities in the global South where western frameworks such as the ICF model often sit out of context for varying reasons such as the affinity people have to their culture and how that shapes their disabling conditions. Nevertheless, even with such theoretical shortcomings the ICF unquestionably anchors itself as a gamechanger for the role it plays in shifting disability understanding from fundamentally a medical and illness oriented notion to a an all-inclusive concept 'where biological, social and cultural boundaries traverse and meet' (Rolston, 2014:45). Thus as a model it has been instrumental over the years for interpreting disability conditions where emphasis is placed on deconstructing barriers while insisting on inclusive spaces which are otherwise 'systematically' exclusive in nature (ibid:46). The next section looks at relevant models of disability which were conceptualized before the ICF model and are equally significant to interpreting disability especially in the current age where debates including arguments within this research advocate for a nuanced disability perspective from the south.

Models of disability

As the debates around disability continue to evolve and the theoretical challenges posed by ICF are unpacked, the process of evolution will over time continue up to when social spaces that are inclusive to PwDs are located and their lived realities given priority at the expense of the impairments ((Mitra & Shakespeare 2019). The key argument in the evolutionary process of the model framework has been a move away from initially focusing on an individual to the modern currency where focus is less of an individual and more to structures of society which (re) create disabilities. Although there are numerous models which tend to frame disability, this study explores three namely the charity model, the medical model and the social model. These models have fairly defined 'new geographies of disability' in a way sympathetic and relevant to the lived realities of the disabled within the global South (Gleeson, 2001:251; Grech, 2009). More precisely, the three models ideally relate to the fundamental objective of this research and the empirical realities in Eldoret as featured in the second half of this thesis. Notably, various elements of these three models have significance for how disability is understood within the context of Eldoret especially on pertinent areas such as culture, medicine, politics, charity, governance and planning frameworks.

Charity/Tragedy model

The charity/tragedy model is one of the most common conceptualizations of disability that tended to theorize it from the perspective of charitable human welfare (Johnson, 2019). This model premised on the traditional retributive concept of disability, led to victimization of individuals whose woes were exacerbated by neglect from the state who in many cases indiscriminately confined them in relief or social housing (Tsai & Ho, 2010). The various crises of political legitimacy triggered different states into enacting laws for these unprivileged groups in the 1980s. Disability as depicted in figure 3 below at best was seen to be an issue of personal tragedy and at worst was as a result of moral inadequacy where PwDs are seen as victims of their disabling circumstances who deserve to be pitied (Retief & Letsosa, 2018) and at the same time confronted with shameful, burdening and inferiority senses (Johnson, 2019) as summarized in figure 3. Imrie (1997) while highlighting charity in disability notes

People with disabilities remain at the margins of society, often depicted as pitiful and tragic characters worthy only of the charity of their 'able-bodied' counterparts. For many disabled people their daily reality is dependence on a carer, while trying to survive on state welfare payments. Moreover, most disabled people have few formal educational qualifications and are generally excluded from labour-market opportunities (1997:263)

In turn PwDs according to Rolston (2014) are devalued while obvious stereotypical connotations of incapability and incompetence get reinforced leading to a perception that the ultimate panacea to disability is charity.

The charity model was rooted in ideas of divine justice and human beneficence, where care for the disabled led in practice to their being segregated from the rest of society (Griffo, 2014:143).

The initial charitable approach was thus overlaid with segregatory practices of social exclusion and institutionalisation, which marked those they took in with a strong social stigma and made them socially undesirable (Griffo, 2014:148).

Such charitable practices would often involve the provision of care in institutions that range from convalescent homes, mental care asylums (Johnson, 2019) and other extremely tragic situations of imprisonment or violent confinement (Kitchin, 1998). Such methods are intended at and used to 'confine and oppress disabled people' (Kitchin, 1998:346), commonly against their wishes. In a context such as Taiwan for instance, 'abandoned persons with disabilities

were indiscriminately housed together with the elderly, the poor, orphans and the sick' (Tsai & Ho, 2010:93). The shelter housing called *jijiyuan*, which in literal terms implies 'relief housing' were provided and funded by charity organisations like religious institutions since similar state-led initiatives were absent or deficient (ibid).

The ideology which hegemonizes normality on the one side and problematizes disability on the other is perpetuated where such ableist thinking patronizes disability with a curing and aiding mentality. The discourse is often reinforced in mainstream media where PwD bodies are advertised and seen as a means to financial and capital gain, all behind the spirit of charitable work. Discussions inevitably centred around charity advertising because this is probably the only way PwDs become visible or their voices heard (Barnes, 1992). This unfortunately is portrayed with euphemistic labels as alluded above reifying the thinking that PwDs all aspire to being normal and that able-bodiedness equates perfection. Despite the critiques as outlined here, the charity model seems highly influential in informing policies on charitable practices as discussed later within the findings of this research. Withers (2012) while describing how capitalism directly benefits and enforces PwDs oppression pinpoints how disabled children are used as imagery for charity fundraising efforts. Undoubtedly, children are seen to be in need of cure and transformation into productive people while disabled adults are often perceived to be non-productive and beyond interventionist processes. Such curative and healing mentality is subtly furthered through the medical model as discussed in the next section. In sum, while the charity model underpins tenets of the medical model, it comes out as key to interpreting how the disabled are treated in societies mostly objectified as in need of pity and help from nondisabled people.

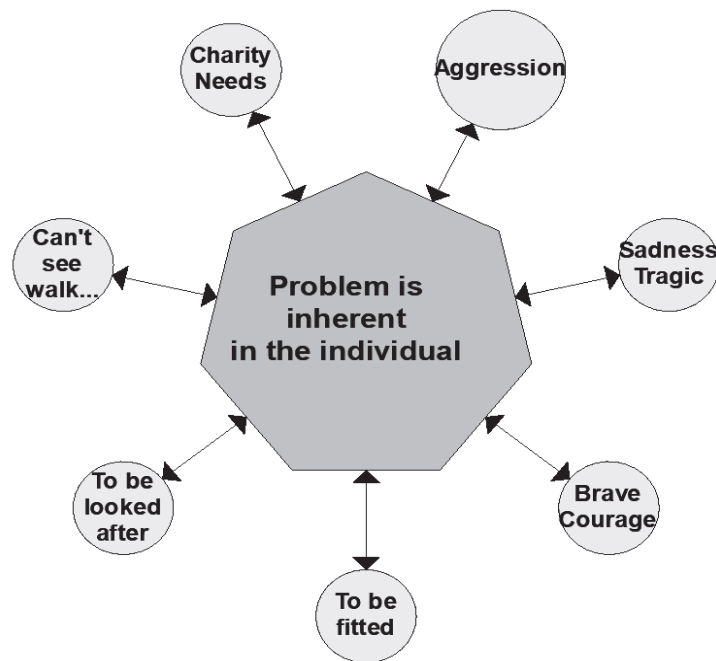


Figure 2 : The charity model (Source: Amponsah-Bediako 2013)

The medical model

A social science framing of disability from the start of the 20th century was focused around the medical model type of conceptualization (Shyman, 2016) making it the most dominant form of theorizing disability in the Western culture 'alongside the rise of institutionalized forms of housing and the increasing influence of medical professionals' (Hemingway, 2011:51). The model presented disability as an abnormality that is specific to an individual's bodily function (Bogart & Dunn, 2019: 652). The body's organic deficiency was seen as the main 'problem' within the context of this model (Shakespeare and Watson, 2001: 11). It posits disability as an issue that is akin to sickness where curing through medicine to attain a normal body is necessary to facilitate ability or mobility (Bogart & Dunn, 2019: 652; Imrie, 1997:263; Valentine, 2003:376). The key to understanding the medical model and why it is inadequate for the study of disability is the "sick role" (Bickenbach, 1993). While that emphasis is usually common case, this research through its findings equally argues of how positive attributes about the medical model significantly shapes the lived realities of disabled people. This is true since PwDs are seen to somewhat depend on various kinds of medical support ranging from drugs to equipment such as wheelchairs and crutches.

In the medical model the individual has a condition (a deficit) which is unwanted or which in the past caused something undesirable in the individual (Parsons, 1951:285). Consequently,

the person is seen as carrying the sick character or conditionally sick (ibid). In that role, the disabled individual is exempted from engaging in social duties and obligations (Parsons, 1951) meaning while on the one hand it can be a form of protection for the disabled, on the other it stigmatizes. 'So, if you are sick, you have a reason for not going to work or to class' (ibid). Indeed, as Fine and Asch (1988) highlight, such thinking promotes the impression where the disabled are viewed as weak and depend on able-bodied persons and that their 'biological condition rather than the environment and social context makes one-way assistance inevitable' (1988:6). As Fine and Asch conclude, assumptions of such nature perpetuate a demeaned and negative imaging of PwDs and that their physical attributes play into other segments of their lives including their socioeconomic status. In summarizing such a critique, Fine and Asch (1988) notes that:

It is the disability, not the institutional, physical and attitudinal environment that is blamed for role changes that might occur. The person with a disability may (initially, or always) need physical caretaking, such as help in dressing, household chores, or reading. It must be asked, however, whether such assistance would be necessary if environments were adapted to the needs of people with disabilities - if, for example, more homes were built to accommodate those with wheelchairs...the physical environment as an obstruction remains an unchallenged given (1988:14).

Since the medical theory of disability remains entrenched in practices around the built environment, to a large extent PwDs experience spatially stigma which in turn reinforces the perceived notion of seeing disability as a derived problem within an individual (Imrie, 1997: 265). Indeed, the medical model centres its understanding of disability at the dichotomy of disabled and non-disabled categorization of society so as to frame functioning of the body and at the same time determine who is supposed to be cured in order to reverse the effects of disability (Shyman, 2016).

In geographical relations, Imrie (2001) argues that exclusive, barriered and bound spaces tend to be (re)produced based on 'symbolic and cultural encoding of the city' that reinforces efficacies of 'civilised' and normal 'bodies' while trivializing medicalized bodies of the disabled. The same is posited by Ellis (2000:21) who castigates modern societies for opposing what he terms as seen to be 'risky bodies' where anxiety of the corporeal body lead to a desired notion of 'healthiness, and youth'. Relatedly, other geography scholars, such as Dyck (1999), Parr and Butler (1999), amongst others, critique the role of the medical model on spatialities of disability. Their discussions reveal how narratives about disability aim to 'propagate a conception of disability as abnormal, deviant and reducible to the physical and mental

impairment or the functional limitations of the body' (Imrie, 2001:233). The binary categories of the medical model namely the normal/abnormal, sick/healthy, abled/disabled, etc shapes social spaces and tend to be naturalized in practice.

Spatial discourses tend to identify with bodily status of abled/disabled where PwDs are seen to be problematic and unwanted (Gleeson, 1999; Hansen and Philo, 2007). The same is evident in the design of buildings which subordinates impairment where designers are complicit in how they make provisions that suit a socio-culturally acceptable narrative. For example, in figure 5, Imrie (2014) illustrates how a house occupant with disability cannot dispose of waste where the body is unable to conform to complicit design of the 'body-normal'.

The outcome, disablement, is illustrative of the power of disabling design discourse as a naturalistic part of the crafting of the designed environment and, as such, it is rarely problematised or subject to critique (Imrie, 2014:16-17)

Apart from spatial influences, medicalization of disability percolates into state and policy where laws are a part of the broader scheme to put undue pressure on PwDs to conform to a certain political or economic narrative that is suitable

Policing, as part of the exercise of state power, was also a feature of disabled people's incarceration into special places or locales, ranging from spaces for schooling, to asylums and dedicated work environs (ibid:17)

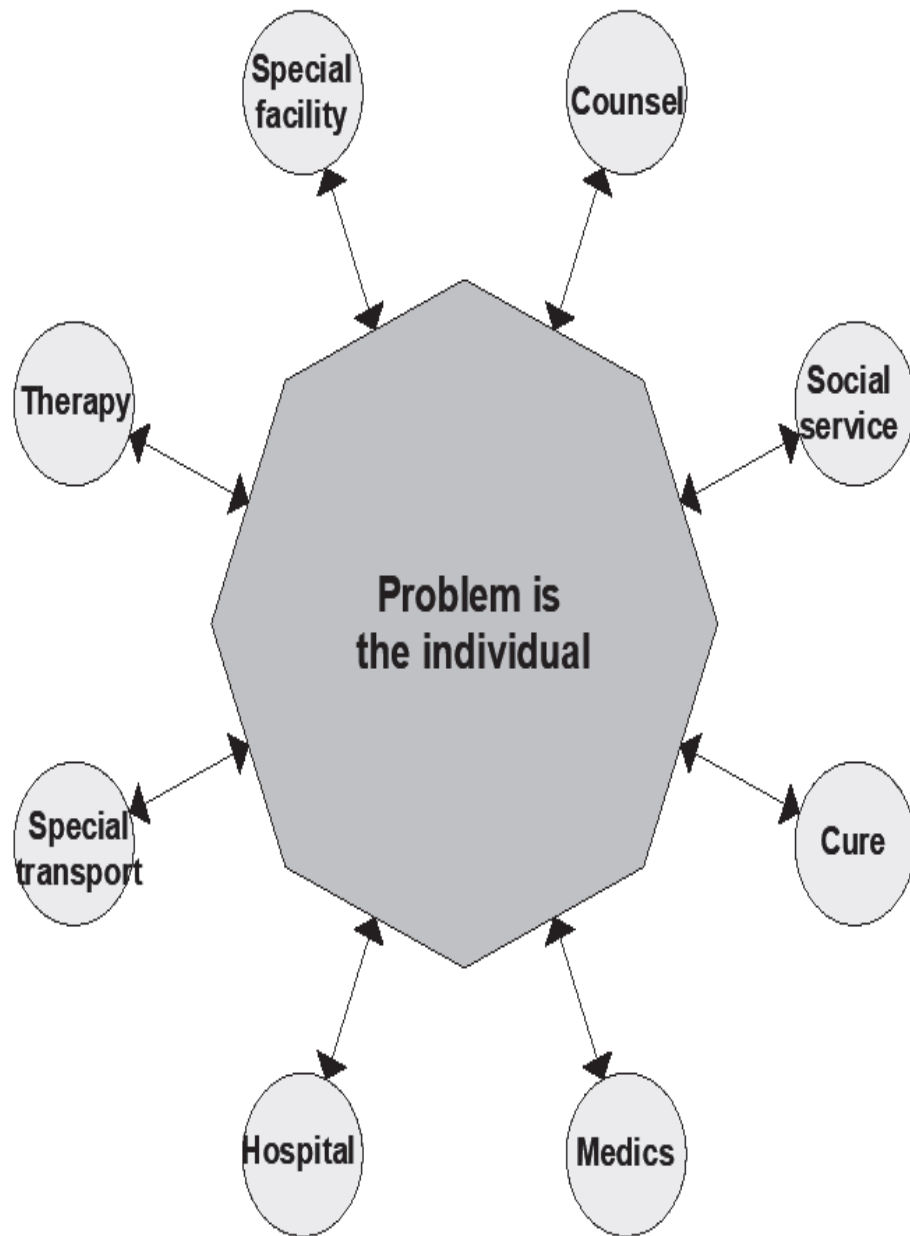


Figure 3: The medical model of disability (Source: Amponsah-Bediako 2013)



Figure 4: A disabled person unable to dispose waste (Source: Imrie, 2014)

Such segregated settings were spaces meant to control the disabled by containing and managing them beyond confines of the society. The existing policies and laws often embody the constructions of the abled-bodied individuals thus framing the disabled in a particular manner. In sum, it is evident that all these conceptual descriptions front the medical model as one that does not accept PwDs choice and freedom both in social and physical spaces. It should however be understandable that while all these criticism and concerns raised are legitimate none at all says or trivializes the influence of medicine and charity towards PwDs lived realities or the existing conditions due to the effects of impairment or that medical intervention needs to stop. Rather, what is being propagated by the critical reflections on the entrenched medicalization of disability is a shift away to a new conceptual platform where focus moves away from the impaired body to take account for other complex realities that entail living with and experiencing disability. Similar to the charity model where norms such as street-begging as a daily charitable practice depict the powerful role of the model in shaping and defining disability, the medical model through the discussions here portends it as a powerful and influential mode to which disability is understood in Kenya thus a critical issue explored in this thesis. The power of medical practitioners for instance in deciding whether one is disabled or not is an example of how the medicalization of disability is significant to the disabled and hence highly relevant to their lived experience.

While the significance of the medical model in the lives of the disabled is indisputable, its application to and meaning for PwDs in urban informal settlements whose lived experiences are dominated by limited access to health services has been poorly advanced or examined.

This research aims to showcase such gaps through realities of disabled individuals who negotiate constantly for services such as access to medical equipment. The social model discussed next moves away from the individualization of disability to encompass the immediate surroundings of a disabled person as the key agency for disablement.

From social model to critical disability theory: a new paradigm shift

The social model sets itself as 'the big idea' which has changed the understanding of disability by being the vehicle to which Disability People Movement (DPM) has been strengthened and in turn reinforcing PwDs consciousness within communities (Oliver, 2013:1024). First pioneered by Oliver within the British context its initial aim was to provide a better understanding of the Union of the Physically Impaired Against Segregation (UPIAS) definition of disability and its general implication. Thus, he states

This new paradigm involves nothing more or less fundamental than a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environment impose limitations upon certain categories of people (Oliver, 1981: 28)

Although not a theory in itself, the model as an instrument used to shift focus away from individualized disability accounts to more structural elements, has undeniably achieved the 'iconic status' as a theoretical perspective whose contents have been consistently dialogued by both its protagonists and antagonists alike (Thomas 2004:573). It contains several key elements which were of fundamental importance to a new disability thinking (Shakespeare & Watson, 2001) at the turn of the millennium. To begin with and similar to the medical model's caption about general medicine, the social model too does not deny the significance or value of medical intervention through rehabilitation or education or work through professionals (Barnes, 2019). The model instead severs the link that exists between the impaired body and disability; clearly making such a distinction as its central precept (Boxall, 2018). In doing that, it 'distinguishes between the impairments that people have, and the oppression which they experience' in the society (Shakespeare & Watson, 2001: 10). The social model thus deliberately shifts focus away from the limitations that a PwD individual has onto the existing problems within disabling environments and cultures which ostensibly preclude barrier free living (Barnes, 2019) by discouraging social oppression which is a product of such existing structures. Oppressive practices imposing restrictions might entail prejudice meted on an individual, discrimination at the institutional level, inaccessible buildings and transport, segregated education systems and exclusive work patterns, etc. In this light, PwDs were seen to be oppressed by social and structural factors as opposed to individuals (Imrie, 2007).

Disability from a social model challenges the individual/medical perspective as an alternative understanding where it is viewed through social barrier concerns therefore shifting focus to existing social inequalities particularly issues around poverty and discrimination (Goodley, 2011). In other words, the model provides the tools and a relevant platform to channel policies and subsequent practices that aim to eradicate tendencies within modern society that perpetuate disablement thus promoting inclusive spaces for PwDs (Shakespeare & Watson, 2001:10). For those advocating for the model according to Barnes (2019:18), it is best to look at impairment as a constant in human beings but 'disability need not and should not be'. By doing that PwDs tend to be less disdained because focus shifts from them to the oppressing forces within society thus connecting with their own experiences. It is not an individual's impairment that is the reason of the problem arising from disability, but it is the failing by society not to appropriate the needed services which fully account for PwDs lived experiences.

The social model has indeed been highly influential. While it carries with it many advocates, it has on several occasions been disputed (Tregaskis 2002; Oliver 2013) with skeptics calling for it to be reclaimed to fit the current status (Allan, 2010) or even left out from disability discourses (Shakespeare and Watson 2001; Beckett & Campbell, 2015). So as to make it more relevant and adequate to the needs of PwDs, various voices have questioned its current theoretical tenets and have advocated for its further development (Morris, 1991; French, 1993; Crow, 1992). Their critiques mainly centre on including experiences of being impaired within the tenets of the social model however this has been resisted by agents of the theory. For instance, Finkelstein (1996) while contesting the same believes that including impairment experiences amounts to diluting the already achieved impacts and outcomes of the model.

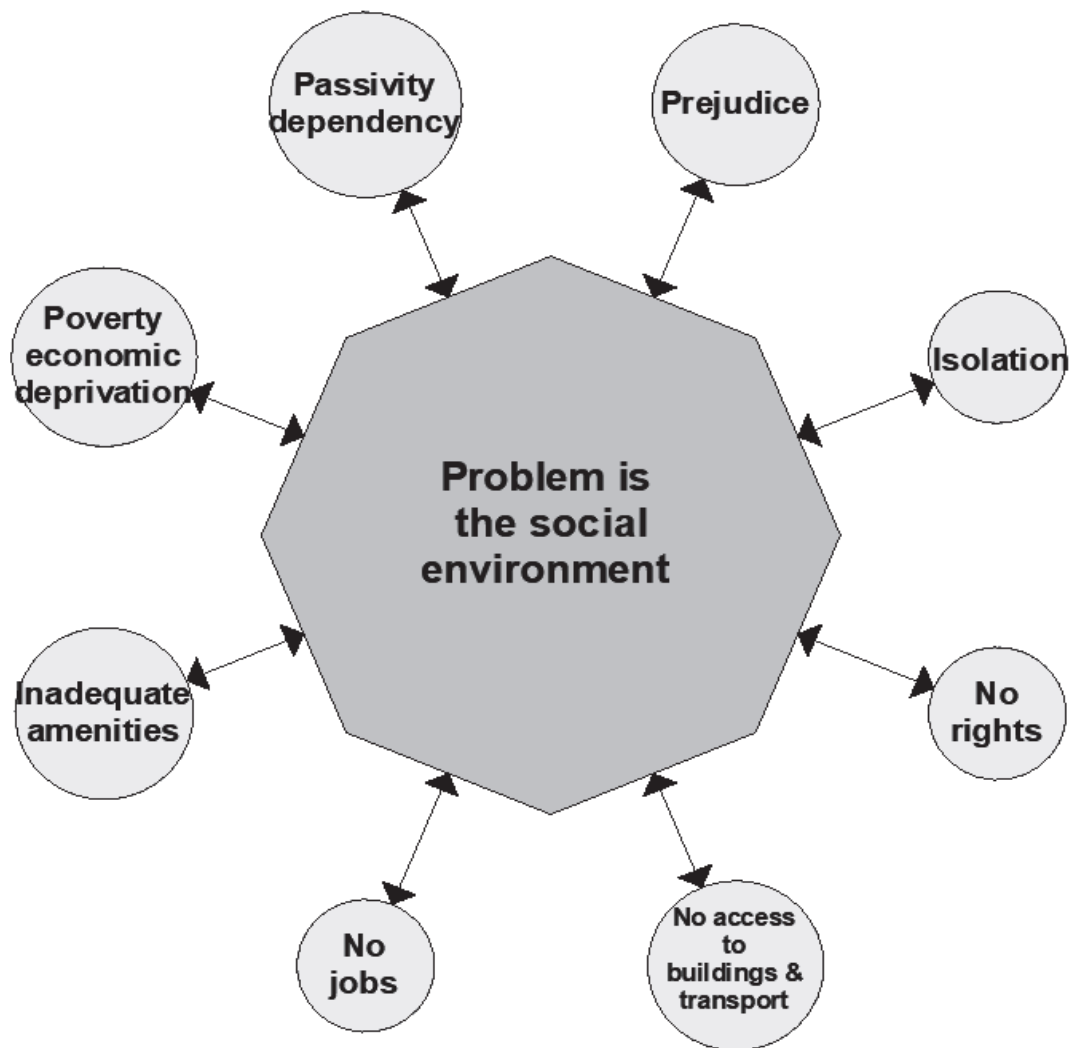


Figure 5: Showing the social model of disability (Source: Amponsah-Bediako 2013)

At the backdrop of such critiques and discontents some disability theorists have turned to other ways of conceptualizing disability; from a rights-based model (Berghs et al, 2019) to a relational disability model which dominates the Nordic countries (Thomas, 2004) to the recent critical disability theory (CDT) (Meekosha and Shuttleworth 2009; Shildrick 2004, 2007, 2012; Mallett and Runswick-Cole 2014; Goodley 2012, 2014, 2016;). As a new way of theorising disability, CDT has broadly been ushered in as Critical Disability Studies (CDS) (Goodley, 2016; Shildrick 2012). Emerging as a powerful force and lens that has given impetus to progressive theoretical expressions of disability such as the social model, CDS ‘boasts of sophistication and nuance’ (Goodley et al, 2019:974). Whilst this is not to suggest that the theories beforehand were simplistic, basic or not critical, some such as neo-Marxist disability

critiques around capitalism were dense and complex (e.g Oliver 1990; Gleeson 1999). Rather, a CDS approach brings on board 'a smorgasbord of perspectives' both from within and beyond disability which not only challenges its current doxa but also innovatively questions how it is identified, embodied and its agency in relation to the wider society (Goodley et al, 2019:974).

While primarily building knowledge praxis of the early disability studies through a productive critique of their limitations, CDS 'consciously' engages and establishes working relations with other related theories such as feminism, postcolonial, queer and critical race creating a 'a rich tapestry of concepts and frameworks' from the various epistemologies and ontologies (ibid:974). Although CDS provides this thesis with some critical conceptual insights, its value and relevance to the disability-informality nexus was deemed less productive. However, while emphasizing such form of theoretical alliances, a number of scholars within critical disability studies have stressed the need to expand critical disability thinking by conceptualizing disability from realities beyond the global North and into the South (Goodley et al, 2019; Grech, 2011; Grech and Goodley 2012; Nguyen, 2018). Similarly, though CDS places disability at the centre of political debates and issues around power, including campaigning against the marginalization of PwDs, it is yet to prove itself as a useful framework in parts beyond the global North. This includes contexts such as Kenya which unfortunately are still ghosted by the dark histories of colonialism. The nature of coloniality that exists in CDS and the politics that follows it such as activism still remain unaddressed to a large extent (Ned, 2022:487). For example, Hutcheon and Lashewicz (2020) while tracing the intersections between ableism and colonialism in Canada challenges white and privileged scholars within the Canadian context to attend to the impulses of coloniality that is embedded in their work which in turn perpetuates ableism. Similarly, Driskill (2010) within the same context highlights how colonialism still wield power and control over communities that are indigenous. As such, CDS and decoloniality scholars have recently posed vital questions on how the processes of colonialism not only reify ableism but how it perpetuates disabling conditions and (re) create new disabled bodies (Hutcheon & Lashewicz, 2020; Meekosha, 2011; Grech, 2012; Grech & Soldatic, 2015). These questions remain critical to any work which tend to oppose ideals of ableism within processes of colonialism making 'disabled bodies' 'invisible entities' (Reed-Sandovala & Sirvent, 2019:1553; Ned,2022). Such questions have then led to a fresh wave of CDS scholarship that calls out the nature of the existing models of disability for their contextual prejudice and their inappropriateness to addressing disability concerns in various global contexts (Cornel, 2011; Erevelles, 2011; Grech, 2015; Jafee, 2015; Kafer, 2013; Meekosha and Soldatic, 2011; Soldatic 2013). Meaning 'scholars have challenged disability studies to decenter its assumed White, western subjects and develop "southern/global theory"' (Jampel & Bebington, 2018:2). This scholarship has seen the rise of 'southern disability theory' which

is later returned to in this chapter. Riding on the wavelength, this thesis builds and extends disability studies using a southern theory lens with specific focus on informality within secondary cities. These urban spaces as alluded previously are often overlooked in favour of larger and more complex primary cities. Yet secondary cities possess unique growth dynamics and challenges which potentially add new dimensions to urban theory. More precisely, the study seeks to understand the lived realities of PwDs within such neglected urban informal spaces from a southern theoretical perspective.

What is theory from the South or Southern Theory?

Southern theory according to Nyamjoh and Morrell (2021) is a rapidly evolving body of knowledge that is comprised of both theoretical and methodological debates about places of the Global South. The theory offers 'a perspective on the process of knowledge production, circulation, and distribution within specific cultural, historical, and political conditions of the global South' (Nguyen, 2018:6). It aims to challenge the universalization of traditional theoretical frameworks through the mobilisation of knowledge from the South, largely undertheorized, as a critical epistemological asset to transform contextual production of knowledge and the geopolitics thereof (Nyamnjoh & Morrell 2021). Through marshalling experiences and knowledges that have otherwise been marginalised and fronting them as legitimate sources of scholarly intellect, Southern theory recognises, repositions and centres knowledge from the Global South (ibid) at the heart of global debates. It is thus both an epistemic and political conceptual framework (ibid).

According to Mabin (2014), conceptual debates around theory from the South are traceable to two commonly cited scholars- Connell (2007) and Comaroff and Comaroff (2012). Connell's sociology book (2007: ix) queries the 'belief that social science can only have a universal body of concepts and methods, the one created in the global North'. She argues that 'the only possible future for social science on a world scale involves a principle of unification' (2007:223) that is, weaving the 'different formations of knowledge in the periphery with each other' while connecting them to the dominant global North knowledge (2007:213). Comaroff and Comaroffs' (2012:1) anthropological work contests the position of western thinking 'as the wellspring of universal learning' yet the global South region which constitute a majority is seen as 'a place of parochial wisdom, of antiquarian traditions of exotic ways and means. Above all, of unprocessed data'. Southern theory, the Comaroffs (2012:7) argue is not about telling the modern way from the 'undersides', rather it is about showing the 'history of the present' from a 'distinctive vantage point' that define a place.

From an urban studies perspective Watson (2014) posits the work of Robinson (2006) who questions the implication of literature on global cities as growth models being applied to other cities. Similarly, she pinpoints Seekings and Keil (2009) who speak against the universalisation of urban theory which promotes European and American experiences. Finally, she identifies with the work of Yiftachel's (2006) gray spaces of ethnocracy, Roy's (2011) 'subaltern urbanism and state informality' and Watson's (2009) 'conflicting rationalities' as examples of innovative planning concepts that go beyond planning theory that is Western-centric and are associated with a Southern theorisation. Mabin (2014) briefly highlights two key characteristics of Southern theory components that are pertinent to this study. First is the component of coloniality/post-coloniality whereby the cultural ills of colonisation still intrude on the present processes of knowledge production that hegemonizes certain people and regions. Second is the pre-existing conditions in areas of the global South where situations of scarceness are common. Such an image usually invokes negativity and the definition of lacking yet in many instances people living in such conditions have their creative ways and means to live. Therefore, Mabin (2014) highlights that

'the South and cities of the South, are marked both by a political economy of insufficient resources to provide on average a decent life for all; and by (post) colonial disabilities. It is in these intersections that those promoting 'theory from the South' endeavor to engage' (2014:23)

Southern theory according to Mabin (2014:23) is mainly defined by power³ and the extent to which it can stretch to destabilise the existing hegemony of northern thinking. That in itself is unsurprising he states since is a purposeful trajectory that is 'set out to unseat hegemonies and in many cases the hegemons purveying them' (2014:23). Mabin's twin characteristics are employed within this thesis to analyse the experiences of the disabled within spaces of informality in Eldoret. However, Southern Theory is not merely an approach to comprehend the urban, it has been applied to other disciplines beyond urban studies, including criminology (e.g Carrington et al 2016) and more recently as explored in this research to disability. In the section that follows, a number of different southern disability approaches are explored, mainly focusing on perceived central issues that lead to an augmented knowledge of disability and

³ Power in this thesis is relational, according to Qin (2018) 'relational power is more likely to be "power to" rather than "power over", for it tends to indicate a co-empowering process during which social actors empower each other through sharability, reciprocity and complementarity. In this sense, power is no longer the ability to control others, but the ability to orchestrate relations for maintaining the process of co-empowerment' (Qin, 2018:241)

urban informality within the framings of a southern theory as the principal conceptual argument of this thesis.

A Southern disability approach

Disability scholars from the South especially those from the African context are in many cases confronted with multi-layered power relation dynamics which disadvantage them in their quest to create and disseminate knowledge on disability and the lived experiences of PwDs from the region (Ned, 2022). The South African case is of particular interest since research on disability has been historically entangled with complex hierarchies of racialised power (ibid). In attempting to redress such asymmetry of power in disability knowledge in South Africa, the process has inevitably involved questions around social exclusion and related power. Such cases reify how scholars from the South are epistemically vulnerable to their counterparts in the North. By adopting Connell's (2000) pioneering work about Southern theory Ned (2022) sums up three key theoretical consequences which are born from Northern thinking domination of the knowledge production space.

'The claim of universality which ignores the harsh realities of persons with disabilities in Africa and the extrapolation of Northern discourse to explain the realities of African people; reading from the center which makes some key debates about disability irrelevant to those whose major interest is on issues of survival and thus inadequate to explain the complex African experiences and gestures of exclusion where African thinkers are either never cited in disability studies and that theorization never builds on theories formulated in Africa as a site with valid knowledge systems (Ned, 2022:486)

Consequently, Meekosha (2011) argues that the time was 'ripe' to develop a Southern perspective to de-emphasize Northern theories which implicitly devalue vital components about disability in the region. While calling for disability studies to be decolonised, Meekosha (2011) criticizes the universalised tendency of colonial practices which render PwDs bodies in the South as invisible. Equally, Ned (2022), writes of how it is ironic that the majority of disabled people live in the Global South yet ways of knowing about disability in the African context for instance are mainly produced without recognising the local epistemology and methodologies. She notes that 'theory is often credited to the North while subjects studied include those located in Africa' (2022:489). In the same manner Grech (2015b) reiterates this trend by pointing out that

Disabled lives in the Southern context are often simplified and generalised in a dynamic of homogenising, decontextualised and dehistoricised discourse. Instead, concepts and knowledge from the global South, the Southern voice and

epistemologies are rarely considered, sustaining an 'academic neo-imperialism' (Grech, 2015b:7)

Scholars from various disciplines have demonstrated beyond doubt the urge for CDS to go a step further and capture disability from a Southern context. However, despite having useful scholarly campaign for knowledge production of and from the South, a few if any are yet to explicitly speak about the everyday situation in urban informal settlements in cities of the global South. By discussing disability in relation to urban informality this study establishes a new dimension to the on-going debates which tend to privilege and promote oppressed PwDs voices through a southern theory lens. Indeed, the current trends of urbanisation especially in secondary cities of the global South is uniquely shaping up and constantly changing and so should be the ways of critiquing their geographies and the processes they (re)create including disabling and informal spaces. Beyond southern disability studies, geographical scholarship on disability still lags behind the trends in development geography which has continued to nurture itself within the global South (Jampel & Bebington, 2018). Furthermore, while such debates tend to mostly happen in the North, a few if any have 'directly addressed disability and development or disability in the "developing world" context' (ibid:1). Debates of how spatial dynamics inform disability experiences have considerably expanded (Power, 2001:84) but 'have largely been urban, Anglophone and Western-centric' (McEwan & Butler 2007:448). The disabled body in industrialised nations has not only predominantly remained the centre of attention but scholarly discussions about disability are often premised on knowledge that is Western in context (ibid). This research grapples with this challenge by focusing on the lived realities of PwDs in their social and cultural formats, the spatial challenges within informality and the negotiations of governance responses beyond their households. Some of these issues are discussed in the following section using a southern theory lens to understand and problematize the ways in which knowledge accounts of disabled people in informal settlements are silenced and maintained in alterity.

Conceptual realities of the disabled voice from the South

The preceding debates have demonstrated the basis to which we can develop concrete perspectives on disability that are premised on Southern realities which then would lead to better understandings of disability and thinking within contexts of the South. That backdrop sets the scene to look at two key conceptual certainties of disability within various contexts in the South i.e cultural perceptions on disability and poverty that characterise informal urban spaces. Since the issues are closely linked to each other, they scaffold together into a spectrum of Southern disability epistemology which helps this research to unpack the empirical findings. For example, the relevant dynamics of poverty in disability spaces blends

with cultural, political and economic phenomena within various contexts producing structural forces which at times create or deny livelihood opportunities for PwDs either at the individual, household or a community level (Eide & Ingstad, 2013). Often as a result of poverty, it is impossible to protect poor disabled people from cultural beliefs and instances of violence (Neille and Penn, 2017). In what follows, the two conceptual realities that nuance disability from a Southern theoretical lens are briefly unpacked.

The hegemony of culture

'The very notion of disability as a cultural concept may be unfamiliar to a range of communities, in fact, some languages do not have a word for disability' (Schumm & Stoltzfus, 2011:xiii). At the same time, disability can have very strong cultural meanings and practices. The fragmented ways that 'cultural traditions conceptualize disability, and the struggle against such conceptualization, is a major theme addressed multiple times in this study' (ibid). There have been wide-ranging writings from various disciplines on the complex relationship between disability and cultural diversity in the South and how that defines and shapes disability, its perception and most importantly how it is conceptualised (Bezzina, 2018; Ned, 2022; Sefotho, 2021). These works depict strong cultural meanings and practices within Southern communities and how disabled individuals have strong affinity to cultural contexts. However, just like other disability nuances, cultural and indigenous disability concepts from a Southern context are often overshadowed by Western thinking, knowledge and existence (Bezzina, 2018; Ned, 2022; Parsloe, 2015). Two prevailing scenarios are at the heart of a cultural understanding of disability in the Southern context. On the one hand some societies positively celebrate disability and treat it just like any other social identity and on the other hand disability is seen as a negative and a sign of bad omen which should be avoided at all costs.

Usually, when indigenous communal practices are referenced when trying to understand disability, a singular narrative that describes a deficient and contextually unwanted body prevails (Ned, 2022). But that is not always the case, on the contrary, Ojok and Musenze (2019) argue against such thinking, they tell of how PwDs in African culture were not always perceived to be handicapped or lacking.

A person with disability was accepted in ancient Africa and given a visible role in the society, witnessed in present time among the Vadoma people. Furthermore, their daily activities suggested integration in daily life and their disorder was not shown as a physical handicap but a blessing from the gods; no one worried over a disability as the identity of all was of humanity (ibid:5).

Ndlovu (2016) corroborates the same by arguing that African cultural beliefs showcase PwDs as full members/citizens of the society with all rights accorded to them just as everyone else. A study by Mugeere et al (2020) about disability in Kenya, Uganda and Zambia showcases how PwDs ascribe their faith and belief to a supreme being that offers them the motivation to keep going even in the most challenging situations.

The second scenario, a negative connotation to disability widely attached to traditional African societies perpetuates an unjustified blend of both political and cultural suffering of PwDs even in the contemporary world (Ned, 2022). The rampant and noxious attitudes such as the 'abduction, killing and mutilation' of albino people in Eastern Africa are fueled by cultural beliefs and political motives that are unfortunately geared at 'wealth and prosperity' (Mwiba, 2019:30; Nyangweso, 2018). Scholarship by Etieyibo and Omiegbo (2016) reflect on how religion and other cultural practices in Nigeria promote discrimination of PwDs through powerful belief systems that beget stereotyping and prejudicial thinking. Communities inaccurately link mental disorders to social ills such as sorcery and as such instigate communal violence to mentally disabled people. Several other studies show the same features of this traditional approach; in Tanzania (Masanja, 2015), Uganda (Mulumba et al., 2014) and Zimbabwe (Mpofu & Harley, 2002; Munsaka & Charnley, 2013; Peta, 2017); where disability is commonly seen as a misfortune, bad omen, an act of witchcraft or a punishment from God where the disabled person should be outcasted from the society (Ned, 2022).

Away from the attributes about political and cultural relations to disability, two dominant facets within African cultures play fundamental roles of defining the lives of PwDs-religion and spirituality. To begin with, moral teachings that are religious assist in establishing the cultural standards to the perceived normal body (Schumm & Stoltzfus, 2011). Through its several manifestations, religion plays a key role and determines how disability is constructed and understood eventually shaping how PwDs are treated (negatively or positively) in any given context (ibid). There is a wide array of scholarship on the overall role of religion on the lives of PwDs (Bennett et al., 1995; Weisner et al., 1991; Mugeere et al., 2020). In geography specifically, Kong (2010) examines the outburst in the geographies of religion in the last few decades and although she identifies various themes in her work, of particular interest to this research is how she highlights contemporary global shifts (such as social inequality and ageing) and how religion shapes human responses to those shifts. In response to Kong's work which categorially lamented the poor integration of geographies of religion with religious studies, Tse (2014) advocates for the use of 'grounded theology' as a rubric to assess contemporary geographies of religion in the current age of secularism. Dinham (2008) explores the role of the Church of England and other faith-based organisations in cities and

specifically urban regeneration discourse at the global. Beyond geography to anthropological literature, Lukalo and Maseno (2021) examines how 'grounded theology' is used to unearth concealed meanings in the everyday lives of PwDs.

Societies in Africa are largely dominated by religions based on Judeo-Christian beliefs-Christianity, Islam faith and Judaism (Ojok and Musenze, 2019). These religious beliefs to a large extent shape how PwDs perceive themselves and also how others perceive them (ibid). The strong belief related to religious systems offers PwDs a way to interpret their challenges and stressors of living with disability on top of the poverty manifested informal settlements. Christianity as an example is enshrined in the Hebrew Bible which has two separate testaments-the old and the new as heralded by the birth of Jesus Christ. In the Bible disability is heavily conflated with sin by an individual or his/her ancestry (Otieno, 2009).. The disabled from the biblical times not only functioned as a reminder of God's abilities and wrath but also the medium in which He passed messages of purity and righteousness though suffering (ibid). While Christianity as a practice is not indigenous to Kenya's religious practices it is endeared by many and strongly shapes how the society relates to disability through various theologian interpretations that either oppress PwDs through stigma or support them through care and various other socio-spatial and political responses (ibid). Christianity in various ways accommodates the disabled needs and can be traced back to colonial practices where missionaries set up schools and empowerment institutions (Akanle & Olorunlana, 2014). In colonial Nigeria for instance, it is argued that since Christianity was about providing for the needy and abrogating practices such killing of twins and banishing PwDs from the society, it became a leverage with which settlers were welcomed in most of African societies (ibid).

Spirituality closely linked to religion, implies to the emotional attachment people have to what makes them excited (Donald 2006). According to Ojok and Musenze, (2019:3) religion and spirituality are not one and the same, while 'spirituality is necessary for religion, religion is not necessary for spirituality'. They further highlight that societies in Africa are rooted in spiritual practices rather than religious norms however scholars educated in the West confuse religiosity with spirituality hence misinterpreting and misrepresenting African religious beliefs. Scholarship on spirituality have in the recent past explored its importance to managing stress and as a coping mechanism. Equally, Walsh (2003) in his work associates spirituality with resilience of families experiencing distress. There are several cases in Africa of how spirituality manifests itself in the lives of PwDs and the rest of society. Notable examples where spirituality has been linked directly to disability in East and Western Africa as alluded above include the killing and violent contexts PwA encounter especially children. The witchcraft-induced murders of PwAs for 'their body parts for use in 'lucky' charms thought to bring good fortune' ultimately leads to social ostracization (Taylor et al., 2019:13). Despite the violent contexts, Baker et al

(2010) depict how PwA children in Zimbabwe and South Africa are profoundly stigmatized and not taken to schools since they believe that children with albinism die young and therefore other children are prioritized.

The paucity of information on the lives of children with albinism in Africa limits the development of appropriate interventions to support, empower and, most importantly, protect them at this time of danger in the region (Taylor et al., 2019:13).

According to Baker and Imafidon (2020) disability debates are created by medical professional and sociologists yet realities on the ground are premised on deep traditional beliefs which vary between the type of disability and region. They highlight that policies and programs on development and planning are not sufficiently informed of the traditional beliefs and deep-rooted cultures which strongly shape disability in Africa. Therefore, a nuanced understanding and awareness of the realities within societies in Africa is imperative if strategies that deal with disability and disabling situations are to be a success. This is echoed by Groce (1999) who asserts the need to frame disability from the local context where traditional beliefs are fully encompassed in planning strategies:

The knowledge of traditional beliefs and practices towards disability is of vital importance if we are to plan and implement programmes for individuals with disability that will make a real difference in their lives and the lives of the communities in which they live (1999:4)

Disability planning therefore has to capture the local context and knowledge about experiences of disability since generalizing and overlooking minor cultural details and intricacies is more often a detriment to PwDs. This thesis sought to unearth how specific experiences of culture and traditional beliefs shaped PwDs within Eldoret's informal settlements. For example, the role of the church and how it shapes disability and how it relates with traditional belief systems or how people in urban settings negotiate harmful practices such as killings for rituals or attitudes of being labeled with witchcraft as discussed herein.

Poverty and marginality

In the recent past, disability and how it relates to poverty has been reasonably accounted for in scholarship (Grech, 2016). Some commentators have described the mutual relationship that exists between disability and poverty and how they are bound together as feeding into each in a never-ending reinforcing cycle (WHO and World Bank 2011). They suggest that while it's not always the case, being poor drastically increases and/or exacerbates the vulnerability of being impaired while disability barriers intensify the chances of experiencing poverty (Grech,

2016). As such disabled people in the poverty indexing qualify as 'the poorest of the poor' (ibid:217). But of course, not all PwDs live in poverty however the vicious circle suggest that disabled people are most likely to experience poverty that non-disabled people (Mitra,2005:10). Since most countries in the global South lack social support systems, being poor in the region has severe implications that threaten life (Yeo, 2001). The main cause leading to the life-threatening poverty situations is marginalisation from essential services such as access to health care which then exacerbates disabling conditions (Eide and Ingstad, 2013; Yeo, 2001). Disproportionately, disabled people live in chronic poverty because they are often not only excluded from social services but are also seldom accounted in research activities (Yeo, 2001). The existing contestation about the exact definition of both disability and poverty could be blamed in part for the limited research on the two concepts over the last two decades (Eide and Ingstad, 2013). That lack of research means a great deal of evidence that supports existing assertions between the two concepts remain anecdotal resulting in an ill-defined and understudied nexus of disability and poverty (Nora et al 2011). In light of the same, Grech states that

The voices and narratives of disabled people especially those living in extreme poverty are notably absent too often spoken for by so-called professionals and experts or by privileged urban disabled people's organisation (DPOs) including those in the global South (2016:218)

For Grech, it is not only qualitative research that is lacking when looking at disability-poverty in the global South, theoretical debates that employ Southern epistemologies are invariably scant. More often, the uneven existence of poverty among PwDs in the South has been incorrectly inferred with accompanying neo-colonial images that portrays an extremely poverty stricken 'dark' disabled figure subjected to deep stigma and ill-treatment (ibid). The framing of this disabled figure is one of weakness, marred with inordinate levels of poverty and who needs to be attended to in the name of development premised from the global North (Grech, 2011). Glaringly, most of the organisations who dominate development in the global South have been accused of taking advantage of the misery and blowing it out of scale so as to gain more funding for charitable activities (Grech, 2016). Unfortunately, and as alluded above, the poverty and disability relationship has been based on anecdotal evidence and in most cases generalised such that it is almost referenced as an expected/guaranteed phenomenon in the region, yet empirical and theoretical knowledge is lagging far behind (ibid). The differentiated nature of poverty is also poorly understood. Thus, disabled voices and realities about poverty remain scanty and missing even in the midst of paradoxically high numbers of PwDs as rendered by development professionals for funding. Indeed, this lack of empirical evidence

results in ineffective action and poor decision-making which limits growth and development (Banks et al 2017). The need to come up with a more coherent understanding of the interplay between the two conceptual realities has accelerated efforts calling for more research that anchors and describes concisely the existing relation (ibid).

As a product of structural forces which crucially causes poverty, the marginalisation of PwDs and subsequent informal living is commonly viewed as a negative socio-cultural practice, as described by Grut et al (2011). However others may argue that it is a reality and a natural response to biting poverty and largely a survival mechanism because of the limited options at hand. According to Hansen and Sait (2011), collective efforts through solidarity can in some way challenge the existing socio-structural and political status of any given society. When poor people under extreme conditions coalesce, they stand a chance to challenge the powerful forces that dominate thus influencing their situation as a collective group (Eide and Ingstad, 2013). Such an argument places the onus of living in poverty and at the margins of society on PwDs themselves as they can at least self-organise to counter discriminatory practices, South Africa being an example of social groups working concertedly to fend off established patterns of social injustices that have entrenched chronic poverty (Hansen & Sait, 2011). Politically motivated marginalisation is also another structural factor and level with which the disability-poverty nexus thrives in the global South (Eide and Ingstad, 2013). In Zimbabwe a study by Muderedzi and Ingstad (2011) showcases how chronic poverty is directly caused by political and structural forces where human rights are violated. Relatedly, in Uganda Muyinda and Whyte (2011) reveal how disabled people and their families are drawn into permanent and chronic poverty due to exclusive and marginalising practices by development agencies where the voices of the poor are trivialised and side-lined even when they seem to matter when tackling poverty (Eide and Ingstad, 2013; Muyinda and Whyte, 2011; Wolfensohn & Bourguignon 2004). When disability and poverty triggers are attributed to socio-structural forces, the role of politics and institutional responses to reversing their effects is underlined (Eide and Ingstad, 2013).

Since poverty leads to marginality⁴ that is manifested spatially in informal settlements it is worthwhile elaborating on the pathways through which poverty and disability feed into each other as shown in figures 7 and 8 below. To begin with poverty increases the risks of becoming disabled most of which relate to poor health determinants (Mitra et al, 2013). These determinants are triggered by the factors (food, health conditions, water and sanitation,

⁴ Marginality is defined as 'an involuntary position and condition of an individual or group at the margins of social, political, economic, ecological, and biophysical systems, that prevent them from access to resources, assets, services, restraining freedom of choice, preventing the development of capabilities, and eventually causing extreme poverty' (Gatzweiler et al. 2011:3)

housing, conflicts etc) enumerated above which can lead to the onset of conditions which then cause disability (ibid). In the same manner

Limited resources in the community, for instance to build accessible roads or buildings, may also make it difficult for an individual with mobility impairment to participate in the community life (Mitra et al, 2013:2)

Conversely, once disability sets in it leads to low living standards and levels that are akin to poverty by adversely affecting 'education, employment, earnings, and increased expenditures related to disability (ibid). While disability reduces the chances of disabled children from going to school to attain the requisite skills for employment, adults who acquire disability later in their lives often constrain children from working due to their unpaid work as carers hence risking being in poverty due to reduced or missing income. Palmer (2011) illustrates the three main reasons why PwDs face economic deprivation and constraints. First PwDs commonly have a lower earning capacity as compared to non-disabled individuals. Secondly, the expenditure (transport costs, medical costs, housing, care giving etc) that is attributed to being disabled put an added strain and drain on available resources. The term 'conversion handicap' refers to the way vulnerable people including PwDs need more income to level-up their living standards with others (Mitra et al, 2013:2). Thirdly, caregiving takes a toll on family members as they get detracted from income generating activities to attending to the disabled (Palmer, 2011).

This affects the financial situation of any given household and is particularly common in the global South where welfare systems are generally lacking (ibid). Where social security grants are available, they are managed as income for the entire family and instead not specified to the disability condition (Ned, 2022). Arguing from a South African context, Ned (2022) notes that

It is well known that many remote African indigenous communities have overpopulated houses which lack sanitation and water, are limited in food security, education and employment, while alcoholism, and chronic diseases of lifestyle are rife (2022:496)

Because of poverty, the grants not only cover the needs of the individual but the needs of the entire family. Ned further points out that stringent requirements and the sustainability of the conditional cash transfers present further challenges which PwDs in the Southern context undergo. She demonstrates that such disability experiences around poverty and other related issues in the global South far exceeds the understandings from a western disability context.

Yet, this thesis argues that, while all these elements linking disability and poverty are crucial and that debates about them are increasingly relevant in the urban spaces of the South, that connection (as detailed above) is not always spatialised or rather understood in spatial terms. In other words, the spaces (both domestic, street and neighbourhood) where poverty and disability unfold, are often poorly examined- particularly in global South contexts. Such a dearth in knowledge underpins one key contribution of this research study which explicitly links aspects of disability and living in informal spaces where poverty is a lived reality negotiated on a daily basis. The next section of this chapter looks at southern urbanism trends where informal living in cities is a key conceptual building block.

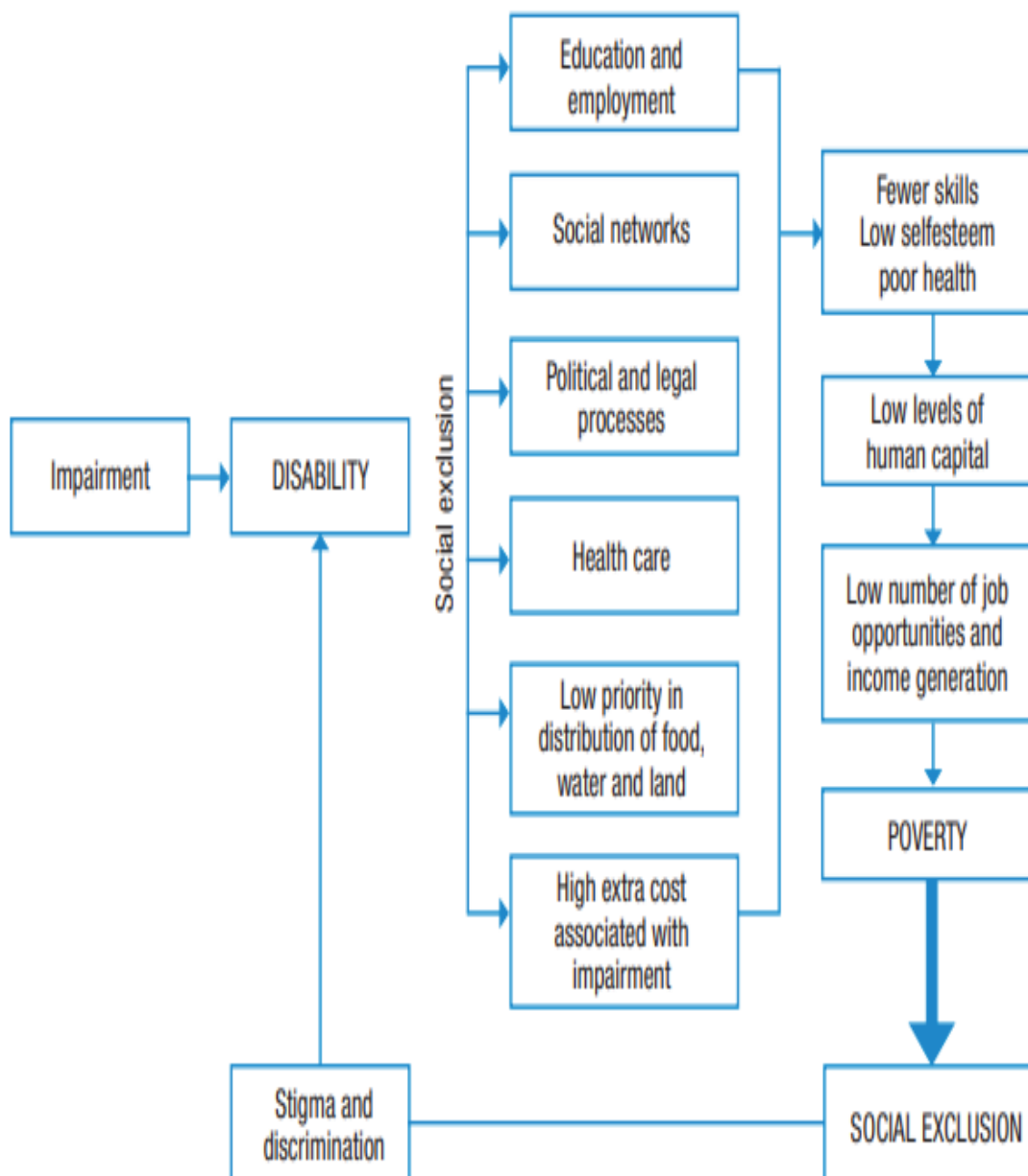


Figure 6: Showing disability feeding into poverty (Source: Yeo & ADD,2001; Pinilla-Roncancio, 2015)

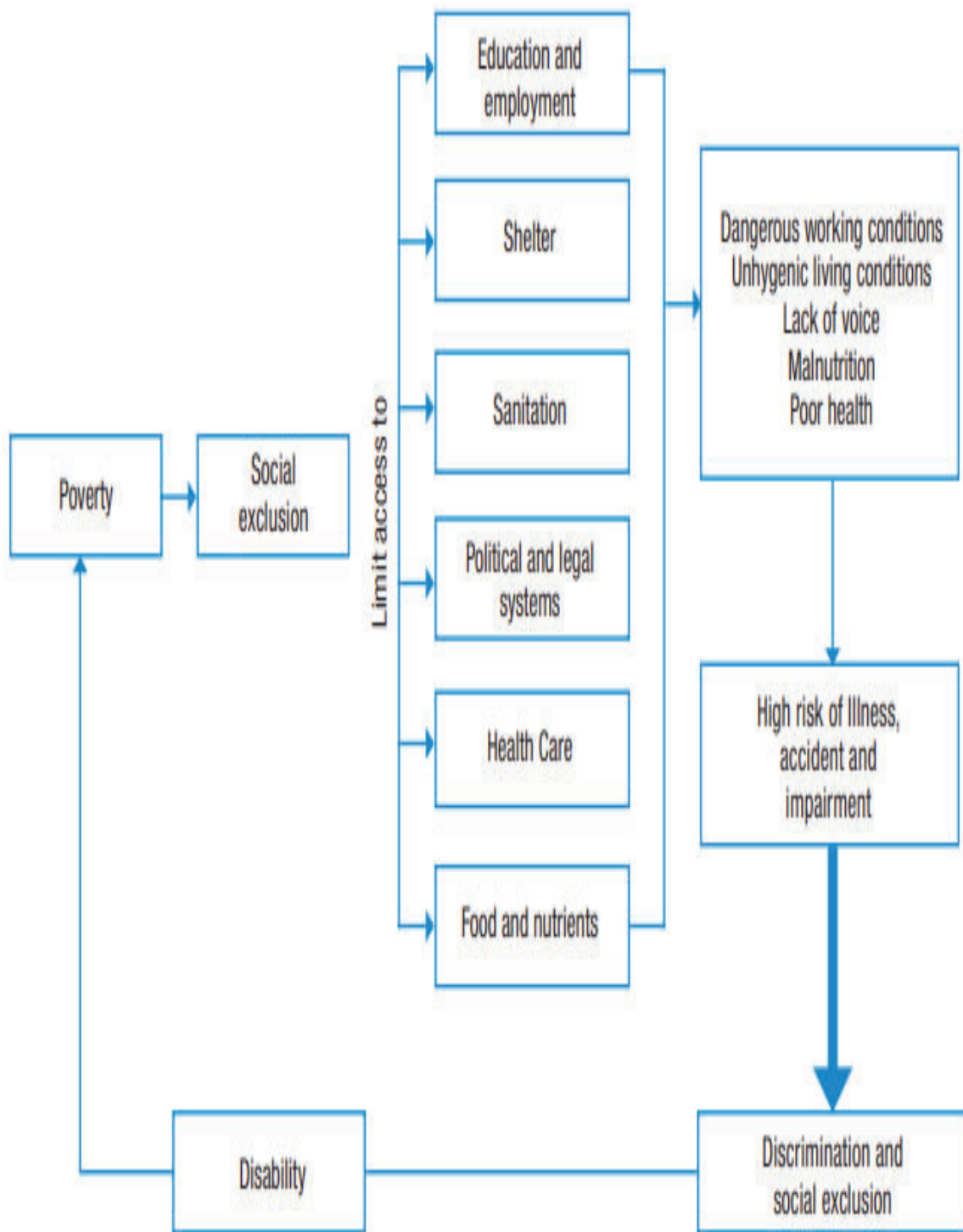


Figure 7: Showing poverty feeding into disability (Source: Yeo & ADD,2001; Pinilla-Roncancio, 2015)

Southern urbanism: urban theories of and from the South

Similar to how disability studies questions the validity of Western scholarship in the global South context, mainstream urban theory has in various ways been pointed out as being parochial because for many years experiences and ideas from the North have been universalized to shape urban analyses and planning trajectory of cities in the global South (Brownill and Parker, 2010; Roy, 2009a, 2011; Watson, 2009a; Yiftachel, 2006). Indisputably, there have been rich urban theories and practices that have come from the North; however, the theories are usually assumed to be valid in other contexts and many aspects are taken for granted. Further, universality is deemed to prevail while geographical specificity is viewed as unnecessary (Watson, 2014). Yet, 'southern cities are socially, materially, culturally, politically and/or historically different from northern cities' (Lawhon and Truelove, 2020:7-8). To say the least, cities of the South are marred with their own unique urban problems such as specific experiences of climate change, traffic congestion, housing deficits and infrastructure shortage which cannot be understood through normative planning ideas from elsewhere (Watson, 2014). This is becoming an agreed upon reality and consensus about the need for a new set of urban approaches that reflect global cities of the 21st century is slowly gaining pace (Parnell, 2012 and the others above) leading to novel urban studies and planning concepts such as Robinson's (2016) 'comparative urbanism'.

Consequently, and since the beginning of this century, there has been a shift to advancing urban theory from the South which has in turn led to a burgeoning literature within geography and planning (Parida and Agrawal 2022). Many have advocated in different ways for Southern urbanism and as such there exists varying converging and dissonating debates within this community of scholarship (Lawhon and Truelove, 2020). Just like any other emerging work with new ideas and thinking, Southern urbanism however portends some ambiguousness and uncertainty since as a collection it is less concise with the sort of theoretical argument being mooted (Lawhon and Truelove, 2020). For instance, Parida and Agrawal (2022:np) highlight that there is a 'dilemma over describing southern cities as all cities in the global South or to understanding southern-ness as a theoretical category' (2022:np). Nevertheless, the ambiguity in itself argues Lawhon and Truelove (2020) is healthy and that the heterogeneity in knowledge produced is a window for exploring further and newer insights and not 'definitive claims or ideological close-mindedness' (2020: 4).

This study while exploring new knowledge frontiers in the urban builds on the works advanced on urban informality through a 'southern' lens of a small and medium- sized city (SMC). Such cities are often overlooked or neglected yet they possess rich and a dynamic urban knowledge (see Parida and Agrawal 2022). The study, contextualised and informed by SMC subtleties,

seeks to overcome this neglect while keeping in mind that informality is perhaps the most stereotyped and common idea which in the hands of western experts positions southern cities as a 'pathological space' in urgent need of 'salvation' (Parida and Agrawal 2022; Schindler, 2017: 60). By describing squatting as a vocabulary to understand the southern urban practice Bhan (2019) notes

The housing that results from squatting – often mistakenly reduced to a catch-all category of “slum”– is perhaps the single most recognizable marker of the landscapes of Southern cities and of writing on them (Bhan, 2019:643)

In lieu of such, this research contributes to framings of urban informality and aims at de-escalating such thoughts by furthering its understanding as a critical component of individual cities in the south that exhibit more or less inequality (Schindler, 2017: 60) where the disabled relative to other population groups are significantly affected. Several scholarly works especially in the global South have reported a number of classified descriptions which define informality as a concept with diverse meanings touching on aspects of spatiality, economic attributes, social and political dimensions all of which must be adopted and suited by the urban poor (McFarlane and Waibel 2012; Roy and AL-Sayyad 2004; Harris 2018; Marx and Kelling 2019; Soliman 2010; Roy 2005). The subsequent sections of this chapter examine how informality is defined and discusses three main types and modes of urban informalities which crystallise emerging views and the need for appropriate conceptualizations that reflect current situations where conditions such as disability are a lived experience in the urban. The spatial character of informal settlements and political nature of such spaces are presented as the main elements defining informality while at the same time briefly conferring the economic qualities of these spaces. While these spaces may lack services such as housing and sanitation, they are key to the underprivileged disabled bodies who often face stigma and other socio-spatially discriminatory processes.

Defining and understanding urban informality

Urban informality has become an important element of urban growth within the contemporary city and is 'taking shape as one of the' most significant modes of urban space production, highlighting an issue which demands a critical and holistic scholarly reflection (Lutzoni, 2016:10). While the concept is commonly used to define spatial issues, it transcends to entail spheres around the economy of places, cultural backgrounds and 'social and political organisations' (ibid:2). The concept is not only seen to be a reality of the economic situation of a place and commonly a signifier of extreme poverty but also an indicator of the extant precariousness of an urban space where poor shelter and insufficient services are the norm

and a key defining character (Kudva, 2009). A number of scholars have explored the relationship between informality and the modern Southern city, which as noted above often exhibits growing inequalities, 'socio-spatial segregation, violence, and governance problems, all of which are shaped and conditioned by rapid globalization, a triumphant market, and the withdrawing state' (ibid:1614). A meaningful and absolute definition of urban informality is not easy to pin as it entails many interdisciplinary interpretations in both theory and practice (Lombard, 2009), the various 'attempts at defining the concept are often linked to specific epistemological frameworks, and more broadly to debates prevailing in specific disciplines, times, and places' (Banks et al., 2019:3). Accordingly, urban informality can be understood as a general conceptual framework that defines the organization and regulation of activities within an area while urban informal settlements may be perceived as the socio-spatial application of the concept (Okyere and Kita, 2015). The UN-Habitat (2006) ostensibly defines informal settlements as urban spaces characterized by inadequate conditions of housing and/or basic services, specifically relating to five features:

- Inadequate access to safe water
- Inadequate access to sanitation and infrastructure
- Poor quality housing and structures
- Overcrowded spaces
- Insecure residential status

Despite critiques (identified earlier) of labelling informal settlements in pathological terms, the empirical work informing this study and interpretations thereof identifies with all these UN-Habitat identified features and indeed utilises them to examine the disability-informality nexus in later sections of this thesis. The discussions privilege the significance of these characteristics for the disabled poor and their carers whose options for housing in particular often limit them to these spaces. Informal settlements popularly referred to as *ghettos* in the Kenyan context, denotes housing areas and services which have developed outside official land development processes and procedures meant for urban development. Unique to Kenya, most of the informal settlements are on private land and have developed in a *de facto* nature, limiting the ability of residents to access life-saving basic services (Ouma et al, 2022).

Various comparative studies in the North and South employ a variety of terminologies including informal settlements, slums, shanties, squatter settlements, shacks and self-help houses (Kovacic et al., 2019). While this study might identify with some of these terms it understands that they are 'neither tight nor concise' however as the case for Kenyan ghettos, most countries have their own generic terms (Soliman, 2021:124). Slum and informal settlement are the most commonly used terms in this research, however, the study is

conscious of the politics that exist amidst these terminologies. For example, a slum as derogatory connotation would at time imply a settlement that needs to be replaced or legitimizing of the frequent evictions in Southern cities (Rigon, nd). However, it is sometimes difficult to avoid using the term (ibid). Some popular global networks such as the Slum Dwellers International (SDI) tend to identify positively with the term while aiming to neutralize its negative attribute. Contextually in Kenya, the relevance and common view of informal settlements being 'dirty and illegal' is a debated argument, for example, Okpala (1987) through his research on the complex ways of owning land through customary and traditional processes reveals that informality and their much argued legalities and critiques are foreign and therefore have been imported.

So in order to reduce these confusions and the seeming contradictions briefly explicated herein, there is urgent need to extensively comprehend extant issues and practices that are emerging from urban informality (Okyere and Kita, 2015). Fortunately, scholarship by various authors in the last few decades have unpacked it leading to a somewhat better understanding of the concept especially from contexts within the global South. For example, Huchzermeyer (2007) while distilling it, contends that informal settlements should never be understood as static spaces but rather be seen as fluid and are constantly in the process of change. Therefore, since urban informality is about responding to changing urban structures and pressures, they are best described in relative terms rather than an absolute concept. Such emphasizes the need to comprehend informality more as a process and less of an output (ibid). Again, the need to continuously re-define and re-understand the concept is inevitable since processes within the urban are fast evolving thus 'making earlier conceptualizations insufficient to capture current processes' (Okyere and Kita, 2015:108). One such key socio-spatial process is the socio-cultural reality of disability which as detailed in the earlier sections of this chapter currently sits as a significant issue within the urban which needs to be defined and understood from the viewpoint of urban informality in cities. These spaces are often riddled with varying realities such as cultural hegemony, poverty and marginality. Digging deeper into the notion of informality below, this research illustrates and draws how the various spatial elements within the urban combine with political undertones and to a lesser extent informal economy of spaces to shape the lived experience of the disabled.

Typologies and modes of urban informality

Informality according to Roy (2005) is often described to refer to urban processes that happen outside and beyond zones that are planned commonly perceived to be formal and regulated spaces. The process of informality may include wide ranging urban scenarios such as

spontaneous processes of occupation of the territory, absence of property titles, self-building of houses, illegal inhabiting in contexts with rapid urbanisation, temporary uses of space, forms of self-organisation and development of urban areas at city edges, etc (Lutzoni, 2016:2).

Formal and informal spaces are however not mutually exclusive. Formal structures produce varying forms of informalities and both formal and informal spaces in cities are intimately related and mutually co-exist. Informality does not imply the reverse of formality, as traditional scholars have argued, but 'a mode that results from the interweaving of the formal and informal, a sort of mobile and elastic way between legal and illegal' (Okyere and Kita, 2015:106). The concept 'informal' according to Lombard and Meth (2016) can be applied to mean housing settlements in cities, infrastructure services, economic activities, social amenities like health services and political events. Lombard and Meth (2016) generally classify informality into three key categories namely spatial, economic and political informality. Although many studies emphasize the spatial composition of informality since it is the most obvious and visible, the three are usually imbricated within the city structures and in most cases intricately related as they intersect in varying ways (ibid). That overlap can be observed through the interconnection between informal politics and housing provision in cities of the global South for instance how in Nairobi informal settlements chiefs, informally control housing and land allocation or even evictions (Lines & Makau, 2017).

Spatial informality

Accordingly, Lombard and Meth (2016) define spatial informalities as practices which happen in urban informal settlements associated with informal housing provision, land occupation, infrastructure services and a combination of these aspects happening simultaneously. Informal housing is the most dominant settlement mode in the global South where recent accounts are that up to 85% of new housing stock happen in an 'extra-legal manner' (Ono & Kidokoro, 2020:384). Acquiring land informally happens through squatting on a private or public land which is often vacant (Lombard and Meth, 2016). The process may be a coordinated invasion as a group action or takes place incrementally over a long duration of time. In most cases, housing and land acquisition happen concurrently, for instance in Nairobi's informal settlements 'the people who occupy land and build structures on it without the permission of the legal landowner are commonly known as the structure owners' (Ono & Kidokoro, 2020:391). Alternatively, housing and land acquisition can also happen through self-help provision using family income in an incremental manner and using easily available and illegitimate building materials that contravene building regulations (Lombard and Meth, 2016). Gilbert (2002) describes urban informality as a spatial process which relates to the art of informally providing basic services and facilities to marginalised urban spaces. These often

defy the existing urban planning conventions which then position them as ill and unwanted. The provision of such services such as water, sanitation, electricity and waste collection can involve a complex web of political processes where the inhabitants perhaps not only provide the services for themselves, but they also petition the local authority or service provider using political machinations (ibid). The processes as indicated overlap and are usually negotiated expansively with deeply embedded political and economic (rent markets for instance) controversies. Spatial informalities and their effects on the disabled are distinctively discussed in this research and have been categorised into three main forms namely housing, water and toilet/sanitation services.

According to Kudva (2009), writings on informal spatiality were anchored on initial studies which focus on the ancient Victorian industrial city. Similar to the present, state responses then were inherited in 'public health and sanitation discourses' geared towards social appropriation and the question of public order (ibid:1616). Importantly, colonial legacies and processes as discussed in the next chapter entrenched segregation of the natives from the foreigners leading to fragmented urban patterns and infrastructural provision that characterise the modern day spatial informality in cities of the South. In recent decades, debates about informality have mostly focused on housing produced for and by the poor within the urban (Kudva, 2009). After the 2nd World War, most cities especially those in the global South witnessed a massive migration of people from rural areas to cities and towns (ibid). Generally, urban literature ties housing informality to the surge in populations given the migration trends where demand out-weighed the supply of houses (Turner 1976; Amis and Lloyd 1990; Hamdi 1991; Agevi 2003; Harris and Arkub 2006). Globally and especially in the South, there have been various measures aimed at solving the informal housing crisis in cities, they range from forced evictions and displacement of people, resettlement through state interventions, pro-poor initiatives such as slum-upgrading (Diang'a, 2011) and 'sites and services' schemes by organisations such as the World Bank (Baker et al, 2022). While these approaches were successful in some countries and were seen as a promising way to tackle the housing problem, in Kenya they quickly became unpopular due to their often slow implementation meaning they could not solve housing for the majority of people including the disabled urban poor (ibid). While relating to disability challenges in Nairobi, Mwau *et al* (2020) describe how low-income shelter is often highly inadequate for PwDs within Nairobi's informal settlements, where the deficient and inadequate water and sanitary facilities imperil their quality of life. As will be evidenced in detail in subsequent chapter, PwDs in Eldoret's informal settlements undergo constant struggles to access these key services. Housing informality in their present format hardly cater for the disabled and can best be described according to Soliman (2021:130) as

physically precarious (spaces which) harbor a complexity of social ills referred to as “creeping cancer”, “urban sores”, “the poorest of the poor” and “growing out of the carapace of the city” (Soliman, 2021:130)

Baker et al (2022) while describing housing options for urban residents in Nairobi, explain how affordability drives them ‘into informal settlements, with poorly constructed structures-- primarily made of cardboard and mud, with no piped water, sanitation, paved roads nor community spaces’ (Baker et al, 2022:np). In other words, the existing conditions of informality places residents in informal settlements against problems that need adjustment to a certain way of life defined by the ‘culture of poverty’ or a transition culture since deprived and frustrated residents experience socio-spatial disorganization. For the disabled the process of adjustment is even more frustrating as evidenced in the empirical discussions of this research where for example accessing houses and toilets is often a struggle.

While housing has been described as the main signifier of spatial modes of informality, another area that appears in contemporary urban research which emphasizes ‘new patterns’ of urban informal growth is the informal provision of critical infrastructures such as water, toilet and energy services (Okyere and Kita, 2015:110). The traditional view of informality strongly suggest that informal settlements are urban spaces which are deficient of or completely lack facilities that provide such basic services needed for survival (ibid). Though on the one hand it is true that urban informality is characterised by the lack of key services as will be depicted in later sections of this thesis, on the other hand an emerging pattern aimed at delivering these services is evident through various empirical works. For instance, through her research in Lima, Johannesburg and Cairo, Aramburu Guevara (2014) identifies informal support networks and organisations within informal settlements as being essential for the provision of basic services like water, sanitation and electricity. As will be illustrated in chapter 5, disability networks help the disabled in Eldoret with viable solutions to accessing these services. Studies by other scholars reveal the same outcome (e.g Gilbert, 2002). By using the term ‘incremental infrastructures’ Silver (2014) describes how in Accra marginalised urban residents in informal settlements ‘seek to construct or reconfigure urban systems’ to innovatively improve access to basic services. In the same way, Lombard (2014) in her work ‘constructing ordinary places’ describes how residents in Xalapa, Mexico secure services for their own good thus the need to re-evaluate the role of urban informality to the wider city. Put together, these scholarships drive back the often stereotypical narrative which show informal settlements as places which are completely deficient of services and cannot support lives including the disabled. While existing networks somehow provide support for the disabled, support that facilitates services incrementally are not sufficient enough and the disabled still left in precarious situations.

Therefore, there is need to expand these scholarly works through an in-depth understanding of informality from a disability perspective.

Low-income and poor neighbourhoods in cities where most PwDs stay and live show clear evidence of a 'new mode of urbanity' (Soliman 2013), which portends the freedom of building (Turner & Fitcher, 1972) and evidences the capacity to reconfigure existing urban spatial patterns (Ismail 2014). Informality as a 'site of transition to overcome arbitrary' urban processes (Soliman, 2021:140), helps the urban poor including the disabled to adjust to the often harsh or missing spatial features in informal settlements through creative ways such as social networks like *chamas* which facilitate the provision of appropriate housing, water and toilet services. Overall, these three have been prescribed in this thesis as fundamental to living with disability or caring for a disabled person.

Political informality

Beyond spatial modes of informality, informal political structures seen to involve non-formal political interventions, dominate the tactical ways in which residents including the disabled resist or invoke the state to action. Political informalities refer to strategies in urban areas which usually contrast formal politics (Lombard and Meth, 2016) and are important in urban governance. While the latter refers to the ways of running a government in a statutory manner, informal politics are broadly about processes of social relations and inter alia include 'forming alliances, exercising power, getting other people to do things, developing influence and protecting and advancing particular goals and interests' (ibid:160). Informal politics within the African context is defined by and grounded on reciprocation and exchange of favours built within a system however imperfect, maintains and promotes social bonds from the top echelons of the society to the bottom (Anyamba, 2011). Goodfellow (2020) argues that political relations are a part of social relations and entail elements which are both formal and informal and that 'power elites' seek their interests by working through both ways (Goodfellow, 2020: 280). The unregulated political dimension he further contends is not all about elites but also involve a stratum of various social groups which are subaltern and in various ways counteracts existing political structures via extra-legal means. 'Much of the political negotiation that shapes public life and economic opportunity therefore takes place in unregulated or informally regulated spheres' (ibid). Clientelism in many cases portends as the most likely display of political informality in cities of the global South.

Davis (2006), draws the various ways in which the politics of informality appropriates a culture and tradition of pushing back often resulting in increased resistance to mechanisms of coping with situations within informal settlements. For example, although neoliberalism shapes the new political order of informality which in turn results in new patterns of urban poverty within

informal settlements in Latin American cities, crime and violence as a way to resist prevailing urban regimes have been analysed as the main outcome of processes of political informality. Bayat (1997) opines a different view about the everyday trends of informal politics in Tehran and Cairo. He perceives 'the overemphasis on the language of survival strategies [as having] maintained the poor as victims, as lacking agency' (1997:56). By describing 'street politics' Bayat suggests a situation of discontent, he articulates politics of informality as being about redressing issues rather than a mere protest where both collective and non-collective action are interspersed throughout the city. According to Kudva (2009) when such activities provokes the state, 'regulatory apparatus kicks into gear and retaliation can be swift and violent' (2009:1617). This scenario where the state is absent then periodically reappears to intervene is significant for informal settlements. Bayat sees such a political vacuum and ambivalence as a determinant for resistance and protest while other authors of informality see it as an obrogation of state's role leaving the marginalised under threat of violent crime and gangs (Magaly Sanchez, 2006; Perlman, 2006). Tarlo (2000) argues that for one to understand the dynamics of politics in the urban poor, the various 'structures' and 'events' have to be captured not just in a given moment but over time. Kudva (2009) sums the politics of informality as 'an everyday politics of resistance punctuated by the threat and reality of systematic yet episodic expulsion and displacement' (2009:1618). Empirical evidence from this thesis illustrates how the disabled are politically prejudiced and displaced by a debased system within the urban governance frameworks. They are ostensibly denied their urban rights and privileges including participating in decision-making fora to voice their concerns for a common future. However, the extant informal political organisations are key to their lived experience and fundamental to their urban survival.

Economic informality

Informality is also witnessed through local-based economic interventions which shapes the disabled lived-experience albeit the context under study here to a lesser extent than the previous two modes. Economic informality involves the 'urban informal economy' of cities and generally captures the 'informal enterprises' such as vending on streets, home-to-home vending and informal transport modes as well as informal jobs (Lombard and Meth, 2016:159) such as car-washing on road reserves. Vending on the streets and the provision of transport informally play key roles within the informal economy through sustaining job opportunities and income generation for the poor within the urban (Kamalipour and Peimani, 2020:123). Informal economies seldom comply to the regulations for instance those that concern taxes, employment conditions or even licensing (Holt and Littlewood 2014). In the context of this study, a number of disabled residents engage in informal work or employment such as street vending and cobbling.

Overall, the three typologies of urban informality not only seldom exist away from each other, but they mutually exist along formal processes (Lombard and Meth, 2016). A key critique to the conventionality of informality is that while it rightly emphasizes the three modes, discourses rarely consider socio-cultural dynamics and how these intersect with informal settlements, informal politics and disability. For example, how social and cultural perceptions affect childhood disability in poorer societies where children born with disability are attributed to curses or the will of God as detailed previously in this chapter. Writers from urban studies and planning have advocated for the role of social fundamentals in defining urban informality as a theoretical framework (AlSayyad, 2004, Castells, 1983, and Huchzermeyer, 2008). From such a perspective, these authors have revealed how social dynamics shape the process of informality and how as a phenomenon informality 'is a product of the intricate social activities and actions' (Okyere and Kita, 2015:105). For example, Friedman (2005) notes that the social attributes of informality, although mostly rendered invisible, stands out as a key asset for informal settlements since it is built and anchored on notions of self-organisation and empowerment aimed at collective action. 'This idea has a strong link to the fight for survival and everyday subsistence guaranteeing a [hand-to-mouth existence]' as argued by Cities Alliance (2021:17). The disabled therefore commonly end up benefitting from such notions where social aid can be easily found notwithstanding the spatial and political challenges discussed above. Friedman continues to observe that principles around the 'moral economy' (e.g. reciprocity and voluntarism) and social power through networks which are a means used by dwellers in informal settlements to enhance their conditions. This research while extending the above contentions, argues for a stronger emphasis on socially-induced dynamics of disability and how that relates to informality. In so doing it adopts an intersectionality framing as discussed next to explore the diverse dynamics that the disabled experience within urban informal settlements.

Intersectionality and the disability-informality nexus

Development debates often view informal settlements and their residents as a homogenous population (Rigon, 2022). Yet whilst the greatest challenge facing residents of informal settlements could arguably be access to housing and other relevant services described above, within the populations some groups experience more adverse challenges than others based on their identities (Earle, 2020). Significantly, such inequality becomes complex when it intersects with other multiple identities including 'gender, class, race and ethnicity, age, ability, citizenship status, and sexuality' (Rigon, 2022:3). This knowledge is critical since planning approaches that do not consider intersectionality end up disadvantaging some people while privileging others (Rigon, nd). The identities not only relate to each other in an intricate manner weaved with power, they are galvanized by multi-scalar hierarchies and power relations

(Rigon, 2022). Most of these identities and the relationships they create are temporal and contextual meaning they are constructed and can be deconstructed (Castan Broto & Neves Alves, 2018). So, if we are to wholly address inequalities in informal settlements 'a relational, contextual and intersectional approach' that focuses on breaking power relations inherent in the identities has to be entrenched therefore making the process a political negotiation (Rigon, 2022:3).

Intersectionality is not a product or total sum of various identities; it is about exploring various multi-scaled identities within a context within a given time and analysing how that shapes the lived experience of an individual or group (ibid). In other words it is about how particular forms of subjugation are produced and manifested i.e it is about power and the power effects of specific intersections of identities. While comparing access to shelter by low-income groups in Hawassa Mogadishu and Nairobi, Earle and Grant (2019) found out that there exist vital dimensions within gender that affects women's access to shelter which are often overlooked in urban informality debates. Most women are affected by discriminatory practices such as divorce and inheritance, education level and care burdens all of which not only affect their ability to pay for housing because of reduced income but significantly precludes them from owning any property e.g land. Further, norms attached to gender affect single women or the divorced forcing them to live alone or rent property because of stigmatization. Earle and Grant (2019) also highlight migrant status and ethnicity as key in African cities to accessing shelter, services and job opportunities. Equally, disability and age according to their research in Mogadishu put the disabled and the youth in vulnerable positions as they are frequently disadvantaged while trying to find shelter and the stereotypical link of the latter to drug taking and potential Al-Shabaab membership. A key argument from their work which is significant to this study is that

stigma, discrimination and a lack of consideration for the needs and rights of PwDs were... apparent in the three cities. PwDs are disproportionately likely to experience extreme poverty and destitution. Their marginalisation is compounded by a lack of practical measures to accommodate their particular needs, seriously affecting their ability to access appropriate shelter and services (Earle and Grant 2019:8)

They then contend that a comprehensive social analysis is vital for urban policies aimed at 'leaving no one behind' (ibid). Planning interventions have to be holistic and integrate the various aspects including ethnicity in relation to other identities such as disability and gender. Elsewhere but in the same region, (Kovacic et al., 2019:615) while comparatively analyzing the governance of three informal settlements namely Enkanini (Stellenbosch) Mathare (Nairobi) and Kasubi-Kawaala (Kampala) found out that gender is a critical issue and that

women and single mothers specifically were poor as compared to men and other women respectively. They draw a conclusion that understanding social differences is key to formulating modest and localized targets that better account for complexities of urban informality and the heterogeneity of the populations.

An integrated framework to understanding the disability-informality nexus

The discussion in the preceding sections reveal how Southern Theory (ST) alongside other relevant theories can be used to examine and understand the disability-informality nexus. Figure 8 below depicts the relationships between the various ideas and concepts which are useful in understanding how disability and informality relate within the context of a secondary city. The framework aptly summarizes how realities of urban informality tied to spatial, political and economic processes shape disabled realities where highly context specific cultures, poverty and inequality are dominant. For instance, as shown in this literature review, there exists a strong connection between disability and spiritual beliefs such as curses especially in deficiently poor urban neighbourhoods that are often neglected by prevailing governance structures. This framework illuminates such intricate connections in a consolidative way to enable a better understanding of the existing relationship between disability and informality.

The intention of this research has been to extend the reach and application of Southern Theory as well as that of critical disability studies by bringing the two into conversation with each other, within the context of secondary cities of the South. This happens alongside two key conceptual frameworks namely intersectionality and nexus thinking as illustrated in the diagram. As previously mentioned in this literature review, *Southernness* in theory is about writing, reading and describing from places of the South rather than necessarily about them (see Bhan, 2019). Reading from this review of literature, it is crucial to consider and reflect on conceptualizations that emerge from scholarship beyond the North which have respect for peripheries and situatedness of knowledge production. Such epistemologies as derived from this research and illustrated in the figure 8 below include local realities of culture and tradition, fragile material spaces and realities around governance where responses entail a blend of both formal and informal structures. These realities as empirically evident in Eldoret are often not fully understood from within disability studies. They also have analytical implications for how disability is researched and analysed i.e what is overlooked and how PwD realities are interpreted. This research therefore seeks to bring to the fore these empirical and analytical realities adding a novel intellectual approach to how the disability-informality nexus can be unpacked using a Southern theory lens. Arguably, much of the literature published using a Southern urban approach at present tends to overlook the complex intersectional realities of disabled lives, this is despite the fact that 'southern realities' crucially determine such lives as they negotiate the everyday urban experiences of secondary cities in the Global South.

Beyond the ever-present notion of looking at Southern cities as ideal sites to conduct critical empirical research including disability within urban informality, it is also vital to acknowledge historical, contemporary and the evolving forms and experiences surrounding knowledge production (see Guma, 2023). Two main historical connotations have been fundamental to how disability and informality are currently understood from within contexts such as Eldoret. First, colonial legacies which have been entrenched in post-colonial practices have continued to affect how the disabled are perceived both by the state and the public. Secondly, state responses to informality (and the everyday views of informality) within Kenya have significant historical origins and as will be further discussed in the next chapter, these practices alongside the dominant realities of living informally, are some of the most significant characteristics of Southern cities such as Eldoret. These cities are often defined by colonial ethos of exclusionary socio-spatial spaces with vulnerable political landscapes and poor economic scales that ostensibly affect the majority urban poor including the disabled. Third, western models introduced to the South tend to affect the disability narrative especially in underprivileged setups within informal settlements.

From the discussions in this review, mainstream urbanisation processes within the south still have their roots often residing from intellectual experiences of the North. With a few exceptions, Northern oriented scholars continually offer theorizations of places in the South in many cases with less regard to local patterns, realities and practices. Importantly, it is then critical to rethink how urban research can be done to enable a less reductionist understanding of subjects and themes such as the cultural and social realities of disabilities as envisaged in this research. Therefore, as an addition to literature on disability in relation to informality, this integrated framework in sum reveals the situated challenges existing in between the disability-informality nexus especially how historical dimensions overlap with realities on ground thus shaping PwDs lives. Overall, the framework shows how southern theorization of emplaced knowledge (as is the case in this study) adds a relatively new way of deepening theory and empirical discourses of disability and urban informality in secondary cities of the global South.

While ST serves as the primary theoretical underpinning of this research, intersectionality and the nexus thinking have also been used to further bring to light other dimensions which are fundamental to the disability-informality nexus. Intersectionality as discussed in the previous section and empirically emphasized in chapter 5 is illustrated in the framework as a way of exploring various social categories. The nexus thinking as used in this study not only brings together conceptual ideas around disability and informality but also brings to the fore complexities of the two concepts considering factors such as social and cultural dynamics. By

introducing intersectionality and the nexus thinking, this study despite benefiting from ST cogently contributes to ongoing scholarly conversations on Southern urban practice.

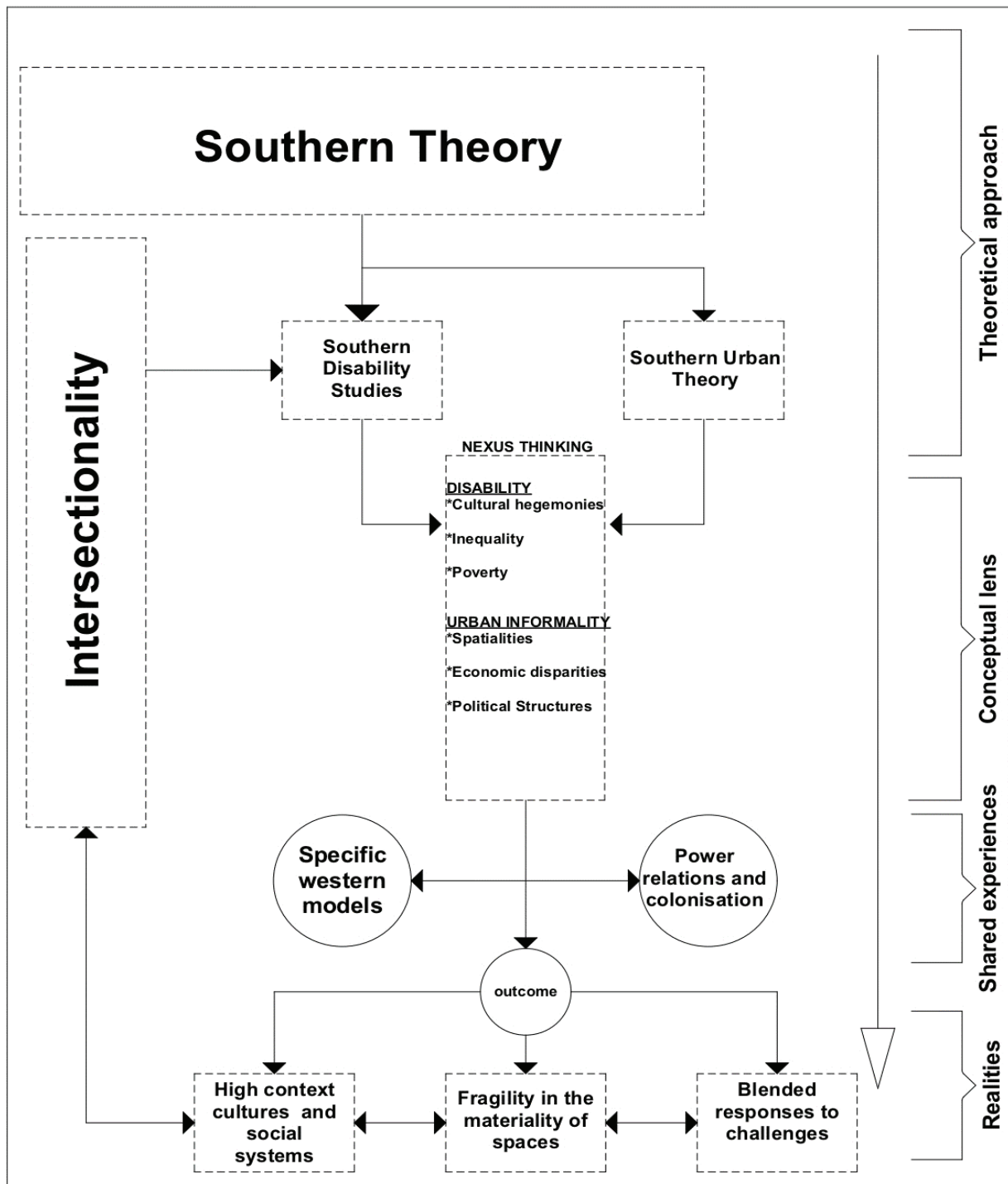


Figure 8: Southern Theory Approach to Understanding disability-informality nexus in Eldoret
Source: Author (2023)

Conclusion

This chapter has argued that Southern theory is vital if the disability-informality nexus is to be understood in meaningful way in contexts such as Kenya. The chapter argues for a conceptual framework that is useful in drawing meanings out of the context-specific empirical realities as presented and argued later on in this thesis. In so doing, the chapter began by presenting an understanding of disability from conventional disability studies which has been predominantly theorised from western perspectives. While the definition of disability as a concept has always been controversial and difficult to pin down, with distinct models offering divergent perspectives, perhaps the most widely cited definition emanates from the ICF-model which understands disability from the vantage of both environmental barriers and specific impairments. Other models hold distinct perspective and this study identified three that are relevant for the Kenyan situation namely, the charity model, the medical model and the social model. Although these models are significant in understanding the disabling conditions of PwDs, they also present a range of challenges including an inability to account for varied cultural notions thus making them inapt to grasp and understand situations in the global South. Southern disability studies has therefore been presented in this chapter to better understand realities within cities of the global South that are otherwise perceived differently in mainstream disability scholarship.

Southern theory has also been presented in the chapter as a basis to deconstruct urban informality in cities of the South. The key argument fronted is that informality as an urban process is a demonstration of the increased inequality and uneven development in southern cities. Three typologies and modes of informality are parsed in the chapter namely spatial, political and economic informalities all of which characterise informal settlements within cities in the South. While describing spatial informality, particular attention was given to housing, water and sanitation as key components that require consideration to make sense of PwD lived experiences. Informal politics is also presented as a key factor to make sense of PwD survival practices and of patterns of exclusion with informal political structures often positioning the disabled as outcasts that are unwanted in the urban. Lastly, economic dimensions of informality are briefly discussed where emphasis has been on put on the various livelihood strategies that disabled residents adopt to fit within the urban. The chapter while adopting informal urbanism as a building block to southern theory, makes an explicit case for viewing informal spaces as diverse places that are spatially, politically, economically and socially distinct. Through intersectional approaches the chapter recognizes the diversity of the lived realities therein including those of disabled residents.

Chapter 3: Situating disability and informality within Kenya

In the preceding chapter, the disability-informality nexus was discussed as an integral conceptual underpinning whose processes influence the lived experience of PwDs in cities of the global South. This chapter explains the research context. It presents a critical reflection on contextual literature on how disability and informality in Kenya is manifested and the trends of the two concepts which are strongly rooted in the legacy of British colonialism. The chapter is organized into two main sections. The first section looks at the history of Kenya's disability landscape during both colonial and post-colonial eras and an exploration of the extant situation of disability in the country while also examining an exposition of socio-cultural realities of disability. The implications of key legislative frameworks on the everyday lived experience of PwDs is also explored. The second section explores the growth of informal settlements in Kenya and some state responses to informality. To conclude, the chapter discusses how the disabled voice has been positioned in regard to urban informality. Overall, the chapter serves to bridge the theoretical understandings in chapter 2 to the empirical realities discussed in the subsequent chapters.

Brief history of Kenya's disability landscape Colonial era

The marching protest by Kenya Union of the Blind (KUB) in 1964 and their activities beforehand generally depicted that disability concerns could not be possibly detached from the former colonial regime and the process of colonization. Although PwDs were historically prejudiced even before the colonialists arrived in Kenya, the situation was without question amplified by the divisive colonial rule (Gebrekidan, 2012). In 1961 Kenya's Daily Nation News Agency reported that 'as countries march forward the blind are being left behind - left to sit in the corner of some dark hut, unwanted, unloved, not understood' (cited in Gebrekidan 2012:107). He continues to highlight that although it was stereotyping and showed an image of haplessness the reporting indeed captured a significant social policy rooted in the colonial legacy. According to Campbell's book *Race and Empire* (2013) the British aristocracy was supported by two major driving forces in early years of the 20th century context namely eugenics and imperialism⁵. Eugenics became the science bulwark which promoted the notion of imperialism thus defending racial structures in Kenya. The term *eugenics* was coined in 1883 by British explorer and natural scientist Francis Galton, who was influenced by Darwin's

⁵ **Imperialism** is a state policy, practice, or advocacy of extending power and dominion, especially by direct territorial acquisition or by gaining political and economic control of other areas (Britannica, 2022)

theory of natural selection. He advocated a system that would allow 'the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable' (see Wilson, 2022:np). The Colonial rule drew on ideas of eugenics to support values of hard work, productive bodies, labour and health. Despite some interests in the welfare of the suffering (evidenced by the passing of some legislations), the regime did not have any interest in protecting the disabled safe from the few exceptional projects by churches (Gebrekidan, 2012). Even after the passing of the Colonial Development Welfare Act by the British government in 1940, disability programs in Kenya were virtually scant and non-existent (ibid).

Evidently, Kenya compared to the other East African colonies had the most visible cleavage of social and class stratification. This was attributable to the reconfigured social landscape through the introduction of huge farmlands and the monetization of cash-crops utilizing natives as labourers while living as peasants in poverty (Zwanenberg, 1974). Such a trend of underdevelopment directly affected the disabled as Gebrekidan (2012) notes:

on the one hand, monetization conferred a market value on a productive healthy physique. On the other hand, the rural areas or the reserves, where most of the disabled resided, lost their communal safety net with the influx of the able bodied into urban areas in search of such wage labor (2012:107)

The reserves, which were in the outskirts of colonial towns were characteristic of poor quality of life which then led to PwDs becoming beggars and vagrants or as described by the Daily Nation newspaper, their lives mirrored to 'social and physical sequestration' (ibid). However, there were no clear records about the disabled around this time.

Historical lenses of disability in Kenya portrays improved government service to PwDs after the 2nd world war when the British introduced rehabilitation services to wounded and disabled soldiers in their African colonies both in West and East Africa (Grischow, 2011). This resonates with charity and medical models of disability reviewed on the previous chapter. In 1942 the British erected an African Rehabilitation Centre on the grounds of the oldest hospital in Kenya the then Native Civic Hospital, later renamed King George VI hospital and now the Kenyatta National Hospital in Nairobi (de Schutter, 2019). While the initial intention of the facility was to provide support to the physically disabled soldiers regardless of country of origin, it was later open to civilians. Campaigns to offer Africans care and rehabilitation gained momentum, for instance, according to de Schutter an anonymous author wrote a pamphlet titled 'Rehab for the African' which argued for the expansion of services to include African citizens since benefits would be both to the colonial medical services and the native population (ibid:229). Such debates compelled the colonial government to not only expand care and rehab services

to the disabled but also extend social programs such as education. However significant efforts were spearheaded by non-state actors through missionaries and charity organisations which mooted various projects which were tailored for various PwD groups. The disability model introduced by the British to Kenya was similar to Britain's Disabled Persons (Employment) Act of 1944 where full citizenship was ascribed to one's ability to fully engage in the labour market (de Schutter, 2019). By this model PwDs were rehabilitated to be productive and thus be defined as full citizens. In other words, PwDs were expected to participate in the workforce for the development of the colony (ibid). This indeed mirrors the current trends in the global South where states offer medical services to the disabled primarily to return them to work ultimately reducing social welfare expenses. Rehab services were therefore an economic motivation which was to turn PwDs into taxpayers and less of a social welfare burden. A PwD was seen as double tragedy to the society if they would permanently remain disabled (ibid). This was the disability trend for most of the years in Kenya's colonial era.

Post-colonial era

After attaining independence in 1963, Kenya developed a national disability policy through the previously mentioned Mwendwa Committee for the Care and Rehabilitation of the Disabled (de Schutter, 2019). Accordingly, 'rather than presenting a radically new programme, the report built on earlier colonial efforts' that had been initiated by the former administration (ibid:232). Specifically, the report stated that 'the fullest use should be made of existing facilities and that elaborate and expensive plans for development should be eschewed' (ibid). This meant that most of the structures from the colonial regime were to be integrated. The continued use of former colonial policies seemed inevitable since there were financial constraints of creating new ones and also the fact that key figures from the former colonial administration continued supporting the new regime even after the country gained independence (de Schutter, 2019). To worsen the matter

upon decolonisation, when British colonial administration overlapped with incoming ministers of the emerging independent governments, colonial governments administered a new classification system to prevent incoming officials from reading certain records... the removal of records from Kenya are but one example of Britain's handling of its colonial archives in the attempt to save face and monopolise the terms with which their colonial projects could be explained (Linebaugh 2022:736)

Such an exercise of concealing and smuggling of administrative records of the colonial past exacerbated the takeover by the new regime hence an indicator of colonial murkiness during the transition process. Despite the bottlenecks in the transition, charity organizations and

missionary societies ran by the foreign settlers continued doing disability work in the country especially the running of schools and churches seen as significant, as further illustrated by Linebaugh (2022)

would continue to play a most important part in the development of services for the disabled and, in accordance with the principle that the fullest use should be made of existing facilities, we hope that their work will be expanded and developed (Linebaugh, 2022:232)

Unsurprisingly, the Mwenda report while being amenable to the colonial ways put ‘more focus on rehabilitation than on care. People with disabilities would be turned “from a liability into an asset’ (ibid). Rehabilitation was premised on reversing disabling conditions and turning a disabled person from ‘being a drain on the country’s economy instead he becomes a wage-earner and can play his part – even if only a humble one – in helping to build the nation’ (ibid).

Governance practices that focused on disability, many of which were positive, surged even faster in the 1980s when the government indeed declared the onset of that decade as the National Year for People with Disabilities which was an endeavor to promote disability issues (Berman & Monteleone, 2022). This was followed with supporting trends at the international level with 1981 being proclaimed as the International Year for the Disabled Persons (IYDP). Following that proclamation was not only a sense to urgently implement initiatives that would benefit PwDs but also listening to their voices and the expertise they possess. The same period saw a surge in DPOs which demanded and advocated for improved services for the disabled within Kenyan communities.

Specifically, research through various scholarly bodies including local universities gained traction in the 1990s and surged sharply in 2005 followed by another spike after the promulgation of the constitution of Kenya 2010. Although outlined in more detail in the empirical section of this study, the new set of legislations capture disability issues and provides sweeping clauses that promote PwDs lived experiences in the country. Some of the key policy events inspired scholars both in the local and at international levels to work and promote the disability discourse in the country (e.g Crawford 2004; Mwendandu 2014). Some forms of scholarship took the shape of comparative discussions while others were embedded on other key issues and studies. The government and its subsidiary partners commissioned reports and national events (e.g census) which all prompted discussions of and about disability in scholarship and practice (Berman & Monteleone, 2022).

To recap, although the British reign ended in Kenya, undisputedly not all the systems and structures imposed by colonialists were unshackled, at present there are still widespread oppressions reminiscent of the colonial legacy either in implicit or explicit forms. The medical model which was imposed by the British remains glaringly evident in the current conceptualization of disability in the country. The colonial power as discussed in the previous section was largely based on the principles of separation and opposition of native knowledge while propagating certain identities such as ethnicity. Currently, policies that define underdevelopment and neoliberalism reinforce these colonial practices 'of categorization, segregation, and control' (Elder and Foley, 2015:736-737). For example, the structure of the educational system in Kenya which is driven by neoliberal forces that are contemporary measures performance with highly competitive examination processes which tend to disadvantage disabled learners.

The status of disability in Kenya

In Kenya, PwDs form one of the largest marginalized groups in the country whose economic, socio-political and cultural spheres of life are in most cases impinged (Katsui et al 2014). Kenya's history on disability suggests that a PwD predictably faces multiple levels of discrimination where gender or a similar identity overlap and intersect to produce an even more complex situation as predicated in the previous chapter (ibid). For instance, while race and ethnicity were intricately linked, increasingly other identity aspects such as gender and class framed disability in various ways. Structural factors key among them legal and policy issues especially implementation can be attributable to the plethora of discriminative and exclusive practices affecting PwDs various spheres of life (ibid). Because of such practices, PwDs are left on the fringes of social life albeit the situation in Kenya is getting better with the increase in progressive policies and practices. Evidence also suggests that most PwDs live at the edges of cities and in urban informal settlements while others languish in poverty stricken rural areas (Katsui et al 2014).

A number of factors determine the prevalence of disability in any given country including how it is defined, the data collection technique and the quality of the process, rigor in terms of sources used and the rate of disclosure which vary with context (Mont 2007; Al Ju'beh 2015). Stigmatizing practices discussed in chapter 5 and inadequate services may lower disclosure rates. Such limitations in many instances lead to statistics that are 'misleading, incomparable and inaccurate' (Thompson, 2017:2). Al Ju'beh (2015) then argues that these limitations lead to low and middle-income countries reporting lower disability figures as compared to higher-income countries. This is echoed by WHO and World Bank (2011) reports which also allude that inconsistencies that result from stigma, poor services such as roads and reliance on data

from census account for the difference in prevalence between countries of the North whose figures are higher and those of the South whose prevalence tend to be lower (WHO and World Bank 2011). However, despite such effects, existing data depict higher prevalence in developing countries (Mitra and Sambamoorthi 2014).

In Kenya just like many other developing countries the prevalence of disability is determined through ten-year census cycles. Although inconsistent with other statistical figures (such as WHO surveys) the latest census of 2019 indicates that about 900,000 people in the country (2.2% of the population) live with some form of disabling condition (KNBS, 2019). The report showcases that there are more PwDs living in rural than urban areas with prevalence rates by residence showing that 2.6% (0.7 million) of people lived in rural areas and 1.4% (0.2 million) of people in urban areas have a disability. Arguably this could be as a result of rural-urban migration patterns which does not favour PwDs whereby in the process of movement they are often abandoned in the villages while able-bodied individuals or family members migrate in search of better fortunes. However, such a hypothetical inference is beyond the scope of this research study.

Elsewhere in other reports related to the census, the Kenya Integrated Household Budget Survey (KIHBS) 2015/16 found a disability prevalence rate of 2.8%, while the 2007 Kenya National Survey for PwDs noted a prevalence rate of 4.6% translating to 1.7 million (KNBS, 2018). Out of the 1.7 million PwDs, 65% regard the environment as a major problem in their daily lives. The World Health Survey (2011) in the country suggests that the prevalence among the working age population is 8.6%, with 11.6 % in rural areas and 4.4 % in urban areas (SIDA, 2014). These estimates conclude that 3.8 million Kenyans live with some form of disability, a figure that is not consistent with the latest 2019 census report. Importantly, the survey depicts that of those living in urban areas 80% reside in informal settlements at the periphery of cities or in extremely poor conditions in rural areas alike (SIDA, 2014). Also, as an argument that suggests later empirical realities of this research, the disabled often reside in informal spaces because these are the landing spaces of first-time rural migrants due to being affordable and accessible.

In the Kenya National Human Rights Commission (KNHRC, 2014) report 'From Norm to Practice – a Status Report on the implementation of the rights of persons with disabilities in Kenya' some of their key findings which are relevant to this study include:

- Issues of inadequate accessibility to most of the buildings whereby most had sub-standard design elements including inappropriate stairways and lack of ramps, narrow door specifications which do not facilitate wheel-chair use. However, institutions such

as hospitals and some special schools had made strides to improve accessibility albeit toilets which largely remain inaccessible.

- Public transportation largely remaining inaccessible to PwDs. Many disabled people have to be assisted or otherwise carried into public transport. Such a challenge negatively affects the lived experience of PwDs as they are restricted to their homes forcing them to miss livelihood and other opportunities.

Demonstrably, these findings are vital for the disabled and most constitute what this research envisages. The issues around access to houses and toilets and how the disabled are restricted to homes are just some of the findings this research aims to further nuance within the context of an informal space.

Socio-cultural beliefs and perceptions about PwDs in Kenya

The history of disability from the colonial period to the current showed an emphasis in medicalization of disability through rehabilitation services. While corroborating with that Berman and Monteleone (2022) argue that although studies which take up the medical model (discussed in the previous chapter) as their basis of theorization have been on the rise in Kenya, disability meaning in the country is predominantly associated to the cultural model. They also caution that disability efforts which disparage the cultural models while overemphasizing the medical model risk a situation where disability issues in the country and other regions alike remain partially addressed. Over time however they contend that the prevalence of the medical model has dominated the disability discourse as it is closely linked to health services such as rehabilitation. Scholarship evidence from the early 1980s in the country emphasized cultural and environmental aspects as significant to disability (Ndurumo, 1980). Importantly, scholars have paid attention to cultural stigma in social facilities and the need to overcome cultural practices that are disabling (Berman & Monteleone, 2022). While there has been a rigorous and on-going debate by Kenyan-based scholars and activists against the devastating effects of ableism, cultural stigma remains at the heart of exclusion and discrimination in the societies (ibid). The cultural model of understanding disability as stated is dominant in Kenya's disability understanding just like other similar societies in sub-Saharan Africa. Historically in such societies according to Groce & McGeown (2013) PwDs conditions including physical, mental or sensory appearances have always been linked to witchcraft or sin or even seen as a form of punishment for the actions of individuals or by extension their relatives.

Such strong cultural beliefs mean children who are born with disabilities are often hidden from the public (Moyi, 2019). This leads to PwDs suffering social exclusion and discrimination and

in extreme situations they are killed because of such wild beliefs (Groce & McGeown, 2013). An example is when people with albinism in East Africa were being hunted and killed for their parts to be used in witchcraft (Franklin et al 2018). In Kenya, it is common for children with disabilities to undergo practices such as being chained, tethered on trees hidden and even left for dead because of such stigma (Inimah, et al.,2012). Recently, a published report by Atieno (2017) narrates of a woman in coastal Kenya who left her newborn baby to die after being born without eyes and a deformed nose, a condition known as anophthalmia. Because of the strong cultural beliefs, children with disabilities are seen as a bad omen and often left to die so as to avoid misfortune and calamity to the family. This thesis advocates for a nuancing of such social and cultural specifiers since as argued by Sherry (2007:17) for one

'to understand the social construction of disability in a particular socio-cultural context, it is necessary to examine economic, ideological, institutional, political, military, ethnic, gender and age-related dynamics present in that society'

The legislative framework on disability in Kenya

The former constitutional dispensation in Kenya which existed between 1963-2010 was rooted in colonial legacies and reinforced existing exclusive and divisive policies (Harroff, 2019). It provided no protecting any kind of rights (social, economic or political) to PwDs (GoK, 2001).

Section 82(3) of the 1963 constitution prohibited discrimination by race, tribe, origin or residence, political views, creed, color or sex; however, it made no specific reference to discrimination against people with disabilities (Moyi, 2019:np)

The legal document, an extension of the 1963 independence laws, had no clauses that ensured the disabled were included and had the right to participate in political processes as fundamentals for democracy (GoK, 2001). The new 2010 constitution brought significant changes to the disability landscape and provided PwDs political platforms for participation and representation. In article 27, it states that

The State shall not discriminate directly or indirectly against any person on any ground, including race, sex, pregnancy, marital status, health status, ethnic or social origin, colour, age, *disability*, [emphasis added] religion, conscience, belief, culture, dress, language or birth (GoK, 2010)

In addition, the new constitution ushered in devolution creating a new political architecture in the country with two government levels comprising of a national government and 47 county governments. By decentralizing government functions and devolving power, Kenya made a strong commitment to an accountable and democratic society. In that regard, it was expected

that a more decisive representation of the people, an equitable allocation of resources and improved service delivery mechanisms would be in place but for PwDs it is still work in progress. The new Constitution safeguards the rights of PwDs which include the right to housing, transportation, accessing facilities such as education and health centres. Within the new constitution political participation, representation, recognition and inclusivity are integral principles that foster democracy in urban spaces [Interviewee, NGO-03, 2021].

However, as many would argue, in the 10 years of the new laws and after there was a promise of the country's rebirth by the leadership, there is still no meaningful change happening as far as the lived experiences of PwDs are concerned because of issues such as the lack of realistic strategies of implementation. Even in the face of the new legislative framework, there exists wide-ranging political issues that impact on the urban realities of PwDs as will be evidenced through this thesis. Apart from the new constitution, other legislation specific to PwDs include the United Nations Convention on the Rights of Persons with Disability (UNCRPD), People with Disability Act (PDA) of 2003 and the Rent Restrictions Act (RRA). These statutory documents enshrine disability rights in varying ways at various levels, for instance while the CRPD works from an international platform the PDA and RRA affect local rights.

As noted earlier, since PwDs reside in informal settlements, the next half of this chapter considers how informality in Kenya has transformed over the years before highlighting the challenge and opportunity for better planning which integrates disability needs.

Tracing informal settlement growth in Kenya: a historical account

This section historicizes urban informality in Kenya illuminating the root causes of informality and the attempts over the years by the state to avert issues such as the housing gap in Kenyan cities. Trends in informal urban growth in Kenyan cities is traceable back to the colonial period (K'akumu & Olima, 2007). The arrival of the British transformed how land was governed in Kenya through the introduction of land ownership concept that was non-existent in the former ways where land rights were mainly communal (Musyoka, 2002). The settlers seized land from indigenous Kenyans using imported laws which then facilitated individual ownership based on titles (ibid). The land alienation process interposed African economies relegating them to reserves and at the margins of urban areas and transferred the most productive resources to the settlers (Overton, 1987). The Africans were not only stuck in reserves as areas unsuitable for European settlement, but reserve boundaries were also drawn such that the natives were required to live in designated reserve mostly based on ethnic lines (Musyoka, 2002). Most cities were out of bound for Africans who were only allowed access to provide menial labour

and entry was by identification famously known as *kipande*⁶ (Fitzhenry, 1979). The resultant spatial stratification was not just mere segregation, it was about political control as the delineation not only created an interface between the Africans and the White settlers but always created ways of controlling economic activities (Overton, 1987). Without considering the needs of the natives, the colonialists adopted the 'no-mans-land' (*terra nullius*) concept to amass huge tracts of land either through private property acquisition or leasing at extended periods of up to 99 years (Oyugi and Owiti 2007). In this period of settler dominance, exclusionary planning laws and zoning regulations were introduced and reinforced to facilitate racial and spatial segregation (Olima, 2001).

So as to ring-fence their acquired lands from invasion and encroachment from the landless natives and squatters, the colonial government introduced settlement schemes to further segregation along ethnic enclaves (Musyoka, 2002). After independence in 1963, whilst these seclusive schemes were sustained by the post-colonial regime some policies including the *kipande* system were either relaxed or abolished enabling mass movement of people from poor rural areas to urban areas in search of job opportunities (Agayi & Karakayaci, 2020; Ehresmann, 2004). This resulted in an upward shift of populations in cities with no necessary concomitant provision of houses leading to housing crises in most urban areas (Amis, 1984). While resembling Europe's urbanization during the industrial revolution, Kenyan urban areas including the capital Nairobi struggled to cope with the huge influx of populations into the city centres (Ehresmann, 2004).

This rapid growth, coupled with challenges of unequal distribution of infrastructure as propagated by the colonial plans and other sectoral pressures soon became a huge challenge for the independent government. There was need for planning, housing, transport, business and the desire to integrate urban residents into developing one city as opposed to the segregated colonial city (Mwaniki et al 2015:7)

To avert the crisis a housing policy was formed in 1963 with provisions for housing and the necessary planning guidelines (ibid). Notably, a key part of the policy was a strategy of slum clearance which was adopted and carried forward from the colonial practice mainly used for

⁶ 'The Registration of Natives Ordinance (1915) introduced what was, in effect, a set of pass controls for African males of working age. Instituted in 1920, the act required every male over 15 years to register before his local administrative officer and to be issued with a fingerprinted certificate of identity. This document, known as *kipande*, provided basic personal details and acted as a record of employment' (van der Straaten, 2019:2). 'It consisted of a small red book in a metallic holder hung around the neck' (Kareithi, 2013)

addressing informality and squatting in cities (ibid). Following suit in 1968 was the enactment of Land Planning Act which was intended to control urban development within the scope of prepared town plans, nevertheless, the preparation and content of these plans was never clearly spelt (ibid). The decision-making was skewed and not all were involved leading to the subordination of critical stakeholders such as tenants (Mwangi 1997; Kimani and Musungu 2010).

At the national level and as a knee-jerk reaction, the 1st regime⁷ of the then President Jomo Kenyatta encouraged people to go back to rural areas dubbed '*turudi mashambani*' which loosely meant let's go back to the rural' in Swahili (Macharia, 1992:228). Although the policy unsurprisingly came short of the expected, Ehresmann (2004) notes that the primary reason for the rapidity in the mass migration post-independence was the reluctance of the government to solve land issues. This is similarly mentioned by Kituo Cha Sheria who noted 'there was no deliberate attempt by the first post-independence government to address the land question'. Ironically, these trends of land injustices happened yet they were the fundamental grounds to which the *Mau Mau* movement⁸ rebelled and revolted against the colonial system leading to the country's independence. The new government which was at the heart of the land administration adopted the old practices of the exiting colonial regime whose purpose was fundamentally to benefit European settlers thus handing down that elitism to a new set of Kenyan elites who dominated over a poor majority (Ehresmann, 2004).

Contrary to becoming an all-inclusive administration as people hoped, the new regime furthered the colonial elitism while trying its best to turn around the country's surging inequality (ibid). Therefore, in an inexplicable and unpopular move, instead of responding to the masses and their land issues via fair redistribution, the new regime required Kenyans to buy back their formerly confiscated lands. Such a policy was devastating to most Kenyans as many were depleted of finances during the colonial years leaving the land ownership to the few wealthy elites who bought back the colonial lands through political clientelism (ibid). As Kituo cha Sheria puts it, "...millions of Kenya[ns] who had been kept on reserves after they lost their land to [European] settlers became landless squatters in their own country," (Kituo cha Sheria, 2000 in Ehresmann, 2004). Meanwhile with miserable poverty levels in the rural areas and nowhere else to go, more Kenyans continued to move to cities in large numbers and settled on the edges of cities (Ehresmann, 2004). The new migrants apart from residing on city peripheries in newly mushrooming settlements engaged in complex sub-leasing agreements

⁷ This research adopts the terms **1st regime-5th regime** to imply the 5 presidential regimes since independence

⁸ Mau mau movement describes Kenya's revolution to the colonial regime

where local leaders especially chiefs were pivotal in granting informal permits for new construction albeit without authority. Unprecedentedly, this process continued uncontrolled causing widespread urban problems for the new post-colonial government to manage. In Kenya, most urban centres do not have existing plans and even if they exist they are seldom enforced (Kimani and Musungu 2010). The resulting effects of that failure to plan or heed to the planning doctrines lead to widespread proliferation of informal settlements, sprawling, congested neighbourhoods and development trends that are incapable of sustaining the urban population given the pressure sustained on existing infrastructures (ibid). The latest changes in Kenya's planning germane to informality have been brought by the new 2010 constitution which has since emphasized a streamlined policy framework on land-use and development planning. The supreme legal document enshrines extensive rights of all Kenyans and for the very first-time citizen's rights on adequate and reasonable sanitation standards are protected.

Challenge and prospect of Kenya's governance of informality

The most glaring feature in Kenya's housing provision is the entrenched colonial legacy which is characterised by inequality and segregated spaces. Demonstrably, such manifestation is a testimony of the inscribed colonial heritage on spatial development paradigms in the various cities. Post-colonial regimes tended to not only reinforce the former autocratic colonial plans and land development mechanisms but also further entrenched them worsening urban situation especially for the poor (Watson 2009b). While referring to countries such as Kenya Watson states that

Colonialism was a very direct vehicle for the spatial translation of planning systems, particularly in those parts of the world under colonial rule when planning was ascendant. In these contexts, planning of urban settlements was frequently bound up with the 'modernising and civilising' mission of colonial authorities, but also with the control of urbanisation processes and of the urbanising population (2009b:173)

The racial legacy is the core root in the way various housing development projects have been materialized by the state in the various postcolonial regimes where segregation along social and economic status is evident (Oyugi and K'Akumu 2007). Such a historical account provides a lens to which we can understand the power relations which keep on determining the provision of housing in the current age and how cotemporary planning brings forth ideals of colonial times (Mwaniki et al 2015). Although there is not much difference in the way the various regimes portray exclusion, in the colonial past segregation was premised on race while in the present economic inequality is more evidenced.

The long-standing urban narrative in most of the Global South which has spanned decades is the dominance of top-down planning approaches (originally imported from the North) and legal instruments (zoning) which not only fail to meet housing needs but disproportionately affect the lower income groups who live in informal settlements (Watson, 2009b). According to Mwaniki et al (2015) housing and land management are the key segments of urban governance where the infamous top-down model is emblematic in Kenya's planning system. Manifestly, there was a widespread lack of participation of the poorer communities in housing and land development programs in the postcolonial periods. Up until the late 2000s urban development in cities such as Nairobi had approaches that were less inclusive and adopted rigid technocratic modes of producing urban spaces (Omenya and Huchzermeyer 2006; Oyugi and K'Akumu 2007). These approaches to the production of space exacerbated the housing crisis even in the midst of decentralization efforts in the 2nd regime (1978-2002) of postcolonial Kenya. Top-down approaches have generally been heavily criticized for producing unequal spaces in cities of the Global South since 'they serve to promote social and spatial exclusion, are anti-poor, and are doing little to secure environmental sustainability' (Watson, 2009b: 151).

In the recent past, approaches which challenge deeply rooted neoliberal structures that perpetuate the top-down colonial practices have been on the rise. Walker and Butcher (2016) in their research on neighbourhood governance structures in Kisumu, found that residents in informal settlements facing deprived conditions (housing, water sanitation), utilize informal neighbourhood-level planning as a critical urban change arena. On the one side, it is expected that citizen participation of urban informal dwellers within the informal neighbourhood governance approaches are leveraged to prioritize the lived realities and needs of the people. On the other side, it is anticipated that widening decision-making spaces challenges 'relational inequalities' both within communities in the settlements and even beyond to the citywide level (ibid:275). Further, Walker and Butcher argue that while neighbourhood-level planning offers a perfect opportunity to democratize planning, it must balance the various competing priorities of planning expressed by diverse sets of people with varying identities of 'gender, age or class, ethnicity or religion, levels of *(dis)ability*' and educational levels (ibid). Another contemporary planning approach has been witnessed through the Special Planning Area (SPA) initiative which was adopted in Nairobi as an innovative way to 'enhance the levels of inclusion and empowerment of low-income residents and thereby improve democratic control over urban policy and planning decisions' (ibid:10). These novel ways to approaching planning are fundamental to urban populations including the vulnerable such as the disabled since they offer platforms where all voices can be heard in decision-making.

Such examples show how formal/informal urban governance processes interact in the Kenyan context to produce innovative ways in planning for and with informality. The processes often involve complex negotiations which as Horn (2021:519) notes must encompass three inevitable conditions. The first one is 'generating and making strategic use of political opportunities', secondly is promoting 'qualitative changes in the way stakeholders see themselves, and how they interact with and relate to each other' and thirdly is managing conflicts which are bound to happen at every stage of the process. In such contexts planning becomes interactive and the urban challenges are saliently handled for better outcomes. Other challenges which bedevil informality planning and worthy of mention are the recent regimes' obsession with modernistic mega housing developments borrowed from elsewhere which disregard low-cost strategies. For instance, with reference to the Kenya Slum Upgrading Project (KENSUP) in Kibera, Nairobi, Huchzermeyer (2008) writes that

one cannot blame Kibera residents for assuming that the project is deliberately attempting to create housing for the middle -class and deprive current Kibera residents of their right to a convenient location in Nairobi (2008:27)

This is a reflection of how housing policies, which as mentioned are embedded within colonial legacies, disenfranchise the poor while favouring the middle-class. The other challenge is the master-planning approach whose popularity and persistence in the Kenyan context is without question. The use of master plans continues to rise in the country even though they have 'been extensively critiqued for being a colonial imposition, modelled on modernist visions of utopian urban futures that are unable to handle existing contextual needs and realities' (Harrison and Croese, 2022:1) such as disability needs.

Conclusion

This chapter has discussed the history of the nexus between disability and informality in Kenya and how the legacy of British colonialism has been key in shaping the current governance of urban informal spaces and PwDs residing in such settings. It argues that past colonial practices affect current spatial planning practices and that the extant inequality in Kenyan urban areas can be traced back to the colonial regime. By doing so it contextualizes in general terms the existing spatial dynamics of Eldoret which is the fastest growing secondary city in the country. Although various post-colonial legislations have tended to address disability and informality in Kenyan cities, the chapter highlights the need to move away from practices defined by colonial legacies and build on some of the contemporary and more inclusive approaches to planning. Notably, a key aspect about the effectiveness of both policy and legal frameworks that promote PwDs lived experience is the extent and effectiveness of

implementation is done which present is inconsistent and arguably haphazard rather than comprehensive.

The new 2010 constitution (as the supreme legislation) is critical within the context of urban governance as it offers forward thinking and approaches that practitioners and scholars can leverage to change the status quo. Indeed, the historical account of both disability and informality and an explanation of the challenges that have continued into various post-colonial regimes provides a fundamental platform to engage newer planning ways such as participatory planning and neighbourhood level planning described in the last section of this chapter. By providing a contextual background of disability and informality in Kenya, this chapter provides the link between the theories and concepts with empirical realities of PwDs discussed in the second half of the thesis. Before delving into those realities, the next chapter discusses the methodological framework that was used in the research process.

Chapter 4: Methodological Framework

This chapter details the research process adopted in this thesis. The rationale for the methodological process is provided here through an explanation of how PwD's lived experiences were explored and analysed. In describing how that process was undertaken, the chapter is divided into four main sections. The first section explores the methodological approach for this research by describing its philosophical position whereby social constructivism and critical realism are presented as a two-pronged paradigmatic approach towards understanding everyday lives of PwDs in informal settlements. It also reiterates the primary aim of the research and how the research questions build into the methodology. That is then followed by a description of how the research design was constructed and the basis that led to the adoption of a case-study research strategy. The next section describes the fieldwork process through the various data collection methods. Finally, the last section presents how the data was analysed through systematic coding and thematic analysis. This section also highlights important research considerations including ethical issues and the researcher's positionality thus fashioning legitimacy to the entire process. The section also discusses the research contextual background bringing to light vital characteristics of the three case study sites.

Methodological approach: Philosophical position

This study combines social constructivism (SC) and critical realism (CR) as its guiding philosophical approaches to gaining a nuanced understanding of the geography of disability through an exposition of PwD's urban lived experiences within informal settlements. Since this research predominantly relies on the participants' views of how they experience disability conditions and the reality about disability itself, both SC and CR were best suited as a two-pronged philosophical approach. To begin with, ontologies of SC recognize the 'distinction between a social reality of human making and an underlying reality not of human constructions' (Klein, 2002:6). The 'reality' is constructed through 'the interplay of actors, institutions, habits and other social practices of subjective belief about reality that over time congeals for the person on the street into a taken for granted reality' (Klein, 2002:7). This suggests that in adopting SC, the study preserved the distinction between an ontology of 'social reality of human making'-what is seen as disability-and 'an underlying material reality not of human construction'-what we cannot see to constitute disability-providing a platform for one to distinguish 'true and objective scientific knowledge from subjective and socially constructed belief'(Klein, 2002:11). An investigation that probes disability issues from a SC perspective brings along various aspects that are starkly different to the foreground as

opposed to a naive realism⁹ approach (Bhaskar & Danermark, 2006). SC is especially applied in feminist studies to demystify and distinguish the social construction of gender from sex which is biologically inherent (Klein, 2002). This would be the case for disability studies in that through SC we can for instance untangle bio-medical impairment from socially constructed disability. SC promotes a unique ontological and epistemological position that is well aligned to methodology of this thesis. This was achieved through gaining a nuanced understanding of the lived experience of PwDs in urban informal settlements. By putting focus on analyzing and interpreting PwDs views about their realities in the way they interact with self and others (ontologies of SC) it is possible to generate meaningful theoretical constructs within disability spaces (the epistemologies of SC). According to SC the process of learning builds on knowledge that already exists, an individual can interpret existing knowledge in new ways and that, that knowledge is a product of human interaction and it's not something to be discovered (Taylor, 2018) . Thus, generating constructivist epistemologies relative to Kenya's disability situation, a direct transfer of Global North disability theories and concepts is de-emphasized. These theories risk disregarding contextual issues such as religion, spirituality, myths and ethnicity and how they influence disability situations in specific contexts. However, there exists a limitation in SC philosophical studies, they promote 'cultism and dogmatism' by only seeing truth as 'social convention, playing by the rules of a particular group' where there is no truth beyond the social construct of the group (ibid:219). In doubling up to CR thinking, this research aimed to overcome such potential impacts.

A CR paradigm adds a different philosophical dimension towards this study and leads to the development of new methodological frameworks that allows this research to examine various social phenomena empirically so as to elucidate the prevailing 'causal explanations that account for them' (Hoddy, 2018:1). This is implied as abduction where research is conducted from ongoing events back to their causes. CR not only objectively defines realities that exist independent of an individual's perceived notions, it also helps in interpreting subjective realities perceived by an individual (Taylor, 2018). CR allows

the researcher to identify, explore and seek to understand the structures and mechanisms that cause events to happen. During the investigation process the researcher can contextualize aspects of the objective world as well as constructs from the social world that influence or determine the link of causation (ibid:218).

⁹ 'The term "naive realism" (also termed "empiricist realism" or "direct realism") advocates the view that reality is knowable through direct experience' (see Klein, 2002:12)

By adopting CR, this study sought to illuminate and critique existing social conditions (Fletcher, 2017) for an informed understanding between disability and urban informality within secondary cities. The epistemological and ontological nature of southern disability studies as opposed to traditional disability knowledge and the complexity of urban informal processes was explored through CR forming a more nuanced understanding of the society and the underlying mechanisms and structures that embody that reality. Through abductive reasoning, this research explored how informality affects disabled people and at the same time how practices of PwDs in turn shape urban informality (a two-fold relationship) thereby anchoring the core tenets of CR which places significance on understanding and discerning reality. Although critical realists have no defined research methods, qualitative research approaches that are underpinned by CR emphasize 'conceptualisation', 'rigorous description' and 'convincing explanations' of phenomena (Clark ,2008:169). In light of such an insight, CR tends to incorporate aspects of 'idealism' through the recognition that 'some things are real although they are only knowable through our concepts of them' (Klein, 2002:12).

In sum therefore, by drawing both SC and CR ontologies and with the theoretical perspectives discussed in the literature section, this research study was premised on i) socioeconomic and cultural issues affecting PwDs; ii) the structural and material configuration of informal spaces; iii) the underlying issues that shape events related to urban governance processes. A practical illustration could be for instance, PwDs may undergo experiences that are discriminatory, experience far-reaching prejudicial practices which are hinged on socio-spatial inequalities. Such events that affect them are usually fanned by underlying structural mechanisms, which largely intersect with the ethnicity, culture or religion of a given society, economic processes, governance styles, etc. In this case SC would be useful in shedding light on the practical experiences that come with disability while CR would unearth underlying causal factors that come with a particular kind of impairment for in certain places visual blindness is seen differently to hearing loss or the other way round. The mechanisms are in turn driven by power relations and ideologies displayed by the perceived binary that exists between ability and disability in an environment. This understanding forms the basis for this methodological framework and guides issues and debates related to disability within urban informal settlements.

The research inquiry

The philosophical section above demonstrates how this research was able to make meaning out of people's lived realities guided by the two research philosophies. SC allowed the participants to extensively and in a free manner express their experiences about disability through an open discussion. Emphasis was put on careful listening of those experiences while

making interpretations both at the time and later on when reviewing the recorded data. Applying an SC framework was critical to gaining the views from participants which nuance their lived realities. CR enabled the study to unravel the realities that PwDs face given their differing and diverse disability statuses within the context of an informal space. By conceptualizing disability and informality, the previous chapters were fundamental in positioning the two ideas within a broad spectrum of existing scholarship hence establishing the existing gap in knowledge which in turn leads to the research inquiry. This thesis as introduced in the first chapter is mainly focused on understanding how PwDs negotiate existing structures within informal settlements and the ways this plays into how they perceive themselves and their surroundings. As such, the primary aim is to establish how informality (re) shapes and (re) defines the lives of PwDs within informal settlements in Eldoret, Kenya through an understanding of their living conditions and their everyday way of life and the links to urban governance. To achieve that the following three questions guided the research

- How do sociocultural perceptions, norms and practices shape the everyday lives of PwDs in informal settlements?
- How do PwDs adapt and negotiate the various spatial and material conditions within urban informal settlements?
- How do urban governance structures shape and define PwDs everyday lives in informal settlements?

To respond to these questions, this research sought to understand meanings of disability as framed by the various PwD experiences and actions through qualitative methods. Semi-structured interviews and by extension life stories were employed as the main technique of collecting data supplemented by other methods namely observation, transect walks and review of documents which were all key in achieving triangulation, an essential outcome for effective qualitative research. Short periods were spent in the participants' homes and places of livelihood opportunities such as their business enterprises at different times but mostly limited to daytime activities. The research questions were further broken down and scaffolded to capture various themes and sub-themes using interview guiding questions (see sample in the appendix), all designed for specific respondents.

Study design: a qualitative case study

A qualitative case study strategy was best suited for this research since it examines a phenomenon within its contextual background and as emphasized by Stake (1995) (and underpinned within both SC and CR paradigms) enables a research inquiry to redefine knowledge out of contextual realities. A significant highlight about a case study is that it

enables one to 'understand a complex social phenomenon' (Yin, 2009:4). Such complexity and dynamism applied in this study when interpreting disability in the Global South especially where informality, a fast-changing phenomenon is the dominant way of life in most cities. Beside the case study being suitable of investigating intricate phenomena, it is also vital in generating rich knowledge about specific contexts and analyzing real-life events that shape change processes. The case study approach permeated well with this research in that it enabled investigations into ongoing interactions and power relationships amongst PwDs and the non-disabled persons within communities in relation to societal institutions. Duminy et al. (2014:23) pointed out that 'the real value of the case study is its capacity to show what has happened in a given setting, and how'. They recommend the case study research method as being ideal for urban research especially in contexts such as the underexplored secondary cities of the global South. Qualitative case studies are generally acknowledged to be particularly suitable in scenarios where questions of 'how' and 'why' are posed (Yin, 2009:13). The research questions that were structured for this study as explained previously aptly relate to the 'how' scenarios hence a justification to adopt case study research design. Such questions trace both action and processes as well as examining the role of agency and structure in describing existing power relations within various actors.

This study largely aligned itself to an 'instrumental case study', which is drawn from Stake's (1995) categorization of cases and at the same time a nested case study approach. An instrumental case study tends to promote how a particular issue is understood while an intrinsic case study on the opposite end 'may be undertaken to learn about a person or phenomenon that we simply want to know more about' (Harling, 2012:2). While both instrumental and intrinsic case studies form a cohort of single cases, this study is a typical example of an 'instrumental case study' as it highlights the intersection of disability and informality and how they are intricately related against the backdrop of a rapidly urbanizing city. It adopted three informal settlements as instrumental cases within a bigger case nest which is Eldoret serving as a case city for exploring disability situation from the context of a small and medium sized city. According to Miles et al., (2014) cases to be researched are chosen on the basis of the conceptual framework rather than sheer representation, while that is legitimate for this research, COVID-19 dynamics influenced in part the choice of Eldoret as a nested case study area.

A number of considerations motivated the choice of Eldoret city as the nest case for this research study, including the richness of information, diversity and uniqueness of the cases, accessibility and those that portray a dynamic urban setting for interesting findings. Before making the decision to carry-out the study in Eldoret, other Kenyan cities such as Nairobi,

Mombasa, Kisumu and Nakuru were all in contention as ideal urban spaces to carry out the proposed research. The choice of Eldoret was inspired by the fact that it is the fastest urbanizing town in Kenya and a key secondary city within the sub-Saharan Africa region which is undergoing rapid urban transformation. Other factors which also played a role in choosing Eldoret for this research is its proximity to the lead researcher especially during the COVID-19 pandemic period and the arguable fact that the city has not been overly researched (as evidenced by the limited scholarly materials) in comparison to the other four cities therefore adding a new set of scholarship for future urban research in Kenya. At the city-scale, three informal settlements were purposively selected and explored to discern the relationship between disability and informality in such low-income neighbourhoods. Their selection was determined in-situ while in Eldoret, meaning the three were arrived at from a possible list of candidates after engaging gatekeepers who were fundamental in providing the initial data about disability and informality within the city. These settlements are Langas, Boma Turkana and Munyaka informal settlements as illustrated in figure 8 below and are discussed in detail at the end of this chapter.

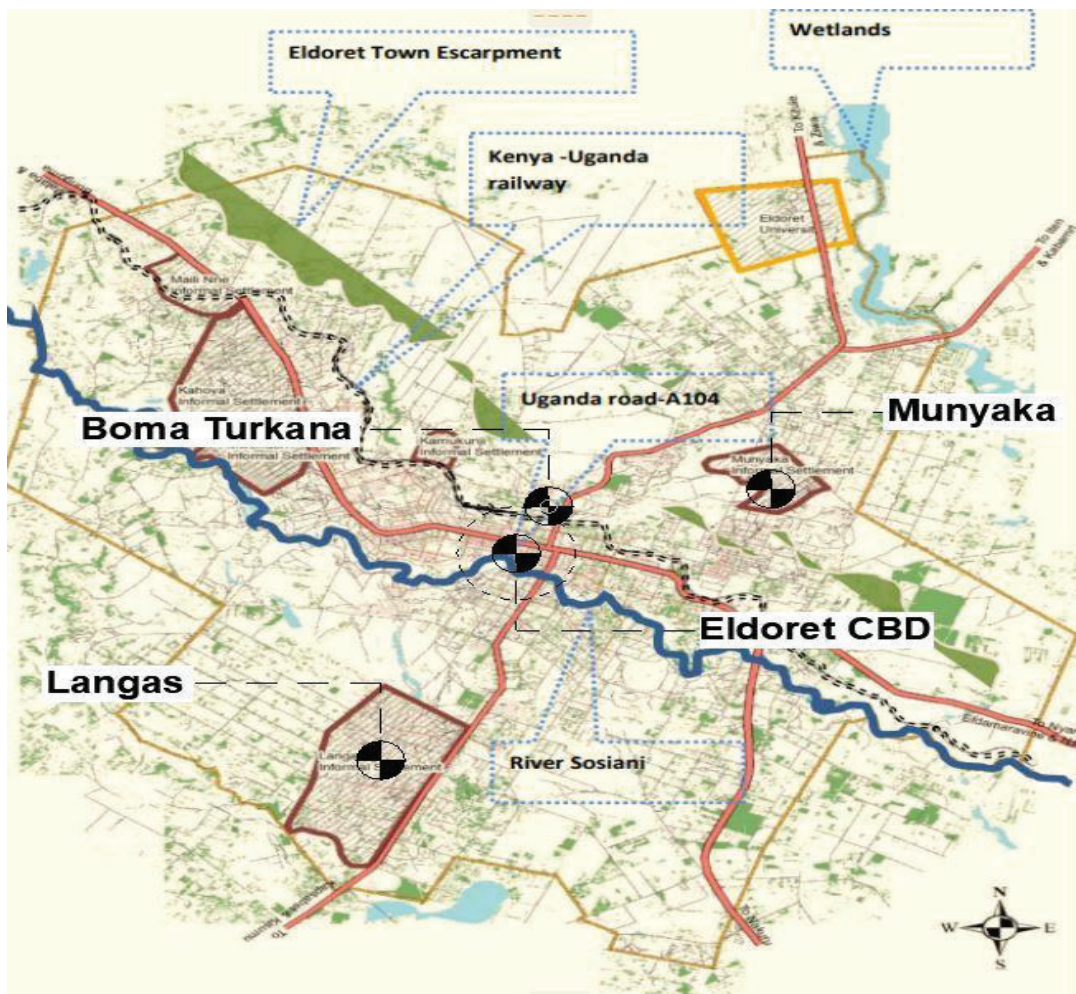


Figure 8: The study areas in relation to the city (Source: Modified from Planning department, Eldoret)

Data collection methods

Since case studies tend to promote the understanding of situations within their contexts in diverse perspectives, it is common practice that they entail but are not limited to qualitative methods as their main data collection approach (Baxter & Jack, 2008). In finding the ‘how and why’ questions relative to this study, for instance the socio-economic and cultural perceptions of PwDs (question 1), the spatial needs of PwDs (question 2), and implications of urban governance for disability (question 3), this research adopted an inductive approach that is consistent to social constructivism and at the same time consistent to the abductive approach of critical realism. The research questions aimed at identifying facts, perceptions and meanings through putting emphasis on people’s lived realities. In probing these questions four qualitative methods were deployed in exploring everyday life in rapidly changing urban informal settlements in relation to PwDs and how they intersect. The use of multiple methods through triangulation ensured various perspectives of the complex research environment were incorporated ‘to get a better understanding of the subject matter at hand’ (Denzin and Lincoln, 2008:4). This study being purely a case study research adopted interviews, observation, transect walks and document reviews as the main data collection methods.

Table 1: A summary of the research methods

Question	Participants/respondents	Preferred method	Activities
1. How do sociocultural perceptions, norms and practices shape the everyday lives of PwDs in informal settlements?	<ul style="list-style-type: none"> • PwDs • Community members • NGOs 	Interviews Observation Transect walks	<ul style="list-style-type: none"> • 26 semi-structured interviews with PwD • Photographing • Diagramming and note taking

<p>2. How do PwDs adapt and negotiate the various spatial and material conditions within urban informal settlements?</p>	<ol style="list-style-type: none"> 1. County government officials 2. PwDs 3. Community volunteers and NGOs 	<p>Interviews</p> <p>Document reviews</p> <p>Observation</p>	<ul style="list-style-type: none"> • Interviews with planning and housing officials • Note taking
<p>3. How do urban governance structures shape and define PwDs everyday lives in informal settlements?</p>	<ol style="list-style-type: none"> 1. County government and NGO officials 2. Statutory documents 3. Newspapers 4. Blogs 	<p>Interviews</p> <p>Document reviews</p>	<ul style="list-style-type: none"> • Interviews with NGO officials, planners • Note taking

(Source: authors construct)

Interviews

Interviews mostly in the form of semi-structured interviews were used as the primary data collection method for this research as they are akin to discursive in/formal narratives which mainly engage with spoken language as the data. The interviews aimed to probe PwDs' lived experiences, including past or current changes to their informal settlements and other stakeholders who deal with their needs. The interviews elicited people's knowledge, local understanding, their experiences and interactions with the realities that the research questions were out to explore. The data was mainly generated through listening to people in meaningful ways (Longhurst, 2003) cognizant of the fact that not all personal accounts of the respondents would simply lead to the acquisition of facts, perceptions and feelings were significant too. This research in adopting semi-structured interviews situated people's experiences and accounts within their contexts so as to understand the complexity of their lives. The interviews functioned well to answer the three research questions that were being sought and also were well suited to the prevailing conditions and practicalities in the field. Although a set of predetermined questions had been prepared to engage the interviewees, the interviews

unfolded in a conversational way thereby giving the participants plenty of room to have a discursive narration of their issues and the feelings they deemed vital (Longhurst, 2003). The use of semi-structured interviews did allow the research to keep a controlled and orderly process that encouraged comparisons between different cases, while giving the participants a chance of roaming, focusing and detailing how they experience disability in relation to many other aspects within their neighbourhood.

The interviews were grouped into four main participant cohorts (see table 2) namely a) PwDs living in the informal settlements b) community leaders c) government officials and d) non-governmental (NGOs) officials. In total 37 interviews were conducted lasting on average forty minutes each in which the shortest duration was twenty-five minutes while the longest was over an hour. Most of the interview durations depended on the prevailing conditions, longer lasting interviews were scheduled in the outdoor spaces but given participants preferences and disabling nature those conducted indoors tended to be time bound.

Table 2: Interview cohorts

Interview cohort	Interviews carried out
People with Disabilities	26
Community leaders and volunteers	5
Government officials	3
NGO officials	3
Total	37

(Source: Author's construct)

Before engaging with participants for interview sessions, focus was channeled into clearly explaining to them about the research process and informing them of the pre-conditions which included gaining their consent and giving them a participant information sheet. To cast away suspicions of any kind towards the process, an introductory letter and a copy of the research permit was availed to the participants. The majority of the participants were comfortable with

recorded conversations apart from a few cases. For example a PwD who was interviewed from his workplace and a government official preferred not to be recorded and instead their insights were recorded in a notebook.

In all the interview sessions and given the nature of this research, I practiced attentiveness, actively listening and always trying to fit my tone with the conversations, toleration of silent moments and always seeking for any interpretation where necessary. In the same breadth, I played a high level of neutrality to the respondent's feedbacks and tried not to be judgmental or retort shockingly to views seen to be contentious while at the same time avoiding to provide cues to the respondents about the 'right' answer or expressing any opinion to an interviewee (Cannell et al., 1981). Since my interviewing skills were still nascent, I mostly relied on my supervisors and peers when support was needed to overcome setbacks. Similarly, a critical challenge that affected interviewing people to a large extent were the effects of COVID-19, initially I thought I would fully depend on telephone interviews but the realities in the field meant that this was not possible (an issue that might need further research). I realized that most participants were unwilling and very suspicious to give information on phone; this made me revert to the traditional one-on-one sessions albeit strictly following the pandemic protocols. The decision to select Eldoret over Nairobi as the research site had a huge advantage; this is because Nairobi had widespread cases of the pandemic and therefore could have posed greater viral risks during the interviews. Additionally, I succeeded in having most sessions in outdoor environments so as to further reduce the risks posed by the pandemic. Each cohort had specific interview processes, selection criteria, recruitment strategy and challenges, a detailed explanation of each is provided in the next section.

People with Disabilities

First on the interview list were PwDs within communities living and working in the three informal settlements. They formed the most critical group of the participants and were in essence the most difficult to approach given that in some cases they were held up in secret and derision because disability in Kenya is culturally seen as an outcasted phenomenon; a key finding elaborated in chapter 5. Consequently, to break that stigma and for ease of recruiting potential participants, the research had to come up with the most promising selection and recruitment process premised on trust and a good rapport as earlier cited. Therefore, to kickstart the process, individual and *chamas* gatekeepers (both discussed previously) were selected as the main mode to which interviewees under this cohort were to be selected and recruited into the research process. The choice of gatekeepers here was based on acquaintance to the study areas and those that could guide the research to sensitively and meaningfully engage with the participants. As such, the gatekeepers spearheading selection and recruiting

PwDs for interviews mainly comprised of village heads, community volunteers and activists who had direct contact with the potential participants and leaders of *chamas* in the various settlements. These were people who had invaluable and rich knowledge about the demographic and socio-spatial specificities of the various neighbourhoods being studied.

After settling on gatekeepers for use under this cohort of interviews, together and based on consent to engage as part of the research process, we drew a list of possible interviewees and then analysed their corresponding disability situations mindful of the risks earlier mentioned. From the list telephone calls were made to the initial and potential candidates explaining to them and introducing the research process with an aim of understanding whether they were willing to engage in the process. Depending on their responses follow-up visits were made either solo or in the company of the gatekeeper albeit the latter was common. The research at this juncture adopted an 'on-site recruiting' of research participants and used snowballing as the main strategy to gain a wide network of interviewees, this meant that each participant who was engaged assisted in the recruitment of the next respondent. Most of the participants were quite open to having a recorded discussion and gave explicit consent except on three occasions where two participants did not want to be recorded and the other totally refused to take part in the study citing personal reasons. The interview questions which had been prepared in English were directly translated to the local Swahili language in verbatim, this was made possible due to my prior knowledge and proficiency in both languages albeit prior revision of the questions was necessary. The translation was important because most of the research participants within this category had little understanding of English and had a higher proficiency in Swahili. One unique case adopted in one of the settlements needed a translation agent where an elderly woman did not understand both Swahili and English but only communicated in her native Turkana language.

Apart from translation payment for both gatekeepers and interviews fronted itself as a key issue especially in this cohort since most participants lived in poverty and expected an incentive or compensation for their engagement in the research. While in many instances that was made either in monetary format or food items emphasis was placed in explaining to the participants the nature of the research which had no funding particularly for their participation and anything they received was merely an appreciation on the researcher's part and not a formal payment. The interviews were evenly spread across the three informal settlements with the largest informal settlement i.e Langas having most PwD respondents while the smallest by size i.e Boma Turkana had the least respondents meaning the population was proportionate with respondent cases. Emphasis was put on PwDs with physical disabilities but parents/caregivers of PwDs with mental disabilities formed part of the respondents.

Table 3: Disabled participants from Langas informal settlement

Respondent CODE	Gender	Type of Disability	Summary of disability condition
LA.01*	Female	Physical and mental	Caregiver to three children with severe disability conditions, because of the three children some believe she is cursed
LA.02*	Male	Albinism and visual difficulties	Lives with albinism and struggles to fit into the community because of stigma and the effects of the sun on his skin
LA.03	Male	Physical	A 38-year-old wheelchair user and a cobbler in Eldoret town
LA.04	Female	Short stature condition	25-year-old woman living in Langas informal settlement and has a short stature (ss) condition, which became evident after she was born. She is a single mother of two and works as a shoe vendor in the city.
LA.05	Female	Physical	A caregiver to a relative with disability
LA.06	Male	Physically impaired	A 46-year-old wheelchair user who works as a cobbler in town

LA.07	Female	Physical and mental	A mother and caregiver to her 20-year-old son
LA.08	Male	Physical and mental	A male caregiver to his disabled brother and works for the local government
LA.09	Male	Physically impaired	A 48-year-old wheelchair user who works as a cobbler in Eldoret town
LA.10	Female	Physical	A youthful woman and a fruit vendor who recently emigrated from central Kenya and came to live closer to her relative. She has an impaired leg and has a difficulty in walking
LA.11	Female	Physical and mental	-A grandmother who takes care of her disabled grandchild - The mother fled to the capital city and abandoned the child

Table 4: Disabled participants from Boma Turkana informal settlement

Respondent CODE	Gender	Type of Disability	Summary of disability condition
BT.01	Female	Visually impaired	-Lives alone without any sustainable source of income and depends on neighbours for help
BT.02	Female	Physical	-A 51-year-old disabled woman who stays alone and depends on her children for upkeep, she also lives with HIV/AIDS
BT.03	Female	Physical	-An elderly woman in her early 60s who stays alone and assisted by the community. She is physically disabled.
BT.04	Male	Physical	-A 67-year-old who physically impaired and uses a walking stick to move around
BT.05-	Male	Physical	-An elderly disabled man who also acts as one of the council members in the community leadership

Table 5: Disabled participants from Munyaka informal settlement

Respondent CODE	Gender	Type of Disability	Summary of disability condition
MU.01	Male	Visual impairment	-Lives with his wife who is his principal caregiver -They also have an informal business of selling charcoal
MU.02	Female	Physical and mental	Caregiver to a child with severe disability condition
MU.03	Female	Physical and mental	Caregiver to two teenagers with severe disability conditions and also living with HIV/AIDS
MU.04	Female	Physical, mental and epilepsy	A single mother and caregiver to her daughter
MU.05	Male	Physical	-A father to a wheelchair teenage boy -The family of the boy live together in a 1-roomed house

MU.06	Female	Mental	-A widow who takes care of her disabled daughter -Also, a street vendor and hawker
MU.07	Female	Hearing impairment	-A mother to a teenage daughter with deafness -Her daughter struggles to live with other children
MU.08	Female	Physical and mental	-A mother and caregiver to a 21-year-old adult son and a single mother -The son is enrolled to a special care school in Eldoret
MU.09*	Male	Physical	-A wheelchair user who has an informal business in Eldoret town -His disability is a secondary one from a recent accident
MU.10	Male	Physical	-A man in his early 40s age who lost his hands from ethnic clashes in 2007 election cycle

*Unrecorded interviews

Community leaders and volunteers

Recruiting this set of participants was relatively straight forward as most of them were known figures in the communities and were all happy to have a recorded conversation about what they do in helping PwDs in low-income neighbourhoods. The community leaders and volunteers mostly preferred being interviewed in the villages where they work apart from one of them who opted to be interviewed in a coffee shop in town. In total three community leaders (all men) were interviewed comprising of one from each of the settlement. For the volunteers, the study interviewed two (a man and a woman) who worked in Langas and Munyaka. Boma Turkana did not have a known volunteer. While community leaders covered themes which included growth patterns of the informal settlements and general disability situation, the community volunteers offered information about the health and social conditions of the disabled.

Government officials

The third group included government officials. They comprised of officials from the county government of Uasin Gishu whose planning and housing duties were mainly within Eldoret municipality albeit they were also in charge of other smaller towns within the county such as Soy, Burnt Forest and Moi's Bridge. Two senior planners in the planning and housing departments and their corresponding junior colleagues in each of the departments were recruited through direct contact from their offices. I began by approaching the senior planners who are the departmental directors in both housing and planning departments and asked for their recommendation on appropriate junior planners to interview. Unfortunately I was unable to interview one of the senior planners who was in charge of housing in the county given her busy schedules and the fact that she was less committed to being interviewed. The senior planner in charge of planning however gave an elaborate insight on planning policies and strategies which were relevant to PwD while one of his lower cadre planners provided his hands-on experiences about the research topic. All the respondents but one in this category agreed to a recorded conversation and had no anonymity issues as prescribed in the University's code of ethics.

NGO officials

The fourth lot of respondents were professionals in non-governmental organisations (NGOs) and related non-state agencies. It involved two officials of non-governmental organizations (NGOs) working for the disabled poor in Eldoret municipality. This category of interviews proceeded formally as most of the questions were discussed in English. The two NGO officials who were coordinators of the Association for the Physically Disabled of Kenya (APDK) and

the Global Civic Sharing (GCS) were interviewed in different coffee shops in Eldoret town. Their interviews were both recorded.

Observation

This research adopted both direct and participant observation as another source of its data evidence and in most cases used both techniques concurrently during formal and informal fieldwork sessions. Direct observation as the name suggests means directly observing events in the 'real-world setting of the case' where case study research is being undertaken (Yin, 2018: 121). Participant observation according to Laurier (2010) entails getting to spend time, live or work with communities or individual people so as to get to know them. It is simply, as the name suggests, a research method where one participates in events and observes while collecting data through 'field-notes, sketches, photographs or video recordings' (Laurier, 2010:116). Participant observation has no formal or systematic way of doing it (Laurier, 2010:117) in this case participation in meetings and engagement in the local settings were utilised as detailed herein. While adopting observational evidence research ethics had to be strictly adhered to, as such, much of what I observed and later recorded had to be relayed to the participants who had to give consent to the process.

Observation was particularly useful in that as the lead researcher I spent most times in the case study sites assessing activities related to disability and informality. Informal activities such as vending of household goods and water distribution modes through *kiosks* along streets in the settlements were keenly observed and recorded through sketches, note-taking, photographing and video-taking which were all recorded in my fieldwork diary. In embracing PO, I took time talking to random people (who were not necessarily PwDs) informally in all the three informal settlements ranging from shop owners, motorcycle riders (*boda bodas*), hawkers/street vendors and religious people to get their general understanding and knowledge of the research topic. In the same manner, I engaged in self-help group (known as *chamas* locally) meetings of PwDs as a participating observer. For instance, in Munyaka I partook in one of the weekly *chama* meetings of PwDs where they were deliberating on their socio-economic affairs and how they can support each other. Such an activity enabled me to have a wider understanding of the issues faced by PwDs. I also engaged in on-line debates about disability in Kenya and listened to discussions about PwDs in the mainstream media, an example being a debate at a local TV station about 'disability and politics'. Such fora allowed me to have a more comprehensive oversight of the geography of disability and informality in the country. Equally, being a participant in such sessions helped me to contextualize my research and have a widened understanding of the subject.

Transect walks and rides

Urban transects are walks/rides that an individual researcher (or a research team) engages either alone or together with local members of a particular community in a city or neighbourhood, the walk starts from a point A to another point B along a defined path or street line (Kagan, 2019; Mahiri, 1998). In this study, transect walks and rides were carried out as supplementary evidence to the interviews and observational aspects of the research. The journeys were undertaken in combination with interview sessions through engaging respondents with relevant questions about various places within the research areas. Further, they were conducted hand in hand with observation by assessing the various socio-spatial conditions and recording the findings through notes, photos/videos and diagrams. Practically the walks or rides lasted for periods of up to 2 hours and were conducted with one or two residents who had extensive knowledge of the various places and people living in the settlements. For example, on many occasions *boda bodas* (taxi bikes) were used to manoeuvre the expansive areas since most of the youthful bike riders had a rich knowledge of the sites as they offered localized transport on a daily basis. As a passenger I would move from one end of the settlement to the other while noting down events. Specific to this research the walks were not particularly distinct from the previously discussed two methods since as alluded above they borrowed specific features from several other methods including making interviews while walking or riding, making observations while walking, photo-taking and sketching.

Document reviews

Besides interviews, observations and transect walks/rides, document reviews also formed a critical source of secondary or 'grey' data for this research. I studied a diverse category of these data sources including

- Legal and policy documents
- General information documents- Census reports

Legal documents that are relevant to critical disability situation in Kenya and processes of urban informal transformation were engaged and their contribution discerned. For this research particularly, the Persons with Disabilities Act 2003 was a fundamental legal document that enshrines all the rights for PwDs in Kenya. It is also the legal instrument through which the National Council for Persons with Disabilities (NCPwD) operates. The NCPwD is a statutory body that is responsible for handling issues about disability in the country. For example, it is expected that NCPwD establishes and maintains a record of all PwDs in the country however a number of participants stated otherwise. The Constitution of Kenya, the

Physical Planning and Land Use Act, 2019 and the Urban Areas and Cities Act, 2011 also formed as sources of information about disability and informality in Kenya. Policy documents at the international level such as the UNCRDP and others at the national level such as the Kenya Vision 2030 are particularly critical to this study. The UNCRDP is the first comprehensive international legal instrument which reflects a global consensus, expressly protecting the human rights of PwDs and provides an authoritative commentary on the manner in which countries should fulfil their obligations towards PwDs. The Kenya Vision 2030 has a provision that promotes and spearheads reforms in Kenya's disability landscape through developmental pathways such as the creation of a disability fund for financial support to PwDs. Information from other sources such as population survey reports, the latest being the Kenya Population and Housing Census 2019 report was fundamental in giving background evidence such as density of people in a certain place. A key highlight of the 2019 census data that is relative to this research is how disability conditions were captured as part of the parameters within the census report. It is however debatable whether the nationwide exercise captured all the relevant information about PwDs in Kenya because the report seems to have captured certain disability categories and not others.

Data analysis

Bearing in mind that case study research leads to multiple data forms derived from several methods and sources, it is key to develop relevant tools for data analysis and interpretation. Qualitative research that is aimed at mechanistic interpretations such as critical disability do impose certain challenges to data analysis because existing theory has to be integrated with the patterns of the collated data (Gläse & Laudel, 2013:np). In this study thematic analysis was the main way in which data was analyzed. Thematic analysis, a foundational qualitative analysis instrument, 'is a method for identifying, analysing and reporting patterns (themes) within data' (Braun & Clarke, 2006:79). It is essential for organizing data on account of certain patterns to detail for ease of interpreting topical issues within the data sets (ibid). After making audio recording of interviews, the first process of the data analysis was to transcribe and analyse them. The transcription was done directly from Swahili to English in verbatim using Microsoft word. This was possible given my understanding of both languages however the process ended up taking a lot of time since I had to get everything well translated to avoid loss of any information. The transcription in as much as it was a tedious activity allowed me to deepen my understanding of disability and informality. The process also led me to identify emerging themes and patterns that would have been challenging if the process was done by someone else.

After the transcription, I then opted to print all the transcripts in preparation for manual analysis as opposed to computer aided mechanisms since doing it manually enables one to make

better representation of the everyday realities of PwDs. The transcript printouts were later filed depending on the research sites and the schedule of the interview. Reading and re-reading of the transcripts followed as the next item which in turn led to the generation of codes within interview conversations. A codebook was then created based on both predetermined and inductive themes that were generated purely from the data. The coding process was followed by categorizing and matching similar codes generating 'descriptive themes' and then 'analytical themes'. The 'themes' entailed issues that were reflected upon by the various categories of participants while describing the various social, economic, spatial and political processes that shape the disabled in informal settlements.

Research ethics

Research ethics aim to address the code of conduct of a researcher during the research process. Prior to starting this research, clearance was sought to conduct it from the University of Sheffield's Ethics Committee within the department. The research clearance (see appendix for approval letter) was granted in November 2020 after the 3rd review of the application because I had to align the research process with the existing pandemic situation. A key highlight of the review process was on coming up with ethically sound ways of engaging the participants while posing minimal COVID-19 risks to them and to myself. After gaining ethical approval from the University, I subsequently sought for a permit to conduct research in Kenya from the National Commission for Science, Technology and Innovation (NACOSTI) based in Nairobi, the procedures and requirements were easily accessed from their website¹⁰. The permit was issued a few days after lodging the application (see appendix for the research permit from NACOSTI). Additionally, and before the research was carried out, the intent to do it was relayed to the relevant authorities within Eldoret key being the county and national government representatives. They both acknowledged the process and were willing to offer any support that was needed. With permission (from all the relevant agencies) to partake on research in Eldoret granted, steps were undertaken to prepare for other ethical considerations, which were necessary prior to engaging the participants. Some of these issues were planning for anonymity, informed consent, confidentiality, and consideration of any potential consequences the research would have to the participants and myself.

The other ethical dilemmas that were experienced include the issues of payment and the emotional breakdown of some participants. While there were no clear strategies to handle both, the cases were approached as they played out in the field. For instance, on payment, it was anticipated that no monetary transactions and/or promises in the first instance was made to either gate keepers or the participants. This is because there were many people who were

¹⁰ <https://www.nacosti.go.ke/>

very willing to offer information or services for free especially after they understood the intentions of the research process. The research worked towards avoiding participants who were extremely vulnerable outrightly insisting for compensation of their time in the process. However, small tokens made in kind were inevitable. Also since disability is a sensitive subject, it was foreseen that it may cause distress to participants especially when they speak and reflect on their disabling experience which at times were emotionally disturbing. In such cases where this arose, they had the liberty to withdraw from the process without any consequences whatsoever- for instance they did not lose their tokens in kind if prior arrangements had been sought. The other strategy adopted to reduce emotional distress was to purge out sections that affected participants while focusing on areas of discussions that were less sensitive.

Positionality

In qualitative research, reflexivity is an issue that has to be considered to a broad extent. Ideally, it implies how researchers understand how processes within research define the outcomes (Mavin, 2019). The position of a researcher can dictate much of the research process considering issues such as one's background, perception, assumptions and behavior. Therefore, as a researcher one has to continuously reflect his/her impact towards every aspect of the process. My training first as a Kenyan Landscape Architect and then as a Planner are some of the strengths that I put into use while sourcing for relevant data and at the same time I used it to critically assess and analyse how things are. Another aspect that entails reflexivity is my positionality as a non-disabled researcher interested in disability studies. Some of the questions that are critical in addressing this issue were:

- Am I as a non-disabled researcher able to conduct such a study?
- Why is it that I am interested with such a kind of research?
- What rights do I have to partake in such research, and will I be able to speak for PwDs?

These questions have been revered by disabled academics and some of them have been critical as to whether non-disabled scholars can efficiently conduct disability research and disseminate knowledge on their behalf (e.g Oliver, 1992). Oliver and other academics of similar thoughts as highlighted by Kitchin (2000:26) 'contend that it is only disabled people who can know what it is like to be disabled and so only disabled people who can truly interpret and present data from other disabled people'. For this research to accept this scholarly sentiment, it would then imply that conducting it is essentially invalid. Nevertheless, other researchers have conversely challenged this thinking (Finkelstein, 1996; Shakespeare,2006). Shakespeare particularly alludes that:

'just because someone is disabled does not mean they have an automatic insight into the lives of other disabled people ... The idea that having an impairment is vital to understanding impairment is dangerously essentialist' (Shakespeare,2006:195).

As outlined earlier the social model's conceptualization about disability posits disability barriers as being created socially within communities. In light of this Finkelstein (1996:32) argues that such conceptualization allows every person within the society both disabled and non-disabled 'to analyse and comprehend the nature of disability'. In other words, and in relation to my position as a non-disabled researcher both Shakespeare and Finkelstein see this research as foreseeable and valid. However, it should be noted that there are experiences that PwDs encounter that may be difficult to effectively relay and is therefore a limitation that could undermine the intended research objectives. To minimise this a consistent effort to maintain sensitivity and openness was practiced, as well as strict adherence to the guidelines of conducting disability research.

Study area profile

This final section of the methodology chapter serves as a precursor to the empirical chapters. It briefly presents the characteristics of the case study sites starting from the profile of the city of Eldoret then specifying the dominant features of the three settlements namely Langas, Munyaka and Boma Turkana. Some of the features which are highlighted include details of the location of the study site, a brief history of the areas and the social-spatial, political and economic landscape. Specifically, trends of housing and the city informal pattern are detailed considering the study is premised on how PwDs experience housing in the informal settlements. Additionally, the governance framework of Eldoret is also briefly captured and some of the guiding legislations which anchor the municipal planning. Given the inadvertent scarceness of available secondary data about some of the settlement areas, additional information was directly relayed by interview respondents both within the communities and officials in state and non-state actors.

The city of Eldoret

As the administrative capital of one of Kenya's most cosmopolitan counties, Eldoret ranks as the fifth largest city in Kenya in size and population density (Omollo, 2019). From the 2009 census report, Eldoret had a population of approximately 252,051 people however that figure sharply rose to 451,384 as per the 2019 census depicting a population growth rate of 6% per year (see KNBS 2009, 2019 report). The city is set 313 km Northwest of Nairobi, the capital city of Kenya. A rapid influx of migrants into the city has positioned it as the fastest growing city in the country while making it a city of diverse ethnicity (Badoux et al., 2018). According to Badoux et al., (2018), the city was founded at the start of the 20th century by settlers from

Europe. The city had distinct zones for Africans, white South African who had migrated to practice farming , Indians who worked in constructing the railway and British colonialist whose influence shapes urban governance even in the present (Badoux et al., 2018).

After Kenya gained independence the 'white highlands' owned by the British settlers were 're-Africanized' and given back to Kenyan natives from different ethnic groups who settled around Eldoret through a program dubbed 'settlement schemes' (ibid). However, this process was marred with clientelism and unequal distribution of resources which led to 'historical land injustices' setting the elites who owned large tracks of land against the landless majority. When the while settlers left, they abandoned large tracts of land which were later subdivided by various cooperatives and land buying groups. This history fueled tensions among various ethnic groups living in and around Eldoret making the city a political hotspot that has experienced recurring violence after every election episode resulting in loss of lives and internally displaced populations. The tribal clashes are normally associated with land grievances and ethnic animosity between the majority Kalenjin population 'who claim autochthony' in the region and the minority Kikuyu tribe who have been settling in the larger Rift Valley for many years.

As alluded above, Eldoret is usually regarded as a cosmopolitan city due to the many ethnic groups that reside and work in the city. The most dominant ethnic groups in the city are the Kalenjin, Kikuyu, Luhya, Luo and the Kisii. Such a multi-lingual social fabric is as a result of the history of Eldoret and is key to understanding discussions around the development of the various neighbourhoods and perceptions of social issues such as disability, gender and aging. Through settlement schemes, the fertile white highlands in Eldoret were re-Africanized where the indigenous Kenyans from various ethnicities were allocated land. This resulted in Eldoret being a city of migrants where the urban agenda was mainly driven by Kikuyu migrants who enjoyed the initial years of independence given the favourable political context at the time. Around this period, the dominant Kalenjin ethnic group were skeptical of living in urban neighbourhoods preferring to stay in rural areas to look after cattle. It is therefore true to note that while Eldoret is mostly seen as a Kalenjin city, their role in urban development became significant at the start of the 2000 millennium.



Figure 9: A typical street in Eldoret (Source: Author)



Figure 10: Key Kenyan cities including Eldoret where the size of the dots represents the proportion of population size, (Source: Salon & Gulyani, 2019)

Langas informal settlement

Located in Langas Ward within Pionner location, Langas informal settlement is the largest slum area in Eldoret city. According to the Kenya 2009 census survey, Langas Ward had a population of 66,973. Langas a low-income neighbourhood is sited about 5 kilometres from Eldoret central business district. Initially, the estate was comprised of various blocks of agricultural land which were later divided into plots and sold to individuals. The settlement is

divided into 6 blocks (block 1-block 6). Langas is a disputed town area, and nobody presently owns the land; there is an on-going litigation process to determine the rightful owners of the close to 1050 acres of land.

'Those living in the settlement do not have genuine land titles that dictate ownership but only have sale agreements' [Interview GO-01]

'The 'residents' or 'plot holders' are the current owners of individual plots in Langas. As the area urbanized, the farm was subdivided over several generations of plot holders into a total of about 6000 parcels. These plot holders have access to the land but no title deeds since the subdivision never followed due process' (Badoux, 2018:34).

Langas which started as a settlement outside of the original Eldoret municipal boundary has limited services. Housing is characterized by low-cost construction materials (mud, iron sheets and boards) sitting on subdivided plots which lack access given the irregular and informal process of land subdivision over the years. The area is congested with poor housing that has insufficient water, limited electricity connection and poor road network. Water a key theme in this research is provided through kiosks and vendors with no clear municipal water connection. Electricity is also poorly connected, and most homes lack household energy resorting to other unsustainable sources such as kerosene and firewood.



**Figure 11: A road in Langas with a wheelchair user negotiating the experience
(Source: Author)**

Boma Turkana informal settlement

Boma Turkana is situated adjacent to Eldoret's central business district towards the northern part. It borders the town's main industrial area and the municipality's abattoir. It is a small settlement of around 200 households mainly inhabited by squatters where the land is owned by a government agency (Kenya Meat Commission). It is an inner-city slum which exudes a different form of urban informality uncharacteristic to the other informal settlements in Eldoret whose primary location are at the city edges. One key social characteristic of Boma Turkana is that the slum is fully inhabited by one ethnic group, the Turkana community, whose majority hail from the northern part of Kenya bordering Ethiopia and South Sudan. This factor among others was the principal criteria to consider it as interesting case which adds a different dimension to the research findings. Since it is a tiny settlement which sits unseen by many, there is paucity of information about its background and origin. However, in a conversation with one of the community leaders from the area, the settlement has been in existence since the colonial days and became an urban hotspot for the Turkana community who settled there while offering their services to Eldoret's main abattoir.



Figure 12: Engaging with a disabled participant in Boma Turkana (Source: Author)

Munyaka informal settlement

Munyaka, a fairly new urban settlement within Eldoret relative to the other two is located approximately 5 kilometers from the CBD. The settlement was established as part of a 300-acre track of land which was initially owned by a white settler and later bought by three people in the 1960s each owning 100 acres (Musyoka, 2006). Later on, in 1983, the piece of land that has since developed as Munyaka was bought from the original owner by a five-member land buying group for the purpose of selling it in smaller sizes as opposed to owning as their property (ibid). The land was later subdivided into several plots, about 969 in number each measuring 450 square metres. Land buyers started buying the plots in 1984 and by 1999 the average population of Munyaka was about 4000 people (ibid). The growth and development of the settlement was fueled by the 1992 ethnic clashes where the Kikuyu who are a minority in Eldoret were forcibly displaced from surrounding areas by the majority Kalenjins and had to settle together in the city (ibid). In terms of services, while the settlement has connections to water and electricity for instance, most homes do not have access except for a few individuals who connect and vend out to others at higher prices. The road network has undergone facelifting in the recent past with newly tarmacked roads at the time of conducting the fieldwork

process. Housing is characterized by mixed typologies although makeshifts like use of mud and corrugated iron sheets are the dominant materials used for construction.



Figure 13: A street in Munyaka (Source: Author)

In summary, these sites forming as case study areas were selected to give balance of inner-city and peri-urban situations, and to showcase diversity in socio-spatial conditions. The study sites were mostly (except for Boma Turkana) acquired by various land buying groups from white settlers during the colonial periods and have gradually grown informally. Time limits, the available resources and the dynamics of accessing various urban areas were the main factors which led to the selection of the three case study sites (Stake, 1995).

Yin states that in case study research, a researcher needs “sufficient access to the potential data, whether to interview people, review documents or records or make observations in the field” (Yin, 2009: 28).

Corresponding to the selection criteria; Langas informal settlement was chosen given that it is the largest, most complex/dense and the oldest slum in Eldoret, Boma Turkana is perhaps the smallest and maybe the most neglected inner-city slum with very unique characteristic in the form of housing typology and social configuration while Munyaka is a fairly new informal settlement and has grown rapidly since. Both Langas and Munyaka as shown in figure 8 are at the periphery of the city.

Conclusion

This chapter began by highlighting the study's research philosophy, which is underpinned by a combination of social constructivism (SC) and critical realism (CR). The combined philosophical approach allowed the study to have a nuanced understanding of disability issues and the realities of PwDs in urban informal settlements. The second section of the chapter detailed the methodology underpinning this research and the rationale behind selection of a qualitative case-study research. Methods used in this research are interviews, observation, transect walks and document reviews all of which have then been discussed in detail. Although interviews were the primary data source, triangulation was achieved via the other three sources so as to ensure research rigor. That rigor and other research considerations such as ethics and positionality are also discussed in this chapter. The chapter culminates by explaining how thematic analysis was employed as the key strategy used to develop themes related to disability and the realities of PwDs in urban informal settlements of Eldoret. The following chapter will discuss the first set of empirical findings by exploring themes and sub-themes that highlighted the social and cultural aspects of PwDs lived realities.

Chapter 5: Sociocultural processes shaping disability

This chapter sets the study's empirical analysis by addressing the first research question- How do sociocultural perceptions, norms and practices shape the everyday lives of PwDs in informal settlements? The chapter presents a critical discussion of various thematic findings that highlight 'social and cultural realities' of PwDs as they negotiate the often-harsh living conditions in informal settlements which as it will be deliberated in the next chapter are in many cases characterised by insufficient services. Demonstrably, most participants interpreted their disabling conditions to being closely linked to how society perceive them, an issue that affects their lived experiences more than their apparent physical conditions. Socio-structural factors such as ethnicity, class and religion reinforced such perceptions that PwDs undergo thus emphasizing the importance of intersectionality earlier discussed in this thesis. A common theme is how some participants felt they were left out of in events such as participating in religious activities for instance or even livelihood opportunities like not being allocated market stalls due to the perceived notion that they may not be able to run a business given their impairment. Such situations exacerbated and become more complex if they are seen to be from a different ethnic background. Culture as a way of life also forms as a critical addition to this chapter where for example many disabling situations were being ascribed to belief in super-natural powers, something this study foregrounds as a missing ingredient in most disability discourses within the context of the global South.

To this end, an understanding of the dynamic lives of PwDs from the fundamental unit of their households in relation to the broader society was established to be a key entry point into the disability situation hence making this chapter a precursor to other research chapter findings. These dynamics involve societal perceptions all of which have a bearing to PwDs in urban informal spaces. The research findings evidence that these underpinnings are intricately embedded to constructs of disability, which varied depending on the condition of the person and the immediate social environment thereby creating notions that shape the lives of PwDs. For instance, it was evident that disability affects various PwDs differently and at the same time affects households and not just the disabled individual due to the extra care and medical expenses incurred. By identifying the complexities associated with these thematic aspects, this chapter will be divided into two main sections. The first and major section of the chapter, spells out some of the socio-structural elements in disability spaces beginning with stigma and discriminatory practices experienced by PwDs. That is then followed by a discussion on informal networks known to many in Kenya as *chamas* which in Swahili simply implies to an informal network of people with a common goal. The other core arguments in this section focus on the geography of care in relation to disability within the milieu of informal settlements.

The second and minor section of the chapter highlights the cultural traditions tied to disability with religion and spirituality being the key issues presented as discerned from participant's reflections on the same.

Social relations within disability spaces

Social characteristics where people get together for their own benefit plays a significant role in the day-to-day lived experience of the disabled within urban populations more so in informal settlements where poverty and disability conflate to make life harder. Social networks both formal and informal are essential in the Kenyan disability situation as illustrated in chapter 3 where issues such as cultural beliefs and myths that affect PwDs are distilled within the networks for shared solutions. The networks can be from the lowest level of the household where relatives come together and provide care to the higher scales of the community where members both disabled and non-disabled come up with innovative solutions to a disabling society. This reflects what is spelt out within the social model which deconstructs social and environmental barriers to inclusive spaces. As posited in the introduction of this study, the disabled population within urban communities are usually amongst those that are exposed to extremely vulnerable situations and as identified in this research must find a way to survive the circumstances at their disposal, where social and economic networks are integral as parts of a means to an end. Most of the participants believed that coming together as a disabled constituency with a common identity (i.e as disabled individuals or families with disabled members) was an ingredient for social emancipation. A key obstacle they had to overcome was the attitudinal differences that they had to cope with from those who failed to understand their conditions eventually leading to stigmatizing practices. Consequently, they had to form informal alliances through the *chama* networks in order to care of each other as detailed in the subsequent sections.

Disability-induced stigma

Stigma, which basically means an 'adverse reaction to the perception of a negatively evaluated difference', constantly featured as an everyday salient issue to overcome in disability spaces (Green, 2003:1361). Social processes that are brought about by stigmatisation impacted PwDs and their families leaving them in situations of outcast dis-citizenship. The narratives as shared by research participants pointed to three key issues which can be best understood through Thornicroft's (2006) typology on stigma which identifies three key issues namely, the lack of knowledge/awareness about disability (ignorance), negative attitude towards PwDs (prejudice) and outright discrimination or rejection in the society. These narratives revealed how PwDs endure day to day challenges and difficulties and the unfairness they encounter while trying to negotiate hardships and the veracities of

living informally within the context of Eldoret. Two kinds of stigma namely enacted and felt stigma were dominant in most participants lives. According to Scambler and Hopkins (1986) both kinds of stigmatising practices are related yet distinct to one another. While enacted stigma is when PwDs are discriminated on the basis of their disabling condition seen as abnormal, socially unacceptable or inferior, felt stigma is the fear that comes along with enacted stigma. However, both stigmatising effects are experienced simultaneously. For instance, since most children with mental disabilities had epileptic conditions, they experienced both sets of stigma. A guardian of two disabled children with multiple disabilities in Munyaka expresses that

Even the neighbours fear him because saliva drips from his mouth. They obviously never want him to enter into their houses. Because of this he is mostly lonely and does not go out with other children [MU-03]

While on the one hand the neighbours abhor their child who's seen as not being socially acceptable because of the dripping saliva and at times convulsions, on the other the family have since developed a negative image about the experience and are oppressed internally. That in turn makes PwDs and their families loose self-value, feel unworthy and end up in a state of powerlessness preventing them from living interactively with others.

Stigma is closely linked with the concept of discrimination since the latter is a product of stigmatising practices which ultimately leads to exclusion be it economically, socially or on political grounds. Participants who felt both kinds of stigma were in some way banished from communities they lived in since they hardly interacted with others. Discrimination implies treating certain people in an unfair manner (Moreau, 2010). Through discrimination PwDs get excluded from given opportunities which are desirable to them or excluded from accessing limited resources from the state. The same respondent above felt discriminated from how the conduct of the local bursary committee¹¹ treated her

of late there has been discrimination concerning that bursary. You are given only if you are known and they do not even consider our disabled children. Nowadays the bursaries are all given out before we know that they had been rolled out [MU-03]

Several forms of discrimination exist within disabled spaces as intimated by the participants. The above situation describes a direct form of discrimination where it breeds out of an

¹¹ Local bursary committee is a group of select individuals in communities who make decisions on bursary suitability of school going children and the extent of their needs thus enabling the state help the most vulnerable

unfavourable treatment to PwDs. When something which seems to be equal ostensibly has unequal effects to a particular social group then it is a form of indirect discrimination (Campbell & Smith, 2022). For example, a participant in Langas lamented about how she is discriminated in social amenities including places like shops

Shops are available but they are not PwD-friendly. This is because most of the counters and shelves are high. If you go and knock at their door, they serve you as though you are a child. And that makes you feel bad. Also, someone on a wheelchair has a problem accessing the shops which have stairs at the entrance [LA-04]

Although the testimony alludes to a spatial dimension of disability as discussed in the next chapter, the situation also showcases how PwDs were exposed to hidden and unconscious practices that are discriminatory both physically and socially. There were also cases of institutional discrimination where organisational norms were affecting the minority disabled persons. However, in most of the contexts, the three forms of discrimination were all constitutive of each other. Ultimately, discrimination leads to exclusion (social, economic and political) which has detrimental effects on PwDs. In the section that follows, some of the everyday stigma situations are illustrated using two interview excerpts evidencing how stigmatizing practices directly affects the overall well-being of the disabled.

The everyday stigmatising practices against PwDs

Mounting evidence in the data highlight sweeping tales of stigma within informal settlements of Eldoret. An unrecorded interview conversation with a female respondent [LA-01], a resident of Langas encapsulates the kind of stigmatisation that disabled people face in informal settlements in Eldoret. She lives together with her three children who live with various forms of disabilities that have affected their physical and mental conditions. LA-01 husband is a *bodaboda* rider (taxi bikes); his work is extremely unreliable, and the income generated is very low relative to the family's needs. The family of [LA-01] faces predictable stigma from the society they live with because their neighbours within Langas strongly believe that her family is cursed given the three children growing up with severe disability conditions. Such perceptions from the community resonates with the earlier discussions in chapter 2 where cultural beliefs and spirituality shape realities around disability in most African communities. The situation at times distresses her family who feel excluded from the community. The family at some point even thought of going back to the village however given the economic situation in most of Kenya's rural areas, they had to keep living there with all the discrimination and exclusion they face as a result of stigma. This life-story of [LA-01] does indicate that disability

is perceived and built along the basis of 'otherness'¹² whereby if one is disabled or has a family member who has any form of disability then you are out rightly stigmatised. The situation that [LA-01] and her family find themselves in forces them to perpetually negotiate their lives and livelihoods in an unfriendly urban space. Their concerns bring to light the challenges the disabled endure, the difficult situations and the unfair circumstances they experience on a daily basis because of perceptions related to stereotypical thinking, misconceptions, limited awareness and a sense of prejudice by non-disabled and ableist urban majority.

Another case of everyday practice which evidence PwD's stigma in informal settlements of Eldoret was demonstrated through the lived experience of [LA-02] who lives with albinism and was the only albino person involved in this research. His experience of stigma and exclusion is relatively different to other forms of disability conditions due to albinophobia- a rare fear people have for people with albinism (PwA). As a PwA, [LA-02] experiences an exceptional or different type of stigma from the stigma other PwDs experience. In some countries in Africa, for instance within the East African region, it is believed that albinos possess magical powers and are therefore hunted and killed for their body parts (Brocco, 2016). [LA-02] narrates of how in the recent past (around 2008), they lived in fear and in severe danger of being kidnapped or killed and their body parts traded for witchcraft. This tends to create some form of societal phobia amongst families of people with albinism and puts them at the margins of any given society, which then makes it hard for government and other development entities to get data and subsequent service delivery to them.

In exploring the two experiences, the wider society tends to perpetuate stigmatisation, which in turn leads to exclusionary and discriminatory practices against PwDs. In 'othering' PwDs the society builds a disability construct of 'otherness' where cultural beliefs (which will be discussed in detail in ensuing sections of this chapter) and physical impairment are the basis for such construction. That process leads to rejection of PwDs bodies, their livelihoods and daily experiences where assumptions about physical inability is the obvious case. Their situation is compounded by their urban realities in that for [LA-01] poverty and the lack of a reliable job by her husband exacerbates that stigma they face, and for [LA-02], although he has a job the fear for his life is a significant concern for him. In the society, those who have visible weaknesses and symptoms of disability as is the case for [LA-02], they are labelled as outcasts. As construed by [LA-02], a lack of implementation of progressive laws and legislations that emanated from the 2010 constitution¹³ and also a lack of education and

¹² Otherness is the result of a discursive process by which a dominant in-group (Us, the Self) constructs one or many dominated out-groups (them, other) by stigmatising a difference- real or imagined-presented a negation of identity and thus a motive for potential discrimination (Staszak, 2009)

¹³ The Constitution of Kenya 2010 (downloadable at www.kenyalaw.org)

cultural norms that support disability within communities sums up their situation both in eking a living and their relations with the non-disabled majority.

The categories and forms of stigma within urban informality

Stigma happens at various levels; the most dominant forms feature at the community level which is born from everyday interactions of PwDs with other social groups. Participants of this study mostly felt the majority non-disabled individuals do not understand their lived conditions and perceived them as outcasts. Therefore, the community relations poignantly affected PwDs to a greater extent. The other level of stigma happens within the family level but is as a result of societal perception; in a conversation with a disability volunteer working in Langas informal settlement it was discernible that there are instances of house restrictions or even chaining of some PwDs by their supposed carers, he notes

Right now, there are still some PwDs who are usually locked inside their houses and neglected by their family members [Community Volunteer]

In such situations and given that he is a community volunteer, he is forced to intervene by discussing with the family about the child's situation or even reaching out to relevant agencies for aid. Family stigma, the volunteer further highlights, stems from the shame and embarrassment that parents experience when confronted with the social challenges of raising a child with disability. The feeling of a child with disability being a burden and the poverty levels in the informal settlements complicates the worrying stigma levelled by parents and relatives towards children with disabilities (CwD). Although, the study did not directly encounter situations of PwDs being locked or chained, the volunteer insisted that some families do practice the act but it is highly concealed given the inhumane confinement and the public image it portrays. He also cites that because of the stigma on PwDs within certain families in Langas, the standards within confinement zones are usually extremely degrading for example access to basic services like toilets are limited.

The reflections by the community volunteer in Langas was corroborated by a respondent at a facility where disabled children lived within Langas. Through the experience and journey of the proprietor in starting the care facility, which now takes care of over 100 neglected and abandoned children with disabilities in the outskirts of Eldoret within Langas, the key factor that drives people to abandon their disabled children is stigma within and outside the family. He categorically mentioned a situation where a child born with disability would lead to family separation because spouses blame each other for the disabled condition of their child. That kind of family stigma is so rooted in many Kenyan societies given the cultural or spiritual beliefs in things like curses, he posits, where either spouse blames the other for the origin of the

disability condition. Stigma pushes children with disabilities into dangerous 'orphanages' in the Kenyan context further substantiating the stigma problem within families. Family pressures and the special needs of the disabled children are the key driving forces to the abandonment cases. This is exacerbated by other issues like poverty, which also significantly determine the care politics of disability.

Finally, self-perceived stigma was also highlighted and noticeable as an issue in some PwDs respondents. According to Taira (2007), stigma is not always about what is done to disabled people but also about how a disabled people perceive of themselves. In an interview conversation with one of the Disabled Persons Organisation (DPO) representative, a female disability activist in Eldoret who lives with disability, described self-stigma as a big concern amongst PwDs themselves. In her experience as an activist who champions for the rights and well-being of disabled people, she points out that self-stigma is one of the greatest challenges in her work. She describes of it as a common phenomenon and singles out a situation of secondary disablement as the primary causal factor to it. In giving a typical example, she underscores an example of a wheelchair user from Munyaka who refuses to acknowledge his acquired disability status (because of an accident) and in many cases isolates himself away from the community while loathing the non-disabled majority. Equally, she explains of a trend within some ethnic communities, giving an example of the dominant Kalenjin speaking community in Eldoret, of having entrenched stigma about disability conditions and therefore are commonly unwilling to allow disabled family members to interact with the rest of the community. She however noted that such a situation is accompanied by strong cultural beliefs (as detailed in chapter 2) where such practices strongly shape how disability is understood and interpreted.

The conceptualization of stigma has been widely criticized as being too broad, inclusive and unidimensional to the extent of obscuring disabled realities (Cahill & Eggleston 1995). While agreeing to this critique, Link and Phelan (2001) highlight five key stigma components which are corroborated in this research study. They include labelling or nicknaming, stereotypical differences, separation, status loss and discrimination, all of which are viewed and perceived from a power relation dynamic which encourages one group to disparage the other (Lucas & Phelan, 2012). These forms, widely experienced by PwDs in Eldoret, reveal that enacted stigma is perpetuated only when there is a power imbalance between the disabled and non-disabled individuals whereby the latter tend to have perceived or relative hegemony in the society. Hence, the processes which lead to stigma of PwDs can be seen to be complex entailing the body's differences, how they are evaluated, the subsequent reaction and the social effect it brings. A brief evidencing of these forms of stigma as expressed by participants

is broadly categorized into two namely 'labelling and nicknaming' and 'stereotyping and otherness'.

Labelling which is usually followed by nicknaming is recognising a difference and then assigning a social category or import to the differences (Green et al, 2005). It was a key social element under stigma in Eldoret since most participants felt the labelling was demeaning towards their lives as it portrayed them all but in a negative manner. For disability, the bodily appearance which is different from the perceived norm is recognised in a certain way. Anthropologists Murphy et al. (1998) posit that PwDs are 'caught and fixated in a passage through life that has left them socially ambivalent and ill-defined' (Murphy et al., 1988:235). They further argue that symbolically PwDs are positioned in a liminal state exclusive from mainstream society i.e they are at the margins of social norms and do not fit into prescriptions of normalcy or traditional social categories. In summation, they state that PwDs are marginalised and avoided as if they spread disability and are contagious. On their part PwDs see themselves as neither ill nor healthy and this breeds social awkwardness in public places (Green et al, 2005). Ideally, this sort of stigma on either side diminishes inclusion and thus a deteriorated interaction between both disabled and non-disabled. This awkwardness is visible in most of the participants narratives of their lived experiences. An activist for the disabled in Eldoret highlighted some of the derogations by nicknaming

...we are called names such as *kilema/kiwete* (physically impaired), *kigugumizi* (stammerer) & *punguani* (mentally disabled) [Eldoret disability activist]

According to the activist while *Kilema* or *kiwete* in Swahili are commonly used words to describe physical impairment, using them to label PwDs is derogatory and thus stigmatises them further. As part of labelling, language is a strong element which frames disability and its impact and while it is contested or appropriated by PwDs, it plays a part in pronouncing stigma practices. Most participants referred themselves specifically to their kind of disability e.g 'a wheelchair bound' or 'retarded'.

While stereotyping as a form of stigma is closely connected to labelling and nicknaming, it refers to the assignment of negative connotations to differences evoked by disabling conditions. The frequency of participants highlighting how non-disabled individuals either pitied them or avoided their presence was reportedly high and prevalent. Such kind of discrimination in turn led to more extreme measures such as abuse or violence meted on the disabled. For instance, a female participant from Langas, who has a short stature condition gave an honest description of how at times she was sexually molested and abused because of her condition.

People think I cannot bear children because of my condition, others think of me differently with my sexuality but am used to how they perceive me [LA-03]

As a form of stigma, otherness occurs when people react to PwD differences to the extent of othering them in a senseless manner. Testimonies from this research strongly indicate that disability as a social construct is built from and based on otherness where PwDs bodies are perceived to be different from the rest. The othering processes leads to overt denial of disabled bodies and the subsequent effect on their lived experience which unfortunately results to PwDs being avoided especially when the impairment is visibly extreme. In other words the person is defined based on their visible appearance thus breeding grounds of being eschewed and even mistreated.

The two broad forms of stigma ultimately lead to unbalanced power relation between the disabled and the non-disabled individuals in the society which drives and enacts stigma causing the loss of status and discrimination from useful participation in social and economic circles of life (Green et al, 2005). In other words, those with disability traits wield less power than the perceived normal people thus are in many ways underprivileged in livelihood opportunities and social life. From the participants' perspectives in this research, their biggest concern is the tail end effects of reactions due to the previous stigmatising practices and how it affects other aspects of their lived realities including familial relationships.

Intersectionality and stigma

As discussed in chapter 2, an intersectionality approach is about exploring multiple social categories such as class, gender, age, ethnicity, etc. and recognizing how they are interwoven together affecting an individual or a group of people in a complex manner. It requires recognition of the 'situated experiences of diverse individuals and social groups' and is particularly concerned with how these intersect with various 'structural drivers of exclusion in unique and situated ways' (Rigon & Castán, Broto, 2021:2). Here the issue of stigma is argued to be intimately shaped by intersectional realities, thus emerging from this broader discourse, 'intersectional stigma' refers to how the converging of multiple identities leads to differentiating patterns of stigmatization among distinct PwDs living informally in Eldoret. A perspective that considers intersectionality within the context of stigma 'is vital to understanding the experiences and consequences of living with multiple stigmatized identities' (Turan et al, 2019) and works to overcome narrow interpretations which fixate on a single dimension of an individual or community's identity. In this research, interview testimonies with different participants revealed situations where they were faced with varying forms of stigmatizing practices and experiences in their lives, associated with different categories of their identity

and the intersections of these with wider structural drivers. An example was a short statured woman in Langas informal settlement who stated in emotional terms how people not only sidelined her on the basis of her disability but that it extended to perceptions of her sexual viability, in effect calling into question her gender given that it is tied to reproduction:

given my condition most people in this neighbourhood look at me as not having any worth, to make it worse they do not see me as sexually viable even if I have had children of my own. That makes me sad.

From the above experience the respondent, apart from suffering with a disabling condition, also has to negotiate her sexuality and gender. From her situation, she is seen by some in the wider society as being sexually inactive because of her disability. This has resulted in social and physical isolation, hence affecting her overall wellbeing. Further, she recounts how men mock her and seldom assume she is capable or worthy of lasting relationships. She also explains of how even after having her children, men tend to break up relations with her and subject her single-parenting. This outcome can be read also as a gendered phenomenon which worked to further burden to her disabling condition. Additionally, she struggles with poverty in the informal settlements, deepening her particular challenges in providing for her two children as a single mother. In sum, as a lived-experience the short statured woman not only has to negotiate with discrimination and stigma associated with living with disability but she also has to navigate stigma that comes with assumptions around her sexual and reproductive health which are fundamental to what it means to being a woman within most African cultural beliefs. This is compounded with her gender roles and economic status/class that come with urban informality. This explicitly illustrates how structural forces such as culture and poverty shape the intersection of stigma and identities like disability and gender resulting to social exclusion.



Figure 14: Short-statured woman with her two children

Another similar experience that exhibits a convergence of various stigmatizing identities was echoed by one of the NGO directors working in Eldoret. Here an intersection of disability with ethnic identity, gender and age shape particular processes of stigmatization and exclusion. He argues that

the Kalenjin community do not associate with some forms of disabilities, they do not especially tolerate children born with albinism, mothers of such children are seen as outcasts and avoided in many cases

The above contention from the NGO worker reveals how disability is compounded by ethnicity since the dominant Kalenjin community in Eldoret maintain particular assumptions and beliefs about certain disabling conditions, which leads to added stigma and discriminatory practices. A core example is their assumption that albinism is perceived to a disabling condition that cannot occur to members of their own ethnic group. In other words its presence within their

own group is denied which in effect downplays the existence of albino individuals and their mothers. This questions the value and importance of their existence and their fundamental rights to socio-spatial inclusion. More importantly, and from an intersectionality perspective, the quotation above strongly suggests that there exists additional hierarchies which shape social integration within communities i.e children/women with a disability in the Kalenjin community are often likely to be socially treated differently from men. This demonstrates how stigma in a complex manner overlaps with gender and ethnic identity while at the same time driven by structural forces stemming from the community's cultural norms and attitudinal differences. While this research did not directly engage and examine experiences of any albino individual of the Kalenjin community, another secondary account by a disability activist in Eldoret corroborates the accounts by the NGO worker above. The activist speaks of how children born with albinism are abandoned by their mothers because of shame and fear of being stigmatized as a result of raising such children. Such abandoned children end up in care institutions as highlighted later in this chapter.

The two testimonies, as evidenced above, demonstrate how identities around sexuality, gender, socioeconomic class and ethnicity intersect and how that shapes disability-induced stigma practices within communities. It reveals how various 'stigmatized identities' (Turan et al, 2019:1) influence, in a complex manner, the situated experiences of the disabled in heterogeneous urban informal settlements of Southern cities. It also showcases how stigma in a multi-scaled way has permeated social relations between the disabled and non-disabled and seems to be an underlying and primary cause for social oppression which results in emotional distress to PwDs and their families. This, as explicated in the examples happens at various levels within the social structure, right from the scale of the family, cascading upwards into the community and even into governance structures. As evidenced by various respondents, ethnic profiling which leads to an additional layer of stigma to the disabled, not only stands out as a social issue undermining their living conditions but also shapes the provision of government services in various ways. For example, one of the respondents suggested how stigma triggered by ethnicity led to exclusion of certain groups from COVID-19 social cushions by the state:-

We have had many challenges especially due to Corona. As the disabled we are badly neglected. There was some financial aid from the government to help us in coping with these pandemic times, but it reached only a few individuals

In this case, this particular individual is claiming that government agencies discriminate against people based on their tribal and ethnic affiliation, thereby perpetuating stigma and loss of trust in institutions which dispense services in seemingly exclusionary ways. Such mistrust in

institutions of governance is further exacerbated by other factors beyond stigma as discussed in the last empirical chapter of this thesis. The majority of these statements, however, were from participants who strongly felt that other aspects such as ethnicity played a role in their experiences of social exclusion. They argue that the majority Kalenjin ethnic group who form the majority of individuals in power in the local governance structures in Eldoret tend to be favoured in disability support since the structural forces that come with robust tribal affiliations leads to exclusion of some PwDs from various government services. This recognition is critical and again reveals the significance of utilizing an intersectional approach, and avoiding seeking to understand PwDs in Eldoret through focusing on 'a single framework' of their 'oppression' which in essence are not separate but 'interconnected and interdependent' (Bastia, 2014:239). Again, this is another way of how intersecting identities shape the lives of the disabled since it derails social inclusion instead intensifying marginalization based on factors beyond disability. Although there were varied expressions of how most of the PwDs faced both social and spatial exclusion due to stigma, there was consensus that community spaces such as schools, shops, recreational spaces and churches ought to be inclusive and easily accessed. Notably, the experience of widespread and multiple stigmas in places like schools left most children with disabilities confined within homes hidden by their parents.

Generally, as demonstrated by the shared experiences from respondents in this research, notions and practices of stigma while often examined as an isolated experience, do not occur in a vacuum, most disabled people experience varied patterns of stigmatisation depending on the intersection of their specific disability condition with other social categories such as age, gender, class, sexuality, ethnicity etc. An intersectional approach provides a lens and framework to understanding the various experiences of PwDs with diverse forms of stigmatizing identities. Such a framework rightly posits that 'social identities are not isolated from one another and simply additive, but rather are interdependent and mutually constitutive' (English et al, 2018:3). As such, interventional strategies aimed at reducing stigma must strongly underscore diversity in assessing stigmatizing and oppressive social structures as opposed to focusing on singularized versions of stigma. Nonetheless, most urban interventions including those witnessed in Eldoret, do not always consider these heterogeneous nature of fragile urban spaces such as informal settlements which have diverse characteristics of residents with various competing needs. They mostly tend to rely on a homogenized perspective to planning (see Rigon & Castán Broto, 2021). While vulnerable communities like the disabled are seen as legitimate subjects in relation to urban interventions, their involvement and representation which is marred by elitism, hardly considers the extant diverse disabled voices within the urban (ibid). This in turn creates and reinforces unequal power relations which promote further structural mechanisms, which if not considered in

development planning, is likely to exclude certain individuals or social groups therein. Even when there are attempts to achieve diversity, the approaches are mostly premised on grouping people based on one version of their most noticeable identity (Bastia, 2014:237). Meaning social interventions often stress and put emphasis on a single dimension of people's identity without fully considering the complexity and reality that come with various intersecting identities. For instance, in the cases above social interventions would lump and categorise people as disabled with an homogenous assumption of their needs while failing to account and acknowledge other evidenced aspects such as sexuality and ethnicity.

This research while advancing intersectional approaches in urban studies, on the one hand challenges the current approaches to urban interventions by accounting for a situated experience of PwDs living informally who are affected by multiple stigmatising practices (and other exclusionary social processes). On the other hand it unpacks the structural causes of inequality and social oppression within communities. In other words, it positions intersectionality as what Rigon and Castan (2018) describe to be both 'a mode of analysis of community diversity' and 'a critical praxis to deliver social justice' aimed at improving a people's well-being. The next section discusses inclusive social structures using an example of the *chama* system as an interventional tactic deployed by the disabled to de-escalate stigma.

Informal networks and the *chama* ideology

Informal networks were identified as a vital tool that supports PwDs overcome their common challenges that are ascribed to disabled experiences in informal spaces. An example as intimated above is stigma and attitudinal differences that they must contend with as a daily experience. The support entails moral support, campaigning for their rights, economic empowerment and lobbying for resources. Most of the residents in the three settlements identified themselves to be a member of a social grouping that had the motivation of improving their lives through coalescing resources informally through savings. Generally, informal settlements exhibit a 'complex, self-organising nature' of 'social interactions and relations' that are vital for urban residents so as to adapt and cope with the often-harsh living conditions (Morgner et al, 2020:490). Such self-organised networks can be understood to be reactionary mechanisms that yield targeted collective solutions to the needs of the urban poor (Rahman & Ley, 2020) such as housing struggles, poverty, water scarcity most of which were witnessed in Eldoret's case.

Existing literature have conceptualised informal networks in different ways for instance it is evident that lobbying for resources can be made easier through federated action that is usually boosted by alliances with likeminded partners like NGOs, CBOs and even the local

government (ibid). Informal networks have also been demonstrated to foster resilience within communities, for instance in Imizamo Yethu informal settlement in South Africa, Harte et al (2006) reveal how social networks play a key role in the mitigation of the effects of recurrent slum fires. In Mathare Valley in Nairobi, Morgner et al (2020) equally depict how informal social networks are the backbone of strong networking thinking that is vital for urban planning and development. This section lends a new way of understanding informal networks stemming from the social dynamics in Eldoret's informal settlements among PwDs. It captures and evidences the concept of the *chama* idea as expounded in the next section to unravel the highly complex relationship that exists in disability spaces relative to informal settlements.

The nature and composition of chamas

The *chama* ideology is not a new concept to Kenya's social structures; it has been used to build communities over the years. The word *chama* is originally a Swahili word, which simply denotes a group of people or a party that involves various individuals with diverse backgrounds. The Kenya Association of Investment Groups (KIAG) define *chamas* as

'any collection of individuals or legal persons in any form whatsoever...whose objective is pooling together of capital or other resources, with the aim of using the collated resources for investment' (see KIAG, 2014).

According to Parnell (2001) self-help organisations (SHOs) including chamas are defined as

'associations that share a number of common characteristics: they all have an economic purpose (some may have direct social purposes as well) and they are owned and controlled by the people who primarily benefit from their activities. They are run for the benefit of their members (Parnell 2001:ix)

African communities have a long-standing history of supporting each other when need arises through community savings. Accordingly, chamas are a form of community savings scheme where groups of individuals coalesce for certain periods bringing together their savings while borrowing from the savings for their own economic benefits. They are the poor person's form of a bank, where money saved by members rotate within the group. In Kenya, various ethnic groups in urban places trace these solidarity conventions back to their rural villages where deep social relations were key in the provision of labour in farms (Shipton, 2007). In Langas and Munyaka, there were strong *chama* networks where weekly meetings were held to vent issues affecting PwDs within the two settlements. These *chamas* were constituted by either disabled people or caregivers of disabled family members whose conditions probably render them unable to attend *chama* conventions and thus represented by their caregiver. However, one such participant from Munyaka highlighted how he attempts to attend the meetings once

in a while although transport costs to meetings and the risk of rogue transport means were the greatest challenge. He notes:

I attempt to go for *chamas* may be once in two months, but I have to be carried by a *boda boda* (motorbike taxi) which are not only dangerous but charge very high for their services [LA-09]

Another participant from Langas echoed the above sentiments

I use a motorbike to get to the meetings (*chamas*) but there is a problem there. I once incurred an accident, and consequently I remained at home for six months, to allow my wounds to get healed [LA-03]

While there were challenges attributable to structural issues such as poverty or transportation and how some of the severely disabled were systemically disadvantaged, all the participants contended how the *chamas* directly shape their lives even with the lack of attendance. For example, the above participants relished the fact that most of their disabled friends would always pass information that came out of the meetings.

The significance of the *chamas* was attributable to how they endeared themselves to them especially the consistency of having meetings on a weekly basis. In Boma Turkana, which was much smaller, they had a *chama* setup but it was not active given Covid-19 circumstances. The *chamas* had clear structures on how they were being conducted including having officials and their own constitution, as illustrated by [LA.04], a resident of Langas

We have a self-help group. We do table banking, and we have tents and chairs, which we rent out, and the money comes to our account... It has a chairperson, treasurer, secretary, and then we are known in the county even by the women representative's office. They usually support us. Officials exist, and members also exist [LA.04]

The definitions above mainly position *chamas* as local economic enterprises or community saving groups, however, in as much as that is the ultimate motivation, this study evidences that for disabled *chamas* particularly, the social dimension is fundamentally critical. Mitlin et al (2011) corroborates this social aspect about community savings group. Their finding posits that the practice of some of *chama* groups in informal settlements of the Global South have evolved from the intended financial savings purposes to entail enhanced social relations, consolidate and protect collective assets and reduce political exclusion of vulnerable groups like women, youth and PwDs. In other words, *chamas* are instrumental for marginalised people as they can consolidate their voices to help bring about changes in governance and planning at the local/citywide level. Such an attribute of *chamas* is explicated in the final findings chapter

of this study. The *chamas* as alluded are primarily for group savings which are geared at accumulating finances with the aim of collective responsibility. The processes mainly involve establishing savings in an informal way within a given spatial area mostly in a residential neighbourhood. The *chama* members, often women in this research and other works alike (Mitlin et al, 2011), make small contributions of money within a defined period, either weekly or monthly or in some cases whenever finances are available. While the contributions in savings are sole responsibilities and every member takes ownership of their savings, the monies are managed and accounted collectively by all the members through ad hoc investments and loaning each other at minimal interest rates.

Although *chamas* vary in terms of composition, as mentioned earlier, the types explored in this study were mainly those involving PwDs and their close associates e.g parents or caregivers. Each of the *chamas* had a well-established structure in their leadership as pointed out by [LA.04] above. They also had rules and constitutions that specified how much money was to be saved and the borrowing threshold amongst members. The fact that they have a constitution in the form of officials and rules is a key characteristic, which illustrates a sense of organisation by women who tended to dominate *chama* spaces as an advantage of their own innovative social system. They also had penalties for breaching the rules and regulations, for instance missing meetings, failing to make contributions in time or late attendance attract a penalty of between 50-1000 Kenyan Shillings. The fine charges were never fixed and would be negotiated for instance for the severely disabled members without caregiver representatives, the leaders of the *chamas* made sure the contents of meetings reached them especially those meetings which were categorized as extremely important. While some *chamas* exempted members who had mobility challenges from such fines, a few of the participants felt such penalties were somehow harsh given their conditions. Demonstrably, the *chamas* fore fronted women as the key stakeholders, many of them had up to seventy percent female composition and were the driving forces behind their leadership. Impio et al (2009) attributes the higher affinity of women to *chamas* to their nature of being socially embedded and their zealously of belonging to one another.

The *chamas* act as conduits which tend to assert the strong social ties amongst women in low-income areas, again showcasing the importance of an intersectional approach when in decision-making processes. A study done by Baker (1992) of *iqqubs* a community savings outfit in Ethiopia similar to *chamas*, highlights that female migrants use *iqqubs* to reassert their financial commitments which are incentivised by pooling their little income together for targeted goals. This was apparent for disabled women and carers in Eldoret, whereby the *chamas* emboldened them with a common identity which provides avenues for various forms of support. As an emphasis of the gender parity within *chamas*, it was well discernible that

most of the *chamas* had few men and presented themselves as a gendered undertaking that focus on women issues. An explanation expressed by a participant in Boma Turkana, who was the village head, attributed it to the traditional African societies' setting where women tend to coalesce to solve problems. According to the same participant, *chamas* tend to involve women mostly because of their traditional chores and duties such as fetching water and firewood, cooking, harvesting of cereals etc where in such instances they came together and helped each other.

Contemporarily the *chamas* have mutated to involve women groups being involved in activities such as chicken rearing, buying land and other assets and household products. A significant narrative by an informant from a previous *chama* in Langas showed how they pooled resources and helped members enhance their housing conditions especially during the rainy season where some parts of their neighbourhoods were affected by flooding. While the *chama* as an informal network is synonymous with women and that some men do have a negative attitude towards them, this research to a lesser extent found that some men also have their own existing *chama* setups or have joined their female counterparts in existing groups. For example, a group of wheelchair cobblers in the city who live in Langas have their own *chama* for social support and playing wheelchair basketball.

I only belong to that basketball group, which we founded back in 2006. There is need for such supporting network because of late I have been facing several financial challenges. As a basketball organization we used to help each other, but currently the organization isn't functioning as it used to because many of our wheelchairs got spoilt, and our finances are low...Sometimes we used to get help from non-governmental organizations whenever we won basketball competitions. But ever since the Covid pandemic started, we have received no help [LA-06]

The testimony of the wheelchair *chama* group clearly evidence the fact that apart from the obvious benefits *chamas* have for PwDs, external intervention is vital, and they have to be in *chamas* or a similar group to gain assistance. It therefore shows that the sustainability and resilience of *chamas* are shaped by structural elements beyond the internal organisation of the group. Indeed, alliances are critical for a sustained growth of the *chamas*, or an equivalent community savings group as alluded previously. NGOs and government bodies according to the above testimonial form an integral support system for *chamas* and such relationships need strengthening for the benefit of PwDs. There were evidence of men joining existing *chamas* after the realisation of how their female counterparts benefitted. Notably, in some cases men's powerful status due to the patriarchal nature of society suggested they had more authority in the *chamas* they participated in but this angle was not further explored in this study. Next, the

discussion turns to some of the cross-cutting benefits of *chamas* in three categories i.e. economic, social and political benefits before discussing the challenges experienced as highlighted by the participants.

Locally-based economic catalysts

Just as initially pointed out, the core function of *chamas* especially those in informal settlements is to boost local economies of particular groups who have a common interest. To put this into context, a participant from Langas recounted

Then in that group, if one of us has a need, for instance if one is in need of a wheelchair, we write a proposal and then we give it to them. We handle members according to their situation. We also give loans and grants to those of us who have business, because we do table banking [LA-04]

The views above depicts how significant *chamas* are to the needs of PwDs in various urban communities in Kenya especially those in informal settlements. [LA-04] highlights specifically on how they aid themselves through lending out finances and material support like wheelchairs and other related assistive devices to members of the group. In that sense, the *chamas* become an integral support mechanism in transforming livelihoods through basic economic models. The idea of table banking, a very common informal financial survival tactic by poor communities in many countries seems to work for the PwDs in Eldoret's low-income settlements. The main feature, which makes table banking a unique and innovative financial strategy, lies with the ease of saving and borrowing money. The laborious process (as put across by the participants) of acquiring money from the conventional lending institutions such as banks and cooperative SACCO's¹⁴ is lessened by such informal strategies. High interest rates, the limited control on fixed assets and collaterals that come along with such formal institutions usually preclude PwDs in informal settlements. Equally, the collaterals associated with formal lending pose extended risks for PwDs living informally as penalties are extremely high, making them avoid such loans.

Therefore, the ease of accessing financial aid from their own *chamas* is seen as an attractive incentive. The *chamas* offer a double incentive since apart from ease of access and lesser stringent terms, they lend at interest rates favourable to their members. Mwangi & Ouma (2012) in their study of generic *chamas* found out that people often joined or pledged membership to more than one *chama* setup to heighten their chances of accessing more funds

¹⁴ 'Savings and Credit Cooperative Organizations (SACCOs) in Kenya are non-profit financial cooperatives owned by members and governed by a member-elected board of directors' (Wood, 2019:np)

when need arises. Although that was not the case in the PwD *chamas* in Eldoret which mostly seemed to have singular memberships, the poverty levels in many households meant that not so much could be pooled as savings from members of the various *chamas*. This was mentioned categorically by a participant from Langas who also reified the essence of table banking, loaning strategies and external grants as an integral way of improving their livelihoods through economic empowerment

We do weekly savings but according to PwDs situation, the contribution is somehow low, like we say every week one comes with 50 bob which is 200 in a month, and then we give out the savings through table-banking, issuing of loans so that they uplift themselves, we also look from outside grants so as to promote the money for table banking, that way [LA-07]

As an alternative to their savings, it's evident from most participants that they also seek out grants that can bolster them financially from organisations such as the Women Representative Office. LA.07 further stated

You see the one for NGAAF (National Government Affirmative Action Fund) for the women rep, we got that and bought tents... yes they gave us money and then we bought tents, so we hire them, we usually hire them out [LA-07]

The women representative office in Kenya is a political office, which was formed to ensure more women representation in the political landscape (see CoK, 2010). Later sections of this thesis will explicate the role of such political outfits in PwDs lives; however, in this case, the position of *chamas* is highlighted as a significant mechanism, which can be used by vulnerable communities living informally to acquire resources. The idea of amplifying the given grants by buying chairs and tents to rent out is equally an informal money generating activity which indicates how a group mind-set in a *chama* can ideally be innovative enough and offer financial solutions within communities. The generated money is then loaned out to the members directly covering their financial needs.

Social and political roles of *chamas*

Apart from economic gains, most participants fundamentally viewed *chamas* and *chama* meetings as places where they could seek social refuge and support on disability issues. Stigma and discrimination as discussed in the previous section of this chapter have far-reaching effects to PwDs. The effects of these social realities are minimised via *chamas* in the sense that by coalescing together PwDs challenge some of the disability stereotypes that lead to the exclusionary practices. A parent of a child with disability in Munyaka who goes to *chamas* regularly indicated:

When you are alone you will suffer from stress because of these disabled children. We usually go through many challenges so going to share ideas in *chamas* is beneficial [MU-02]

Social support in view of the above participant is an integral part of *chamas*. In addition the *chamas* also assist sick or bereaved members cope with difficulties. Through the *chamas* members organize events such baby showers for mothers, buy gifts such as for weddings and assist orphaned and widowed members. This means *chamas* are considered as integral unifying faction that binds PwD families within communities together, a participant from Langas shares similar thoughts to MU.02

We usually meet every Sunday, and we meet only for an hour, we basically talk our issues and how everything is going on with one another, we have a chairman and a secretary, so if anything happens, they usually communicate to people and then we get organised [LA-11]

Other participants including MU.02 felt they were advised to be in groups to obtain help from the government and other development agencies. She stated

...of late, we have been told that we must be in groups in order to obtain help [MU-02]

This implied that there was a predetermined notion (which could be true) about getting disability aid from organisations and that being in a group like a *chama* is hypothetically an advantage.

In this region of Uasin Gishu, we have been told to be in groups so as to get help, but still the child has not been helped (by external organisations). We usually meet together and do table banking, which is helpful to us. You can take a loan from there and use it to cater for the child's school expenses, and you can also take a loan to simply buy food [MU-02]

Challenges facing *chamas*

Similar to other organisations *chamas* too had their own set of challenges as shared by some the research participants who were in positions of leadership within the *chamas*. LA.07 an official in their *chama*, the Langas Disabled Self Help Group described a situation where members would take up loans and later default on them putting pressure on the group's financial security. She notes

The other is a loan, but it is very challenging, there is one I once applied from UWEZO fund, for PwDs it has become very challenging, you give someone money and he/she

just says I am a PwD yet it is money to be paid back, so far on the issue of loans I won't dare take it again [LA-07]

The experience above sums up the challenges that come along with group initiatives, causing some of them to collapse or become redundant. Some participants felt that the *chamas* were not so beneficial to them or are least beneficial for their livelihoods. A male participant MU.01 from Munyaka, narrated his experience with his *chama*

Ever since I joined that group in 2018, I have never received any support from that group... Sometimes, we would be given as individuals five chicken or three chicken to come take care of at home. Some survived, while some died. That is the only benefit I received [MU-01]

A further probe into his negative viewpoint revealed that he had not attended a number of the weekly *chama* meetings and had possibly been penalized as per the *chama* rules. Contrastingly, the participant's spouse posited that *chamas* have been beneficial to them and they should actively be involved in *chama* activities going forward. However, it is not to suggest that *chamas* are perfect for PwDs. Some *chamas* can pose as avenues to social ills, for instance some participants would share experiences in other places where rogue officials end up either directly stealing the group savings or engage in corrupt practices thus negatively affecting the membership.

Overall, with the right structures, *chama* groups can become conduits that support sustainability in contexts such as informal settlements. They promote lives of the most disadvantaged people in urban informal settlements where a majority of the disabled people are abandoned. While that is true, as witnessed in the above discussion *chamas* come with wide-ranging challenges. While generally it is not easy to manage groups especially in informal settlements, dealing with disabled members with varying conditions is more challenging especially where rules have to be flouted to accommodate some members at the expense of others. Handling group money in varying amounts and situations is not only problematic but worsened in contexts where extreme poverty is widespread. Another issue is when non-professional personnel keep financial records adding another layer of risk. Finally, since *chamas* exist as informal financial institutions, expected malpractices such loan defaulting which is common even in formal financializations can easily ruin the existence and sustainability of the *chamas*.

Chamas and how they shape disability

The relevance of *chamas* to PwDs in urban informal settlements seems undeniable through the testimonies highlighted by the various participants. To the disabled poor and living in urban

informal settlements in Eldoret, the chama phenomenon to them is a critical pillar that not only enhances their social well-being but also promotes their local economic development. A similar study by Mwiti and Goulding (2018) sheds light on how chamas have been pivotal in empowering women from deeply patriarchal communities in Nairobi slums characterised by oppressive households, gendered exclusions and inequality. Their focus on Mathare and Kibera slums highlights women in chamas whose gendered values intersect with their lived realities ultimately affecting their interventions. In the same way, this section of the thesis briefly accounts how PwDs value chamas and the strategic importance the chamas have given their situations. The overarching takeaway from this argument is that in the disability realm, chamas play a critical role in enhancing the livelihoods of PwDs both economically and socially but the latter where their well-being is supported during the *chama* circles supersede economic gains. In building social networks, PwDs tend to commence to address their common urban problems through sharing of ideas and even tackling urban issues that afflict them together.

The dynamics of disability care in informal settlements

Disability care according to Morrison (2021:1) entails 'a complex set of emotionally felt experiences, bodily practices and social politics that connect people, spaces, places, and things'. In linking this definition to this work, this research sought to understand in a holistic manner both the lived experiences of caregivers or providers and that of the disabled care recipient within their spatial contexts of the home in an informal settlement and even outside of the home in other care spaces. Care geography has extended beyond the medical, and has been considerably researched in the Kenyan context (eg Geissler 2013) and elsewhere. A new way of conceptualising care through social relations within spaces posits a different way of looking at it with relevance to contexts such as urban informalities in the global South. In this section, a discussion of the care situation for the disabled in Eldoret's informal settlements is presented so as to build on existing approaches within geographies of care (which have received increased attention in the last two decades) in an effort to better understand the concept as a key component that shapes disability. The need to understand the elements of the geography of care and the way it is fashioned and transformed across diverse contexts has been emphasized by Hanrahan and Smith (2020) and Middleton and Samanani (2021) who point out the urgency to theorise care beyond the global North and the need to suggest new and radical ways of thinking about care within the social world respectively. As noted by Hanrahan (2018:63) 'although there remains a general lack of research focused on care in the global south, researchers have explored' expansively the specific impacts of global social phenomena such as the HIV/AIDS epidemic in sub-Saharan Africa. This empirical analysis on the disability care situation in Eldoret's informality aims to build and move beyond such

research by highlighting some specific experiences and strategies informal households go through and adopt to fit in with their disability needs. Such an understanding about care geographies underpins the overarching theoretical argument for this study which is to flesh out disability components within a southern perspective and mindset.

At the onset of this empirical research and while sourcing background information about the care landscape in Kenya, it was apparent from one of the key informants that there is an existing bias in knowledge produced locally between formal health care provision relative to informal care happening in homes of the disabled where emphasis has been put on the former. Yet, the latter according to the data generated from most of the participant's is the most dominant especially within urban informal space where precarity is an everyday experience affecting processes of tending care to PwDs. This corresponds with arguments by Parr (2003) who noted that care issues have mostly been attended to from within medical geography, whereby institutional practices which were either formal or semi-formal dominated the understandings of care, and primarily probed questions of access to care, its unequal distribution and the nature of its governance. Although, some domains of care e.g parenthood or home-making do have longer legacies within geography of care, their framing however has been discrete instead of being taken as forms of care as they predominantly feature in situations of informal care (Middleton and Samanani, 2021).

Indeed, the understanding of care as expressed by participants in this research relates to the medical model of disability as discussed in chapter 2 where notions of care are built and founded on health systems. Meaning systems of care are at the core of disablism since they can often promote and advocate for ableist structures and the thinking of (re)constructing disability to normal status. On the flipside, scholars of disability who premise their arguments on the social model of disability and by extension the CDS do perceive care as a decision to be made by and with the disabled person as a right. Specifically, Rogers (2016) argues for a model of disability which enshrines the ethics of care built on sustainable social relations between both the disabled and the caregiver. In view of that disability care within the context of an informal settlement is clouded with complex relations of the home and beyond. Kenya's population is growing unprecedentedly and disabled people (due to aging, accidents or diseases like HIV/AIDS and cancer) in need of care are growing by the numbers lading pressure on families for informal care at homes and both the state and non-state actors in providing up formal care services for all groups of PwDs.

While care in formal institutions is an uphill task (due to cost burdens), an interview with an owner of a care-home for children with disabilities suggested that most families resort to ad hoc ways of caring for their PwD members including homecare, organised informal institutions,

neighbourly or friendship-based care. All these tend to be incidental and do not involve any payment. Meanwhile care in basic institutions such as schools and children care centres involve payment. The latter cater for the needs of abandoned children with disabilities who fall victim to family disputes that brew from disability as elaborated in chapter 2. The below vignette with one of the participants in this research illustrates the various dynamics that come along with care for PwDs in informal settlements. While reflecting on her lived experience with short stature condition, the participant who hails from Langas narrates

Another challenge is that, as a PwD, sometimes you can give birth to a normal child. Then sometimes a normal person can give birth to a disabled child and wonder whether they should throw the child away or what not. *Such parents bring up the child in a care-less way.* They feed the child, but do not consider that the child needs to go to school. Because they have no experience with PwD, they neglect that child. If a child is disabled, there is a chance of treating the disability if it is noticed early, and if the parent acts promptly. So, if people were aware about how to handle disabled children, the situation would be much better even when caring at home... Sometimes a child can be born normal, then at around seven years of age, a disability sets in. Then life turns on a dark channel. The parent knows not what to do. Some even contemplate committing suicide. It is good to be mentally prepared so as to handle such situations [LA-04]

The views by LA.04 shows how important care is for disabled persons whilst at the same time expressing how care is burdensome and problematic to families as it strains people to the point of committing suicide or infanticide as she narrates. Additionally, construing from her views, there is a belief in medical interventions within the Kenyan context as the primary solution and medical professions wield immense power over conditions of disability. Both articulations of care draw on individualistic models (i.e charity and medical) discussed in chapter 2. According to her although care through health systems is preferable and that formal care provision is fundamental many practices of care are provided within homes meaning disability care begins at home and in many cases ends there. It also portrays the care-less situation in disability spaces which at times as elaborated by the participant leads to exclusion.

PwD care practices in Eldoret's urban informal spaces

The care situation in most of the homes visited during the fieldwork expeditions mirror the above sentiments by LA.04. It was challenging for both the caregivers and the care recipients alike; care was not being adequately provided in some families while in others there was an extreme sense of resentment and despair about the process in turn affecting the well-being of caregivers to the point where suicide or infanticide as expressed by LA.04 was a tangible risk.

While care is at times inevitable, people usually do not always welcome it especially if there is a feeling of oppression and power imbalance (Raynor & Frichot, 2022). Interviews highlighted that while on the one hand the experiences of being cared for by someone else brings forth room for exploitation and manipulation especially when someone's dignity or way of life is compromised on the other hand it is accompanied with feelings of ambivalent affection. A participant in Munyaka while describing how his neighbour treats her disabled child illustrates such ambiguity in care for the disabled:

In most of the days she stays at home taking care of her disabled son, carrying her out to sun bath. She has never been the same again before she got her son who was born disabled, nowadays she interacts less with us...am worried at times because she locks the boy inside the house [anonymous respondent]

The above experience highlights how care challenges at times can produce a deprived way of life (through confinement of the disabled child) but at the same time caregiving creates havoc to caregiver's life both socially and economically due to their loss of livelihood opportunities and social relations at the expense of care. Milligan and Wiles (2010) frames this understanding in a way that we must look and draw distinctively from both lenses of 'caring for' and 'caring about' and that geographers have to synthesize both forms of care in how they are distributed. Care processes are not only shaped by physical spaces but are also dictated by social and emotional dynamics where each form of spatiality generate new relationships which eventually define the care experience (Middleton and Samanani, 2021). This was the case in Eldoret as the participant above illustrates a scenario where social dynamics, space and place all contribute to strongly shape the care situation. Collectively, several other geographers have worked on care scholarship and have shown how place and space are integral to both the caregiver and recipient of care (Morisson et al 2020; Miligan 2000). Although the traditional focus on both the spatiality and relationality of care practices supported by the state through social support schemes are still dominant, a focus on non-traditional household care arrangements is on the rise (Raynor & Frichot, 2022). In this research, while respondents adopted varied care practices and strategies including tying and locking up the disabled as a complex part of care practices, they were mainly categorized into two namely care at home and in institutions.

Home-based care

The wide spectrum of participant's experience of care was best captured by following closely how members within households related to each other given disabling conditions while at the same time looking at how they negotiate disability care given the existing realities of their housing e.g the size, security of tenure and other services. Scholarship on the geography of

care frequently depict the home as a particularly vital space for care where the dynamics of caring for and being cared for are imbued in most cases with emotions and interpersonal connection of the body (Middleton and Samanani, 2021). The home is the basis for care, meaning how the home as a space performs has a direct impact on caring for the disabled. The care practices within the homes happened within inadequate and sometimes makeshift housing making that process a constant negotiation of recreating a suitable space within the home. A participant in Munyaka encapsulates the struggles of caring for disability in the home

Caring for my son is not easy here. We have two beds in this room. I can't sleep in one bed with him, you know because of his condition. In fact, if it were possible, I would take another room. But I am not able to do that [MU-07]

Fundamentally, in Eldoret it was observable that while the home as a space for care was integral and the social relations extremely vital, given the poverty situations that impeded the majority from outsourcing care, most families relied on their relatives as home-care providers. This was evidenced by a couple in Munyaka, the spouse illustrated how she has to prioritize her blind husband care duties:

There was a time when I had to be away because of some problems in the village. I left him with my mother, who helped him during that period. But whenever I leave, I don't stay there for long [MU-01]

Given the circumstances of her disabled son, participant MU.07 is forced to provide care within their one-roomed house even when ideally, she would sleep in a separate room away from her grown up son. In this case the disabling conditions affects her freedom to live independently and privately influencing the relationship she has with her son. Although, she has to closely attend to her disabled son, the fact that they own and live in a one-roomed house adds another layer of complexity. This complexity is showcased when care intersects with disability and the space within the home to produce social relations beyond the norm which forces a mother and a grown-up son to cope in the same dwelling place. Ideally, from the participants views, her son who is 21 years and regarded a grown-up was never to share the same living space with her at least according to her privacy, traditions and social way of life. Thus, disability care as a practice within informal or poor quality homes breaks that social norm leading to a new way of negotiated living that perhaps is uncomfortably awkward to both the caregiver and recipient. While home-based support was commonly rendered via relatives, extendedly it also happened through neighbourly and friendly relations, which are built out of deeply nurtured and revered social interactions within the informal settlements of Eldoret. While this conceptualisation of care may be less common in more formal spaces which are more privileged, in informal settlements it is an incidental practice as people live close to each

other to the extent of sharing almost all of their lived experiences. An illustration of a woman with a disabled children (son and daughter) carries with it the testimony of such care relations

Everybody in the neighbourhood know of my disabled children, there was a time one of them was sick, I had to leave my daughter with a friend who lives not far from here, we help each other here in our neighbourhood [MU-06]

Raynor & Frichot (2022) posit that the 'informal care' or care not formally structured is practiced without any form of payment. The findings here evidence the same where homes double up as care sites and relatives and friends become secondary custodians of care. Unsurprisingly, this suits the prevailing conditions within informal settlements mainly characterized on the one hand by a lack of affordability given poverty levels and on the other hand strong social relations that enable extended members of homes including relatives and friends taking care of disabled people temporarily filling the space left by the primary caregivers. However, while this showcases how informal settlements have strong social bonds, the situation varied from one informal settlement to the other given the extant dynamics such as ethnic composition.

Institutional-based care

Although most of the care provision was informally provided within households as the preceding section confers, institutions such as schools and churches were pivotal as care destinations for PWDs especially children. Several respondents alluded to intentionally taking their children to both regular schools and specialised ones for the sole purpose of care either on a daily basis or for an extended duration. One participant in Munyaka highlighted how they take their son to a neighbourhood school fundamentally for care

He is just one of those children who we take to school, for the sake of avoiding having them here at home. You know it is better for him to be in school [MU-02]

While she added that the act was intentional for care, she also lamented about the scarcity of disability specialized schools which she felt the state has not provided enough since the available ones are located in far-flanked areas in other towns. The above experience meant that the provision of care was being imposed on regular schooling institutions with no specialized disability care structures. While the parents interviewed felt their children had the right to attend school with the rest of the children, the institutions felt the state had not prepared them to handle disabled children. Although such could be read as a political issue it directly shapes care since both the disabled children are negatively affected by existing spaces in the institutions which do not cater for their needs.

Some participants alluded to taking their disabled children to the few specialized institutions in the country albeit they had to foot the significant costs that came with it. While describing such care condition in schools in Kenya, a mother to a mentally disabled boy in Munyaka explains

Currently he is at home. He was in a special school, Kapsoya which he was being taken care of. It is now a year since he left that school because I lacked fees. I am now looking for a polytechnic for him, so that he may start learning to do things on his own. I was told that there is such a polytechnic for the disabled far away in Bungoma (a smaller town in Kenya) [MU-03]

The literature on care geographies as argued by Raynor & Frichot (2022) indicates that whereas institutional support by the state is generally on the decline, and that home-based care support is quickly becoming popular. This is expressed by the above participant who juggles taking care of her son in Munyaka while trying to look at the right institution where his needs will be aptly accommodated with care being the number one consideration. She underscores that there is need for the state to provide more of the specialized schools which then would deter people from taking their children to regular schools. The insufficient institutions in the country for disability care and the lack of trained personnel in the regular institutions are the key issues that make this type of care practice unpopular although it has relevance as highlighted above. The relevance of institutional care relates to the charity model of understanding disability where disability is viewed as a burden in society and institutions in this case become refuge places and a solution to disability as a problem.

Gender relations and care

Many participants' care experiences demonstrated that they heavily relied on informal care at homes or from neighbours as described in the previous section, meaning disability care seen mostly as a burdening social process is strongly shaped by household and home relationships where gender is an imperative element. The majority of carers of the disabled were women (mothers, grandmothers, female siblings) evidencing the gendered nature of disability care. The gendered phenomenon can be traced back to how parenting and homemaking is structured along feminine lines especially in African societies where mothers and daughters are assumed to be care takers of the home. Thus, like many other societies (even in developed nations), women tend to out-number men in care-related chores including disability care as witnessed in Eldoret. Adherence to this stubborn norm shows the social expectation within the context but may not necessarily imply the preference of an individual.

Women in general, keenly felt the long-term needs of disability care and indeed bore the double brunt of caregiving and in some situations as family providers in their various households. In notable cases single women were taking care of their disabled children with fathers significantly in relation to care duties. This clearly led to stressful and depressive situations amongst some of them especially the mother caregivers who tended to combine so many roles with those of care for their disabled children. A number of them regarded themselves as full-time stay at home women and were sole caregivers to their disabled relatives. One of them who hails from Langas and is a single mother to a mentally disabled son noted:

Besides the expenses for the other children, my disabled child has to be well fed and taken care in a special manner. Also, consider the fact that I am a single mother and I solely depend on my own hustles [MU-02]

Porter (2011) has argued that although various scholarly works reveal women as experiencing extended restrictions that constraint their abilities to participate in daily activities, restrictions that are entrenched in cultural traditions as discussed in the next section significantly inhibit the unlimited participation to their routines. For disability care specifically, the long-term effects can be devastating in so many ways for families in the low-income neighbourhoods. Given the important role of women in informal care for the disabled within families, their involvement in the labour market is usually affected negatively thus increasing the risk of depending on others for financing basic needs, heightened poverty and exclusion. Additionally, women participants in this study experienced other economic impacts such as the lack of transport and medical expenses for disabling conditions, lack of job opportunities and overall poor living standards.

Elsewhere, there were several respondents who were older women and grandmothers and had been forced to become caregivers to disabled children of their grandchildren. For example, there was a case of a disabled child who had been abandoned by a young mother who fled to the capital city leaving behind her grandmother for care support for her disabled child:

Today I was told that a girl from Langas had gone to Nairobi in search of work and left her disabled child with her grandmother [LA-05]

Another similar case was reported by a social worker who told of a family where a grandmother was left to tend for two disabled and four other children who were left to her after the death of her son and the wife through HIV/AIDS epidemic:

I know of an old woman who takes care of about six children two of whom are disabled, who have to go to school and who have to be fed...the breadwinner for that family is the old lady who is about 70 years. We usually help her whenever we can, for example by providing uniforms for the children. Such circumstances are a big challenge [LA-05]

In as much as women were the primary caregivers in homes, men as described by LA.06 do play a role in care issues, albeit indirectly, in fact some specific roles such as provision of money for care financing were a prerogative to men.

I have a husband. We help each other to take care of our disabled son who is our firstborn... we struggle with life in order to take care of him, my husband buys his drugs, food and also pays for his school, I tend for his home needs [MU-02]

Work on male caregivers through research by Giesbrecht et al (2016) and Giesbrecht et al (2019) showcases men's caregiving experiences towards family members with disability conditions in Canada. They offer a contrasting situation with the one witnessed in Eldoret where most men were practically missing in homes as spaces of informal care. However, in Eldoret, a few of the men seemed to play roles directly of caregiving and a further investigation revealed that men of the Agikuyu community, who were the majority in Munyaka settlement, had directly played into disability care roles as compared to the other communities including the dominant Kalenjin community (in the larger parts of Eldoret) who seemed to distance themselves from home care roles. Ethnic and cultural backgrounds are thus significant in shaping men's involvement in disability care. The consequences of care, however, do impact the men in the long run, for instance Hanrahan (2018) in her work in Ghana, sheds light on the relations between daughters and their parent's dependency once they become elderly where they must negotiate such care roles with familial labour. In that case, there is a significant change in women's labour where the end results are a strained relationship with their husbands. By this example in the sub-Saharan region, the social and material reorientation which happens in families once care is enacted is showcased.

The gender dynamic which to a large extent tended to define care issues for the disabled, intersects with other social issues to further define and shape care in informal settlements. Such issues which include the age of a caregiver, marital status and the household position distinctively defined care roles and ultimately shaped the lives of the caregiver and the recipient. This highlighted the social framework against which care in families with PwDs was defined. The discussion in this section showcases how care is a fraught process that involves managing a myriad and sometimes conflicting/competing roles. Meaning once care is constituted in any family, material and social relations do shift to a different status. As a part of these intersecting social structural strands, cultures too impact on how the disabled are

taken care of, for instance in some communities' men were tabooed from taking care of children and helping in housing chores. While this trend in most communities in Africa is driven by deeply sited forms of patriarchy, the cultural tenets weigh strongly, the next section briefly looks at some of these cultural tenets and how they shape PwDs lived experiences.

The place of cultural traditions in disability spaces

The PwD Act (2003) (GoK, 2019), the main legal document that enshrines disability rights in Kenya indicates that cultural relations greatly shape how people perceive the disabled and has been a barrier that they constantly struggle to overcome. One of the clauses in the act captures how culture can dispense harmful practices to the disabled, it states

Harmful practices include behaviour, attitudes and practices based on tradition, culture, religion, superstition or other reasons, which negatively affect the human rights and fundamental freedoms of persons with disabilities or perpetuate discrimination against such persons (GoK, 2019)

Although negative cultural connotations about disability are widespread as stated in the act, some cultural practices admonish negative attitudes towards disability conditions and conversely seek to protect the disabled from harmful social practices. This means culture is an ambivalent construct which shapes disability in both ways as discussed previously in this thesis. Using participants views the negative cultural practices are defined while making a connection to how such practices shape their social relationships and their environments particularly the urban informal space. The demand for the broader inclusion of PwDs into society is a new discourse that is linked to African Christianity (Clausnitzer, 2021) for instance as a cultural practice. 'In some African cultures, the concept of disability, as a distinct and recognisable category, does not exist' and tends to be mostly alien to a number of communities (Ogechi & Ruto, 2002:64). The uneven manner which culture, religion and medicine position and define disability is a thematic issue constantly addressed in this thesis. With the seeming paucity of scientific information that explicitly explains the causes and definition of disability in most countries within the Global South such as Kenya, communal narratives have emerged to explain the presence of disability (Bunning et al 2017). For instance, among the Nandi community who form the majority of the population in Eldoret town, a woman who is impaired, at least as per the definition of disability in both North and South, is not considered to be disabled if she can give birth unlike a woman who cannot give birth due to infertility. These kinds of narratives underpinned by strong traditional beliefs and practices are then handed down from one generation to the next and affects how PwDs perceive themselves and also how the society view and respond to disability situations.

In the process of carrying out this research study, although not envisaged as part of the inquiry, it was evident that disability situations were closely related to and intertwined with strong cultural practices like religiosity, spirituality and ritualistic activities which have indeed been underplayed by the hegemonic theories shipped from the North. Failing to engage and understand the disability situation in Kenya based on cultural practices, would amount to omitting significant philosophies that are used to cope and live with disability especially in the context of Africa where culture past and present is largely endeared in the social fabric. That further reifies the need and relevance for a southern theory lens when trying to understand disability in global South. In building to that, respondents in this research highlighted religion and spirituality as the dominant facets of culture that played fundamental roles of defining the lives of PwDs and the understandings or misunderstanding from the local context about the concept of disability. The argument is based on a couple of cases in the research data that highlight the particularities of religion and spirituality in defining disability.

Religion

Religion is highly regarded in Kenya and therefore given its value to people's lives it became a critical finding, which featured in this research. As alluded in chapter 2 of this research, societies in Africa closely align to religious beliefs from Christianity and Islamic doctrines (Ojok and Musenze, 2019). In Eldoret, a good number of the research participants kept referring to God and their belief in His word (found in the bible) and how He is aware of their current circumstances. For example, within the Turkana tribe who are the majority of the squatters in Boma Turkana informal settlement, children with disabilities are perceived as God's gift to them and they ought to take care of such children if they are to avoid God's wrath and vengeance. An informal interview with a local pastor in Munyaka highlighted how many parents took their children with disabilities in for prayers in the hope that they will be healed. He narrates of the kind of faith that the parents have for divine healings upon their disabled children as one which keeps them believing in prayer. Further, the pastor admitted that he had never witnessed any disabled person who genuinely got healed apart from televised pastoral events in the local media. In the Kenyan context, the practice of healing through prayers is featured in most religious organisations. Christianity, which was the dominant form of religion practiced by most of the participants, sees disability as an anomaly in need of cure and fixing just like a medical condition or illness. This feature then pits its understanding of disability at odds with models such as the social and rights-based models as discussed and conceptualised in chapter 2. The practice of seeking divine interventions and healing of disabling conditions was common since most of the interviewees indicated that they had at least once attended pastoral sessions, crusades and gatherings with the expectation of

reversing their disability status just as the local pastor alluded. A male respondent from Langas highlighted

In 2010 an evangelist from abroad came here to Langas and prayed with us offering healing of those who were sick and even wheelchair users [LA-03]

Similar to the local pastor from Munyaka, it was unclear from the participant whether they received healing or not but his apparent condition suggested that these healing practices were futile. Beyond healing, disability is religiously observed paradoxically, both as a gift or a curse. Some participants observed that their disability could be as result of a curse from God while some mentioned that the disabling conditions of their relatives was a Godly manifestation and therefore was a blessing to their family. In fact, if in situations where a PwD dies, a participant in Langas strongly believes that it was the will of God for the death to happen

So, it was so difficult for me. In fact, when she died, it was because of God's love and mercy. He saw it fit to relieve us of that burden which was a blessing to this family [LA-06]

Demonstrably, such thoughts which allude disablement as an act of God, is an acceptance which showcases a stoic belief. Meaning disability as incidentally something beyond the control of human beings. This is not however to say that biological and medical involvement in disability is less considered as compared to religious intervention. Whilst medical intervention from the respondents seem not to provide real comfort, a religious belief that disability is subscribed to a supreme being proved more fundamental to PwDs and their caregivers in Eldoret. According to Mugeere et al (2020), theological studies about disability have explored the various ways in which religion has engaged (or lacked to) with disability notions. They describe two facets of how disability is viewed from a Christian perspective which relate to findings of this research. First is how disability is conflated with sinning and the notion that it depicts a form of punishment from God for wrongdoing. This ultimately leads to PwDs being subjected to stigma based on religious grounds. The second interpretation ascribes disability to a form of suffering similar to the Biblical saga of Job whose long-term misery signified obedience to God. This finding on the role of religion on PwDs is illustrative of the significance of the southern theorization of disability (detailed in chapter 2) where religion as a key segment of cultural practices defines and shapes disability especially in the African context.

Spirituality

Spirituality is a relationship between an individual and what excites him or her with which she or he has an emotional connection (Donald 2006). According to Ojok and Musenze, (2019)

spirituality and religion are not synonymous with each other: Although spirituality is necessary for religion, religion is not necessary for spirituality. A few cases in the data highlighted spirituality as a central theme in the lives of PwDs. Responses from interviewees pointed out that spirituality is a pivotal aspect to the lived experience of PwDs and thus plays a role in improving their quality of living. The discussions with research respondents also showcase that possessive nature of spirituality does impact on the feelings and well-being of disabled people and their caregivers. In a specific case, a mother to disabled child in Munyaka found comfort in supernatural belief which she says helps her to negotiate the disabling condition of her children. Since one of her children suffers from epilepsy, she rarely uses medical interventions as a diagnostic process instead she places her belief in spiritual forces as the solution for a reversal to perceived normalcy. The dominance of spiritualistic interpretations and practices in relation to disability even with proven medical prognosis was common to most of the respondents, especially the older generation.

Consequently, respondents such as spiritual leaders alluded that spirituality empowers PwDs by making them confront the negative attitudes they encounter in within the 'ableist' society. It provides a platform to place blames that come with disabling situations both on the side of the disabled person and perpetrators of negative disability notions. In other words, it provides a framework of interpreting the negativity absolving it to spiritual intrusion and possession. Schulz (2009) found that PwDs use spirituality to describe the disconnection they experience with regard to their relationship with others, to the rest of the world and the intimacy to a greater power. In a way, they express spirituality via their actions which would be aimed at bridging the social disconnection they undergo. In extremely difficult situations, respondents of this research also mentioned that they are at times seen to be cursed or in possession of demonic powers. The examples earlier discussed under stigma of a woman who had three disabled children and the person with albinism also evidences spirituality. Since people believed they were cursed in some way because of wrongdoing, such a notion propagates the negative impact of culture through spiritual belief. Wachege (2012) observes that, in many African communities, the fear of curses and cursing is real.

Apart from the odds that come with curses and related supernatural beliefs, spirituality also bears some positive attributes as discerned from the data. PwDs indicated that spirituality provides them with embodied resilience which is useful to negotiate and cope with that negative social environment. This was evidenced by a mother to as disabled boy in Langas who strongly felt that her child being born disabled was an omen for greatness bestowed to her family's ancestral fathers.

When I got this child, I could not believe it but again I thought of it as a blessing from the ancestors for good fortunes, in fact his grandmother came the other day to bless him as a gift to the family [LA-07]

The situation above highlights how the belief in supernatural forces shapes disability as it enhances resilience and the ability to cope and keep going. In a similar endeavour Greeff and Loubser (2008) explored how spirituality and resiliency relate amongst the Xhosa in South Africa. They reveal that spirituality made the disadvantaged families cope with issues. They culminate by highlighting that the more spiritual a family is the more resilient they become and are able to endure varying challenges.

Conclusion

The findings in this chapter have shown how social-cultural realities often adversely shape disabled people's lived experience in informal spaces within Eldoret, and what PwDs do to overcome this situation. The realities are further shaped by spatial and economic conditions of poor neighbourhoods, entwining with poverty creating a multi-layered set of perceptions which either debunk or worsen how disability is conveyed and understood. Stigma which stems from misunderstanding and misrepresentations of the disabled creates attitudinal differences which often leads to discrimination, marginalization and overall exclusion. The experience from the participants also revealed ways of overcoming stigmatizing practices. One of the key strategies they have used is entrenching their social networks through the use of *chamas* which provided a critical platform for sharing knowledge and experiences of how to overcome stigma and its impacts. As a spillover effect these *chamas* have then morphed into strong local economic actors which enhance empowerment and improved living conditions of PwDs through informal financial practices where *chama* members borrow and save money. The *chamas* provide important spaces to convene and to manage social, economic and political situations that affect them as their strength lies in their unity in otherwise often-oppressive spaces.

The arguments in the chapter have also sought to demystify how care in the context of informality influences the lives of disabled people. While realities of poverty meant that the disabled mostly depended on informal home-care services provided through family, friends or neighbours, institutions such as local schools and churches were key players in the care geographies of the disabled in informal spaces. However, in many cases the practices blend into each other forming a hybrid care approach. The participants expressed how they would take their disabled kins for institutional services when resources were available and then turn back to homecare when they run out. Importantly, that is not to insinuate that institutions of care were readily available within the informal settlements. On the contrary specialized care

schools were reported to be very few within Eldoret, and respondents would resort for instance to taking their disabled children to regular schools posing additional challenges to such institutions which are less prepared for disability care. Apart from care, the position of cultural traditions within disability spaces has also been discussed in this chapter. While medicalization of disability is still rampant in Eldoret and most other parts of Kenya, people equally construed their disability through religious practices such as Christianity and spiritual beliefs like superstition. These practices, especially those grounded in African spirituality are not commonly considered within western accounts of disability yet they are sacred to many of the participants. Overall, the findings in this chapter indicate that disability knowledge can be constructed using local realities. The next chapter explores the spatial conditions shaping disabled lived experience in informal settlements.

Chapter 6: Spatial and material elements in disability spaces

This chapter explores the second set of empirical findings and addresses the second question of the research- How do PwDs adapt and negotiate the various spatial and material conditions within urban informal settlements? To respond to this question, interview responses from both PwDs living in the informal settlements and the elites or experts working in the planning/housing departments at the county government and the officials of NGOs were examined by way of thematic analysis as described in the methods section. Fieldnotes, sketches and photographs taken through observation and transect methods and analysis of documents relevant to the situation of disability in Kenya were also central to the findings discussed in this chapter. The primary argument in this chapter is that the spatiality of informal settlements has fundamental impacts on the everyday life of PwDs and they therefore have to find ways to adapt, negotiate and cope. The physical conditions within informal settlements deter them from fully participating in social, economic and political issues as engaged citizens thus disenfranchising them. The analysis of these conditions forming the key sections of this chapter, centre on housing, water and sanitation which as evidenced by the data were the key spatial components that shaped lives of PwDs in the informal settlements.

The first section which details the housing experiences of PwDs in Eldoret's informal settlements, begins from a general viewpoint of the issue and then funnels down to informal housing relative to disability. The discussion here resonates around the different types of PwD housing which is mainly informed by the mode of ownership or tenure. The section concludes with a summation of the various housing challenges and struggles that PwDs undergo. The second section discusses water problems relative to disability where the core argument focuses around the available water infrastructures and the challenges to accessing water from a disability perspective. Finally, sanitation which was identified as another integral spatial component for PwDs is brought to the fore in the last section of this chapter. The key argument here being on sanitation facilities and the barriers to a healthier environment within informal settlements in the lives of PwDs.

PwDs housing experiences in informal settlements

From the data generated, housing is perhaps the most basic feature of urban living as it shapes and frames people's daily experiences and also give physical character to a city. Specific to disability, housing is a fundamental issue to the lives of PwDs and especially for those participants who live in extremely disadvantaged areas within the informal settlements where existing conditions are poor, access is an issue and at times the absence of shelter is dominant. As such, it was on the one side frequently mentioned by the research participants as a concern that shaped their lives and on the other, they were starkly observable features

that affected their everyday living experience. For instance, many of the participants complained of the sizes of their houses in connection with their disability situation with limited possibilities of changing the situation—a critical finding which will be explicated in later sections. Under the broad theme on housing and disability, empirical findings in the form of typologies and challenges experienced by PwDs as far as housing in informal settlements of Eldoret is concerned are presented and discerned in this section. This section in sum argues that existing housing realities in informal settlements of Eldoret have extended effects to the disabled which produce particular geographies of disability.

Typologies of PwD housing in Eldoret

From a general standpoint, housing in Eldoret's informal settlements is a blend of many features apart from Boma Turkana which displayed a homogenous character in the materiality of the houses. Meaning most of the houses were constructed using the same materials i.e mud-walled houses with corrugated iron sheets as roofing. Low-lying temporary houses made of mud walls and iron sheet roofs were the standout feature and was the most recognizable theme in the three study sites. To a lesser extent, iron sheet walls were used in some sections while in others natural stone and wood were adopted as construction materials. In many cases the households were communally organised where a standard plot (50 feet by 100 feet) could accommodate several single rooms. Importantly, apart from Munyaka which had pockets of storied houses, low-lying housing as alluded was the dominant characteristic. This implied that vertical scaling as an issue affecting disability housing experience in many cities including the capital city of Nairobi and its informal tenement landscape (Huchzermeyer, 2007; Mwau & Sverdlik, 2020) was not a dominant concern in Eldoret. However according to one of the planners interviewed, current housing trends suggest that as the city grows tenement housing is foreseeable in the future.

Specifically, housing types of the disabled in Eldoret's informal settlements were shaped by a number of factors key amongst them is need which is defined by the extent of the disabling conditions. Another important factor which will be explored in the next section is affordability. The latter shapes housing choices such that the higher the level of affordability the more convenient the housing type. PwDs housing needs varied according to their impairment meaning they do not constitute a homogenous group. Every PwD had varying needs and that determined the level of support they receive especially from their family members whom most acted as their care givers. The needs ranged from none at all where some were able to fend for themselves to multiple layers of complex needs which called for full-time dependency. For most participants it is this level of need that shaped the kind of housing they lived in, for

instance a short statured PwD in Langas narrated how she looks for housing that have lower doorknobs or locks to suit her

It is good (her house) because it is near the road, and then there is water. Whenever I migrate, I consider the availability of well water and tap water, the state of the toilet and the height of the door locks. If the height of the door locks is too high for me, I can't move into such a house [LA-04]

This is a classic illustration of how a particular disability condition shapes housing choices and subsequent type and characteristic suitable to an individual.

An experience that mirrors LA-04 situation was witnessed in Munyaka where a mother to a mentally disabled child highlighted how she prefers housing units that are quieter and those that occupy individual plots because of the nature of her child's disability.

I pay rent. Due to the condition of this child, I can't live in the same compound with other tenants. I had to look for such a house as this which stands alone in its compound [MU-04]

For [MU-04] above her child's needs forces her to look for housing detached from other houses whose inhabitants might not tolerate or struggle to understand and come to terms with her child's condition. This limitation in housing choices is an example of the stigma practices discussed in the previous chapter. For such special case housing she asserts, cost is a primary issue thus tying back to the affordability component of housing. Balancing the need for certain housing types given one's disability and the capability to afford was a significant issue which PwDs grappled with on many occasions. For example, a physically disabled person would struggle to live in housing that has steps on the door, yet this style of housing may have been the least costly. The most common housing types occupied by PwDs in Eldoret were shared rental houses, caretaker housing schemes, and owner-occupancy housing all of which had various dynamics as discussed herein. These housing types were mostly characterised by materiality where owned houses had better features that could accommodate the PwDs' needs better as compared to rented units.



Figure 14: A short statured participant next to her house (Source: author)

Shared rental housing

Most PwDs lived in shared rental housing in Eldoret's informal settlements which meant that they were mostly tenants and their properties had landlords who either lived within their household premises or outside. On the one hand the shared housing schemes in informal settlements was least preferred because of their rigidity in terms of accommodating PwDs needs as alluded by MU-04 for instance, since they are initially constructed without considering them as possible tenants. On the other hand, they are the most affordable for them as is the trend with most people in informal settlements where land and subsequent house ownership is an extremely difficult process to secure due to the exorbitant prices as explicated in chapter 3 where land since the colonial period has been a scarce resource which the poor have limited access. This kind of shared housing scheme was seen to be the most popular amongst locals as it had a two-pronged beneficial outcome. First, for the tenants or occupiers, it was affordable and at the same time well perceived because of security and the sense around safety where neighbours help each other in case of any threat or crime. Secondly, landlords or property owners saw this type of housing provision as a way of maximizing profits from the rental income. Services were provided in bulk, for example toilets were shared hence production costs were reduced. Also, it was seen to maximize the plot utilization as construction occurred up to the plot boundary. Shared rental housing in Eldoret

mainly comprise of up to 12 single-rooms within the same plot facing each other with common spaces such a corridor and sanitation blocks as depicted in figure 15.



Figure 15: Shared rental housing in Langas (Source: author)

The rooms in most households measure 10 square feet (3x3 metres) or in exceptional cases up to 15 square feet. The rooms serve to provide for all the household activities i.e sleeping, cooking and living. The rooms are partitioned by a curtain as a screen to separate the living space and sleeping area for instance. The rent expenses were determined mostly by size and the quality of the houses. The most affordable rental houses were in Boma Turkana since the houses were made of mud as walls hence considered lower quality and temporary. In Langas and Munyaka there were more permanent structures which comprised of varying building materials including natural stones and iron sheets. Notably, houses that had better construction materials were priced higher in terms of the rent paid and often had more salient features which suited the disabled, for example having taps inside houses.

The rental system involves various competing actors necessitating power play and relationships which goes beyond landlord-tenant relation into local governance structures. While on plan, rental housing owners are compelled to make provisions for PwDs, during implementation they reduce the size of rooms, thus are able to create more rooms hence

earning more income and save on costs-this is problematic especially for disabled tenants who desire spacious living rooms. This ultimately leads to maximization of profits that rides on the high demand for housing. In addition to practices which create more rooms to generate additional rental income, there were other practices in which developers produced housing which fail to serve the needs of PwDs. The director in charge of planning in Eldoret commented on this situation

there is a very big challenge, especially in the construction industry, we realize that the law actually supports the private sector to decide what they are supposed to do. Because, for example, these building plans, when they have been submitted to our offices, they are mostly brought here, but by professionals who are in the private sector. So, majorly the designs are left for the private sector to decide how it will be. Now, when you want to provide for maybe people with special needs, you realize that I might say that those people are actually left out by the private sector, because people don't really appreciate that we live with people who have special needs. So, mostly, you'll realize that a building goes to maybe eight floors or has steps but without a lift or ramp for access, where these facilities for people with special needs are totally left out. So, I think it is an area whereby the planning and generally the county has to focus on to ensure that people with special needs are able to access such buildings or houses, but for now, unfortunately, there is nothing specific we are doing about it. But because it is an ongoing discussion, I think it is one of the things that we will ensure it is realised in future planning frameworks for our county [GO-02, Eldoret]

The official highlights how rental housing developers within Eldoret have least considerations for PwDs yet there is need for them to be factored in as a vital clientele for housing. From his statement, the regulation of planning and development is arguably haphazard in the county as it perpetuates the impunity meted on PwDs through sub-standard housing. A mother to a disabled child describes the woes and experience of living in a one room shared rental house. She recounts

Let us just say for us here, we are just staying because we do not have any other means but for cooking in particular it is usually stressing, because you know for him he does not know the *jiko* (charcoal stove), he doesn't know anything, everything here is just messed up, at times he falls down, as you can see he has bruises all over, for the *jiko* I have to wait for the girl to come so that he helps me with him so that I can cook without the risk of him burning himself...like for instance if you start cooking he cannot stay still, if he goes out, there has to be someone looking after him, and as you know usually how plot residents are-someone will walk away and leave something

somewhere, so it's a problem even if he is outside, you really have to be there [MU-09, Munyaka]

Notably, as a feature related to inflexibility, disability in shared accommodation is seen to create and perpetuate confinement and limited freedom from a housing perspective.

it's just me to sit here because you cannot go far, probably just close the door because if he leaves he won't know the roads he won't do anything, so if I get out I close the door, so its just living by closing him inside the house [MU-09, Munyaka]

While such houses are confined and do not allow for privacy and flexibility for the disabled, they also have their merits. A key feature about this kind of housing is the strong neighbourly relations discussed in the previous chapter as a way the disabled can be taken care of as a type of home-based care support. Since residents lived in rooms within the same plot and sharing the same gate, they shared the open space and would interact on a daily basis. Meaning they knew each other's issues and if one is disabled or has a relative who had a disability, a majority of neighbours to the disabled participants were always willing to help out when need arose. In this case in as much as rented housing would be less favourable to the disable and their carers, especially in a material sense and exude less freedom, on a social basis they reinforce relations which are beneficial to them.

Caretaker or 'borrowed' housing

A section of participants lived in houses as caretakers and custodians to land belonging to other people. In this case they tend to live in an existing house that belongs to the property owner or alternatively put up a house for themselves if the land is vacant. For example, in Munyaka a family with a disabled child were living on a 'borrowed' parcel of land and were the custodians as seen in fig 16. The housing as seen in the figure is purely constructed using iron sheet walling unlike the use of mud which is more commonly used where one pays rent or owns the house. Housing constructed from mud is seen to be semi-permanent and offers increased comfort. A single mother whose child lived with both a physical and mental disability and whose house is pictured in figure 16 expressed how the condition of her family's house affect their lives

When it gets cold during the rainy season, it becomes very cold inside the house, because the roof and walls are both made of iron sheets. The children catch cold, and they start coughing. The one with a disability suffers most [MU-04, Munyaka]

A further probe into the issue revealed that the owners of the land were opposed to the process of setting up new structures built from more permanent materials which would provide greater comfort. The reason behind it is that it would jeopardise the ease of putting up new construction in case there was need for them to develop the land in the future. However, in as much as the landowners discouraged them from having comfortable structures, their custodial significance cannot be underrated. Also on their side as caretakers, such arrangements positively suited their disability conditions in terms of privacy and cheaper rent. By putting up a temporary house and subsequently living in the land it is believed that they take care of it to ward off any malpractices such as 'land grabbing' a phenomenon common in many towns in Kenya.



Figure 16: Caretaker or borrowed housing (Source: author)

Owner-occupancy housing

Owner occupied households were the least common typology of housing by PwDs because they entailed owning land which to many was never an easy process. However, some participants lived in their own households where the form of ownership varied from buying the property to inheriting the house/s and land. In Langas and Munyaka most owners reported to

have bought their properties although they openly stated that they lack any proof of ownership apart from sale agreements appended by local chiefs and village heads. Interestingly, in Boma Turkana which was a squatter settlement where the land belongs to the state, some participants owned properties through inheritance within the informal structure and therefore were not paying any rental fee. An elderly disabled woman in Boma Turkana described how she acquired her house

this house, I do own it since it used to be my father's house, so when he died, he left me here, I am the only child, so he left me here to stay in this house [BT-02, Boma Turkana]

Despite owner-occupied being the most inaccessible to most PwDs because of the extant connection between disability and poverty as explicated in chapter, the few cases where the disabled lived in their own houses, they alluded to being comfortable since they would construct their houses to suit their needs. For instance, a mother who has a disabled son noted:

yes I bought this place with the help of a friend, it is in 50 feet by 100 feet, we bought then divided between two of us.. you can even see we have not build permanently... because you see like now he is 20 years (disabled son), so you see the house is small for a person who ought to stay well like him, for his condition he needs very spacious rooms..we plan to build a permanent house since this is our land.

Apart from the privilege of building more permanent and well-suited houses for the disabled, owner-occupied housing commonly had plenty of space outside which participants indicated as being key for their disabled relatives as shown in figure 17 below, one of the owner-occupied houses in Munyaka.



Figure 17: Owner-occupied housing in Munyaka (Source: Author)

Housing challenges affecting PwDs

The housing situation in Eldoret's informal settlements does expose PwD's lives into greater risks because it perpetuates their disability conditions thus imposing further disablement. Disabled people face a myriad of challenges while looking for housing and are not only likely to be discriminated but also charged higher rental fees (COHRE, 2004). Several of the participants suggested that their houses in many ways affected their living conditions which in turn exacerbates their disabilities. For example, a wheelchair user describes his shelter and notes that housing constructors in Kenya care less for their disabled needs:

The house is good, but the Kenyan builders are not well equipped with knowledge on how to build disability-friendly houses. So, there are challenges which we endure. I usually have challenges in using the toilet for example [LA-06, Munyaka]

His sentiments suggested that housing and disability are two aspects which are intertwined and the former significantly shapes the lives of PwDs. According to an account by an NGO worker in Eldoret, while juxtaposing differences in housing in various geographies, notes that the conditions in rural areas beyond the municipality are much better as compared to similar prevailing conditions in urban informal settlements.

But the persons with disabilities in urban areas, those settlements, those informal settlements that we're talking about, right? The housing situation was dire; it was it was really poor. It was really poor. It was mud houses, poor drainage, no toilet, congested area, not permanent structure. So that's it. Something else I noted about disabled people is that they struggle more on housing issues compared to normal people [NGO-02, Eldoret]

For the NGO official, his accounts clearly illustrates what the general housing conditions within the informal settlements in Eldoret look like and specifically how the situation is in relation to disability. He even refers to disabled housing as perceived to be irregular housing. He also cites existing features about informal settlements which were distinctive to Eldoret relative to other cities, the temporary housing is made from mud (earth-based shelter material) as shown in the figure 18 below unlike a city like Nairobi where shelter materials are of industrial products like *mabati* (corrugated iron-sheets), recycled metal, cardboards and timber (see Makachia, 2012). The mud houses are an extension of a typical traditional housing typology in rural Kenya where mud and thatched houses predominate the traditional building form. It is however important to note that in as much as the mud was used in walling of the houses, a few houses for a section of participants were built from *mabati* walling.

A different perspective which details more elements that affect PwDs is reflected by another NGO worker, he states

the houses themselves are so squeezed. The, the landlords in those informal sectors are sometimes even forced to compromise the building standards, the doors are not the standard doors, most houses I've seen, they have, they always have a step before you get get into the house. So, if you have some a person with disability who stays there, and they're using a wheelchair, then their wheelchair will have to be to be used up to a certain level, then they're lifted to the house. So, most tenants in the informal sector have compromised the building standards for the houses themselves [NGO-01, Eldoret]



Figure 18: An elderly disabled woman next to her house in Boma Turkana (Source: Author)

The two officials give an overview of the challenges and struggles that PwDs and by extension their care providers encounter in informal settlements. Since most housing provided in the settlements is basic and does not incorporate details such as ramps, PwDs struggle to access even their own rented houses. The building regulations and standards are rarely enforced in the informal setting and therefore the rights of tenants are more often abdicated. He describes how wheelchair users if unaccompanied would never in their disabling situation freely use their spaces. Such a challenge which resonated with most participants *inter alia* are summarily discussed in four main parameters namely tenure security and evictions, size and arrangement, affordability and preference and homelessness.

Tenure security and forceful evictions

According to Raquel Rolnik a former UN Special Rapporteur (2008-2014) on the right to adequate housing, countries ought to adopt legal requirements that enshrine citizens to live in secure, peaceful and dignified homes where the principle of tenure security applies to everyone with or without formal titles and where any kind of evictions and displacement has to be justified and proper alternatives provided (Rolnik, 2012). Security of tenure is a fundamental aspect in housing which is integral to the development of both formal and informal settlements in urban areas. The tenure comprises of housing and land statutory frameworks that enable people to stay in a particular place in a secure and dignified manner (ibid). The

lack of tenure security in most of Kenya's informal settlements in many cases prevents people from investing in meaningful housing (makeshift housing) due to fears of eviction (Kim et al, 2019). Makeshift housing is often at risk of demolition and forced eviction especially of vulnerable urban populations which includes PwDs who may be viewed as soft targets. However, several steps are involved before demolitions are carried out which often includes resistance protests, legal processes and at times compensation which is usually backed by political processes. For PwDs in Eldoret's slums, evictions and the threat thereof, were apparent through respondent's views. For instance, in Boma Turkana, an elderly disabled woman narrated that

this house, I do own it since it used to be my father's house, so when he died he left me here, I am the only child, so he left me here to stay in this house, as I wait for the 'ratili', there is that 'ratili' for KMC (Kenya Meat Commission), that time when they will come over to evict us, we stay here as 'slammic' (squatters), so when the government will say it wants to use its field (land), we will be evicted. We do not know where we will go [BT-02, Boma Turkana]

According to the participant they live in fear of facing an eviction similar to other evictions in the country which tend to displace existing lives and livelihood opportunities. There are various ways in which forceful evictions can happen to inhabitants of an urban space. The most common is the developmental-based evictions on public land which are often carried out for the public good, but they usually affect the most vulnerable in communities. The other type of urban evictions happens on private properties that have been encroached by squatter populations. Langas for instance is largely inhabited by families who do not have the legal rights of ownership exposing them to the risks of eviction, in fact the rightful owners of the land have in the recent past been in court seeking to repossess it. However, this claim and demand for eviction was prevented by an Eldoret environment court which compelled the state to compensate the rightful owners of the land halting a forceful eviction of over 200,000 people living in the settlement (Kipsang, 2018).

Apart from forceful evictions by the state on the basis of development projects, some respondents alluded to being evicted from their rented houses by their landlords and the local authority in the case of government houses (Nyaboke, 2020). Such evictions in turn push people into the urban peripheries of Eldoret municipality like Langas where basic services are either lacking, poor or inadequate. An eviction story as headlined by the Standard Newspaper reported that over 256 families were evicted from county government houses in Macharia estate because of their inability to pay rent that had been doubled from 400 to 800 Kenya shillings (Rutto, 2019). One of those affected was a wheelchair user currently living in Langas

where he says was the most realistic place for him to move to after the forceful eviction. He explains how the evictions were carried out by the enforcement authority in a violent and discriminatory manner thus affecting him more as a disabled person relative to the rest. In Kenya although a law exists which is intended to protect tenants from evictions, participants spoke widely about frequent harassment and evictions meted on them by landlords. A participant in Munyaka expressed his experience of an eviction by his landlord

I once came home and found that the landlord had locked my house with a bigger padlock and left an eviction notice which stated I had to vacate after I had paid all his rent arrears. It really affected my family as my wife had just given birth and my business was closed because of COVID [MU-09, Munyaka]

The impact which such evictions have on PwDs is often not emphasised enough in literature and policy materials. One of the NGO officials notes that apart from the disabled other similar population groups like children and the elderly are implicit victims of the process where sexual and gender-based violence happen in the displaced communities. The situation as at the time was also exacerbated by COVID-19 lockdowns and restrictions as most participants who were informal workers in Eldoret could not raise their monthly rent since their businesses had closed. The situation becomes even murkier if one considers a disabled person being for instance a woman and living with HIV/AIDS where in many cases they may undergo unseen realities including harassment by house owners and possible evictions from their homes. An HIV positive and disabled participant from Boma Turkana alluded that

I usually do casual casual jobs, I just get called for a casual job then I go for it, at times there are no jobs, and you then cannot pay for rent [BT-02, Boma Turkana]

The situation of the participant is a composition of different dynamics where her disability intersects with living with HIV, having an unreliable livelihood situation and all this leads to getting harassed by house owners and ultimately getting displaced. The combination of all these issues has an impact on her housing condition and lived experience. Apart from displacement via evictions, the lack of tenure security by PwDs constrains them from accessing finances to invest on improved housing (Nabutola, 2005). Although this is not unique to PwDs, responses from disabled participants seem to position them paradoxically. This account is substantiated by one of the interrogations with a planner about planning dynamics of informal settlements in the municipality

Okay, as I said before, those areas are just categorized as special planning areas, obviously they also have their guidelines, and it having insecure land tenure, you find

that most of the houses that are being constructed there are either temporary, semi-permanent, because of insecurity of tenure, that people doesn't have, someone doesn't have a title. So, you'll find that he is afraid to come up with a permanent construction or just a compact or dense-high density development. Also, because sometimes they fear that maybe they have encroached the road reserve or any way leave or something like that, yes [GO-01, Eldoret]

The planner, who oversees development control and approvals at the county offices in Eldoret elaborates on the issue by mentioning insecurity of tenure and the subsequent lack of titles as a major factor that contributes to the adoption of informal housing. Tenure insecurity according to him is coupled by fear of encroaching on public utilities such as road reserves escalating the trends where flimsy houses and trading utilities like temporal sheds (known as *kiosks* in Swahili) are erected so as not to incur huge losses if future demolitions are carried out. This is corroborated by an interview conversation with a wheelchair trader from Munyaka who has an informal business premise in the inner city of Eldoret where he cites non-existing tenure as hindrance to the development of his hawking business. He however contended that since he is disabled local government officials tend to be tolerant to him relative to other informal traders. Such livelihood experiences seen as unjust to some, extended issues of tenure beyond the housing and land experience which are the most common when discussing tenure security in informal settlements. The power relation between PwDs who on the one hand do not want to be favoured as compared to the majority non-disabled individuals is a complex chain of events because on the other hand as mentioned, they are tolerated by state agents who are supposed to enforce city regulations and by-laws against informal trading such as unlicensed hawking in the central business district.

Size, space arrangement and home-crowding

Size of houses and the arrangement of spaces within households is an important yet under explored factor that significantly affects disabled people. To most of the respondents of this research regardless of the type of disability they had, size of houses was frequently mentioned as an important cause of both physical and emotional stress. This was established and was continuously cited as an issue that limits the housing experiences of PwDs and their families. Living in small, confined and shared rooms with less privacy and inescapable noise levels without bathrooms and no outdoor spaces influences the disability conditions of various PwDs and their caregivers. Wheelchair users for example struggle to easily move indoors due to the limited spaces and missing housing elements such as bathrooms which were desirable made their lived experience different from others in the informal settlements. This situation was

reiterated by most participants in the three informal settlements, for instance a blind woman in Boma Turkana responded that

This house...so you know I might say it is small since it is not enough for the children, even you can see for yourself, you can see how but because I do not have other means am just forced to cope [BT-01, Boma Turkana]

The assertions by BT-01 describes the challenges linked to limited spaces within informal settlements that are not sufficient for PwDs. As a blind person manoeuvring in the one-roomed house which serves her as the living area, kitchen and sleeping space is an everyday struggle to cope and survive. A similar respondent, MU-01, who is also blind had a similar experience

so, the room is a bedroom, a living room and a kitchen [MU-01, Munyaka]

The spatial layout of the house as seen in fig 19 seems to create tension between various uses of the spaces because the same room serves to provide all the fundamental needs of a home-living area, cooking area and sleeping area. The tensions include bumping into household possessions and furniture and difficulties with locating objects which might be misplaced in between the congested internal spaces of houses.

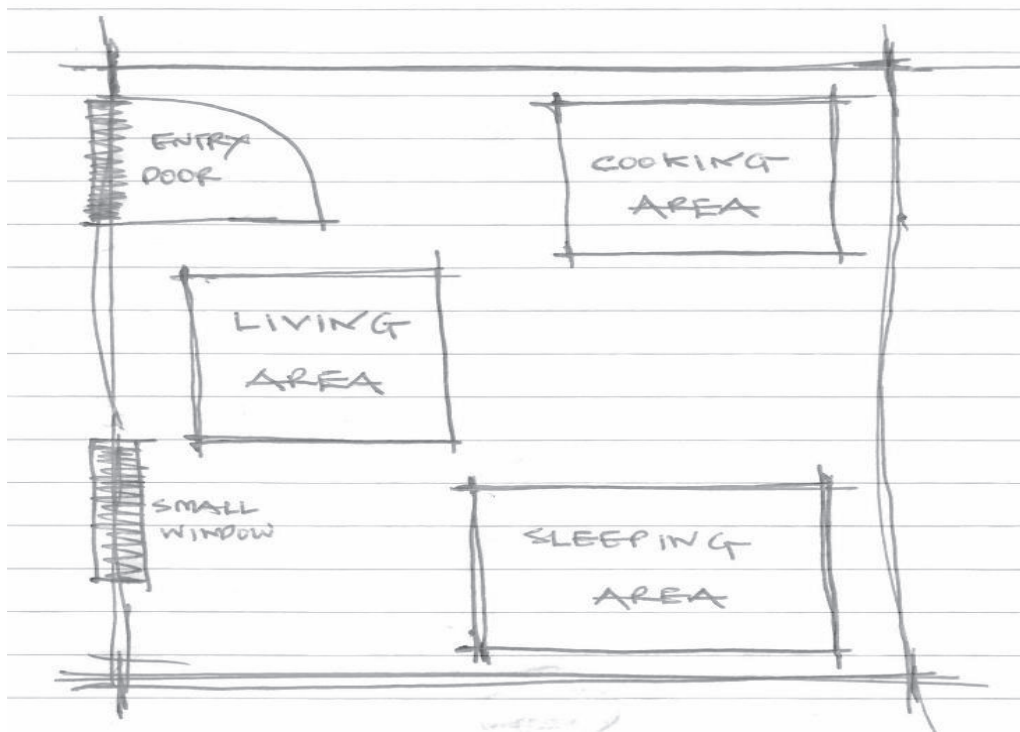


Figure 19: Field sketch showing the layout of spaces in BT.01's single-roomed house (Source: Author's construct)

Housing size and disability overlap to create other realities such as the lack of privacy one participant in Munyaka whose daughter has a hearing impairment narrated.

Yes, size of the house is a problem. She usually complains a lot, saying that she is a mature girl, and she doesn't love sleeping together with the younger children [MU-07, Munyaka]

For MU-07 that tension created by living in a small one-roomed house derives an inevitable domestic conflict between her deaf daughter and the rest of the children something she says she must try and continuously manage. Necessary activities such as cooking and studying (in the case of her other children) are conflicted and overlap with size of the house and the needed privacy to her daughter. Since she is already a youth who is disabled, her age intersects with her condition, which to the rest might be seen as a violent conduct as she struggles with hearing process forming an intricate situation to navigate altogether thus revealing the intersectional realities discussed previously in chapter 2. This makes living in a one-roomed house with a disabled member a constant process of negotiation which not only affects the PwD person but the whole family. She goes ahead to narrate how her family cannot move to a bigger house because of costs that comes with it coupled with poverty and other competing domestic needs. The incapacity to move into more favourable housing often leads to crowded homes which are detrimental for PwD's wellbeing. Size and crowding were directly related and formed as critical elements in disability homes. The drivers that influence on the size of a house leading to home-crowding are factors such as family size, age, sex etc. For instance, respondents with large families seemed to experience greater challenges as compared with those that either lived alone or do not stay with family. An elderly disabled woman who lives alone described her house to be adequate for her needs

The house fits me because I do not have a big family nor do I have many things, the children and grandchildren are away, so it is fine for my needs at the moment [BT-02, Boma Turkana]

Large families often end up in crowded households where the house occupants exceed the dwelling capacity leading to physical and mental constraints especially but not limited to PwD family members. However, while living alone can ease cases of crowding as the above participant contends it can be challenging if care which seemed necessary to the majority of the participants is needed and reliance on it is from a caregiver who is a family member.

Demonstrably, various groups within families were seen to weave together with spatial experiences such as size of the homes and therefore affected participants differently. At the

same time physical realities for the disabled means the use and experience of spaces is more demanding e.g spacious areas needed for wheelchairs; privacy needed for violent PwDs and safer outdoor spaces for those with mental instabilities. Also considering that PwDs and their carers usually spend most of their time at home, they tend to be more affected by such effects of crowding. These realities mean that the experience of the home is felt differently by various people. Whereas PwDs and their carers have a higher affinity to the spaces at home other members of the family who go out to look for income experience the house in a different manner. However, that is not to say PwDs do not engage in livelihood opportunities in fact a number of them had established business entities both formal and informal within the settlements and in the city. Ultimately, the argument is that size does lead to crowding which impacts PwDs more than any other social groups and the situation is worse in poorer households since over-crowding is often inevitable because moving to a more spacious house would involve costs as discussed next.

Affordability, quality and choice (preference)

Affordability, quality and a limited choice of housing strongly characterised the difficult living conditions faced by PwDs in informal settlements. Most of the PwDs whom this study interrogated do not participate in stable income generating activities and are often forced to live in flimsy, poor quality housing made of makeshift materials like mud, old and rusted iron sheets, polythene materials etc. An NGO worker in describing his experience with working with PwDs in informal settlements stated

so, in places where persons living with disabilities live.... Most of them who are renting tried to live in places where their rent was as low as possible, as low as as low as 2000 shilling...and those conditions are not good (meaning PwDs live in lowly rented houses whose quality is jeopardized) [NGO-02, Eldoret]

Affordability is closely linked to the quality of housing where low-cost houses as posited by the NGO worker have compromised standards with regard to quality. Most PwDs as indicated do live in such rented informal housing and in as much as the rental fee is low, they struggle to pay for it as most of the household income goes to other livelihood priorities such as food.

challenges like...may be just household food stuff, because we at times lack money but God usually helps us, we never sleep hungry, he does bless us [BT-02, Boma Turkana]

Similarly, another respondent from Munyaka stated

I pay 3,500/- for this house. This amount is quite big for me, especially during these corona times. The money which I gain from my hawking business is only enough to buy food for my children. But the landlord does not understand that. So, it becomes a matter that requires perseverance [MU-06, Muniyaka]

Considering the relatively low rental fee in informal housing which in turn makes it relatively affordable as compared to other housing types, many of the participants had the opinion that landlords absconded their roles of improving the quality of their houses exposing them to risks and other varied forms of tenant exploitation. For example, a widowed woman who has a disabled child had lighting issues with her house, she narrates of the situation with her landlord

My landlord, upon receiving such a complaint, always says that he will take action accordingly, but he doesn't do anything. So, I have to always leave the lights on during the day as you see [MU-06, Muniyaka]

The housing market in Kenya is predominantly provided by the private sector with a few cases of government housing which in most cases tend to be affordable and are of better quality as highlighted by one official

Yes. We, yeah, there are a couple of persons with disabilities who are living in government houses, with a good number of them were living in their own compounds, because we did research, and we were asking them about about housing and so on and a big number bigger number are renting [NGO-02, Eldoret]

From the two responses above, landlords who as stated dominate the housing market are key players in shaping the experiences of housing for PwDs. Notwithstanding that monopoly, there seem to be a sense of unresponsiveness by the landlords on maintenance issues and tenants bear the burden of living in uncondusive spaces. The government houses inhabited by PwDs although relatively affordable are very few and do not meet the demands for housing, a gap filled by informal housing. As explicated in the previous section, self-owned houses in informal settlements were the most preferred since they could be constructed to suit the needs of various household and privately rented housing had the least considerations for PwDs. However, the high cost of land makes owning houses in urban areas even in informal settleemnts, a pipe dream for most PwD communities. In addition to the challenges of housing, open space is a further spatial reality for those who are disabled and homeless. The aspects around homelessness are briefly mentioned in the next section.

Homelessness and houselessness

The glaring reality of homelessness and houselessness is difficult to probe in Kenya's housing landscape because of insufficient or a lack of data, and also since both were not in any way recorded in the last national census and housing survey of 2019 (KNBS, 2019). It is relevant however when we consider urban informal spaces whereby many of the informal settlements in Kenya are characterized by conditions which are constitutive of families being rendered homeless or houseless. While doing transect walks/rides in the streets of Eldoret central business district and within the settlements in the case study sites, it was discernible that most of the beggars on Eldoret streets had varying forms of disabilities as shown in the figure 20 below.



Figure 20: A homeless PwD begging along Eldoret streets

The disabled beggars position themselves strategically at various nodes along the streets where they would spend long hours seeking money from pedestrians. Discussions with a few

of them revealed that they are either homeless or live in informal settlements within the municipality

“this is my street end, I come here each and every morning to beg, at times I get lucky to find enough money for food and sometimes I hardly get anything, it becomes difficult during extreme weather conditions such as rain or high temperatures. The situation is worse when you consider that I do not have a house or home, I sleep on the street”
[ES-01, Eldoret]

Synthesis of PwDs housing in informal spaces

Housing attributes as described in the preceding sections depict how the disabled residents are most affected as compared to the non-disabled residents living in similar conditions. These attributes in many cases combine to form multi-layered and complex challenges which often PwDs have to contend with for example when they have to struggle with limited house spaces which are rented at relatively high costs with low-quality finishes which exacerbate their disabled conditions. The housing regulatory frameworks whose mandates are limited in informal spaces have not been useful in the process to improve the realities of the disabled since some of the spaces do not offer secure tenure hence houses are provided informally. In addition, services are often scarce. These housing realities are a dominant feature of cities in the global South, where insecurity of tenure, poor quality housing and limited application of regulations shape the lives of PwDs significantly. These realities evidence why a Southern Theoretical approach to the disability-informality nexus is appropriate and relevant. Beyond housing water as a key service is unpacked in the subsequent section where emphasis on how the disabled access it and the challenges encountered is at the heart of the discussion.

A table explaining the relationship between house typologies and PwDs’ navigation strategies:

Housing Typology	Key issues	Navigation Strategy
Shared rental housing	-Houses constructed without taking into account PwDs material needs such as accessibility and internal space configuration	-Minimal structural adjustments to the houses to accommodate their needs. This could be in the form of changing of existing

	<p>Houses in this category were not only perceived to be secure in cases of crime but were also affordable since landlords provided services in bulk meaning rental income was maximised</p>	<p>facilities within the rental houses such as adjusting door knobs as narrated by a short statured woman and one of the respondents from Langas. Others include physically lifting disabled people over steps or guiding blind persons within the house.</p>
	<ul style="list-style-type: none"> -Limited outdoor spaces that do not meet the needs of PwDs -Limited privacy given the overcrowding that comes with shared housing -Shared facilities including toilets and bathrooms are mostly inaccessible for various disabling conditions 	<p>-Extra care initiatives provided to help disabled members of the family cope with space limitations and the privacy challenges, such care initiatives might include involving third parties for care such as involving family members or neighbours. This ticks back to the discussions around care in chapter 5.</p> <p>-Other strategies include navigating through existing conditions for example a physically disabled person clutching on toilet walls. Such narratives are expressed in detail in the last section of this chapter where toilets and their usage are discussed.</p>

Caretaker/Borrowed housing	No housing tenure/security i.e PwDs lack ownership rights of the houses	Have to contend with temporary and makeshift buildings Play caretaker role to the owner as compensation for occupation
Owner-occupied housing	Owning land and a subsequent house is expensive and unaffordable to most PwDs,	Use of informal and localised financial structures such as <i>chamas</i> to coalesce finances for buying land and dividing amongst themselves

Urban water insecurity in ‘informal disability spaces’

The global community envisages to achieve a universal and equitable access to safe and affordable drinking water for all by 2030 through SDG 6.1. To be considered accessible and affordable, ‘water supplies should be located on premises, available when needed and free of faecal ...contamination’ (Danert & Healy 2021:1). For many PwD residents whom this study interrogated, challenges in accessing water that is of good quality was something that shaped their urban lived realities. A caretaker aunt to two disabled boys in Munyaka expressed that

we have water from the municipal. It does not come all the time, sometimes the taps dry up... If you are unable to pay for two months, they come and disconnect you.... a child, like Churchill needs water all the time, for example for the sake of cleaning him and his beddings [MU-03]

The lack of it or its availability in various neighbourhoods was seen in many ways to determine how people lived as those who easily accessed it were seen to live comfortably while the opposite was true for those who struggled with access. The effects that come along with an

acute water shortage in cities within sub-Saharan Africa which are urbanising rapidly, are extensively felt in poor informal settlements (Dos Santos et al., 2017) leading to urban water insecurity, a nuanced expression for everyday household challenges in search for domestic water in cities (Jepson, 2014; Adams, 2018). In such settlements, households with disabled people are in a constant struggle to fill that gap, for instance many participants in this study would either have to draw water from a well provided by a house-owner or buy water from a neighbour, vendor or water kiosks for general household use and for drinking respectively. Being disabled and living in an informal settlement therefore shapes the process of securing water as physical limitations often reduces the ease of accessing water. One of the ways could entail the physical impracticability of drawing water where one has to be assisted and thus dependent on someone else. A participant in Langas defined how he struggles with accessing water

for water it's my wife who...we have a water well but for drinking my wife goes to fetch...we usually buy it but this one gotten from the well for washing clothes it's my wife who draws from the water well [LA-03]

The above experience by [LA-03] who is a wheelchair user aptly relates how PwDs are dependent on others for services in this case; his wife helps him draw water. In her absence he further explains

for example, the time when I was not married, if I saw someone I would ask if it is a Saturday, if anyone is close by I would kindly ask for him/her to assist me in drawing the water, even if it is going to the bathroom [LA-03]

Another interviewee from Langas echoed the same

concerning water, I would like to have access to tapped water due to my condition. But the water which is available comes from a well. Whenever my wife and children go to the rural home, I have a hard time because I can't draw water for myself... so, in such situations, they have to fetch the water for me and fill a big tank that can last up to a month, till they return from the village. So, I request landlords to consider this kind of situation [LA-06]

Both the experiences of [LA-03] and [LA-06] illustrate the role of neighbours and the intimate connection people have in informal spaces as detailed in chapter 5. It displays how critical these relationships are to the most vulnerable including the role they play in provisioning services such as sharing of water or helping out in accessing water for PwDs. Another respondent from Munyaka who was visually impaired was open about this situation

I don't go fetch it myself, the kids go fetch it or I seek aid from the neighbour to go fetch for me... yes, they do, I do not go there myself, that I can't lie to you, that I can manage to go there [BT-01]

Still, the experiences by [LA-03] and [LA-06] emphasizes the role women play within homes in African societies as caregivers to the vulnerable including PwDs as discussed in chapter 5. Meaning, a shortage in household water supply inextricably shapes their daily lives given the care duties that are entitled to them. In most developing countries, fetching of water for domestic use is seen as a woman's role meaning in case of a water crisis, they bear the burden as they are expected to find ways of sourcing it for their families (Adams, 2023). Women worry more about lack of water not just because of the lack of water itself, but because the ability to provide water for their household is what defines them as wives. It's driven by masculine expectations—a married man does not fetch water (ibid). Many of the men I interacted with in the study area were quick to point out this norm and scorn at those who try to challenge it. Therefore, for women as observable in most households, water is a personal issue as they are responsible for their family's survival and hence are expected by all means to find water for drinking, cooking and washing. Consequently, inadequate water within homes unduly affects female family members more than their male counterparts (Pouramin et al, 2020). They face limited choices in their struggle to secure water for their households, as they have to endure long queues, walking long distances and even having to pay more for it. This clearly depicts the interlinked relationship between water, gender and disability as the shortage of water affects women more because of the additional duties that comes along with disability.

Despite the gender dynamics, water scarcity in some households who had difficulties over the supply of water was seen to cause intra-household and inter-household conflicts and/or tensions between residents themselves and the house-owners/landlords or even the municipality. The situation is compounded when disability is considered where a woman must provision water for the family regardless of her disabled condition or the caregiving duties earlier highlighted. The shortage of water breeds tensions within households in that if a woman happens to spend more time fetching water, other responsibilities such as care, and cooking are affected hence tension and possible conflicts with their families (especially husbands). The same happens between households that have a disabled member and those that do not have as such tensions are normally escalated to landlords as described by a woman in Munyaka whose daughter is deaf

I usually suffer because of that. At first, we used to fetch the water thrice a week. But the landlord later complained that the bill has become too big. So, nowadays we fetch

only twice a week; on Monday and on Friday. The problem with Friday is that the water often disappears on this day... one day the landlord complained about my family because we fetch the largest amount of water due to our family size. So, I decided to start fetching only once per week from then, on Tuesdays [MU-07]

Seen differently but to a lesser extent compared with larger urban centres such as Nairobi, tensions also existed between informal water providers and water utilities.

A further issue is the impact of a lack of financial resources caused by disability induced poverty which makes one unable to pay for bills as highlighted by MU-03 above where the consequences are the threat of disconnection from providers. Overall, many participants decried costs that come with water insecurity just as they did with rental fees. They highlighted that they mainly buy water for drinking from neighbours who have a supply of piped water from the municipality or from communal water kiosks. A participant from Boma Turkana recounts of this

it is hard because, when you do not have money then you cannot have the water, its only when you have is when you can fetch it, and also we just accept because its somebody's work, what do you do..its someone's job [BT-01]

Closely related to the above cost constraints, the interviewee below from Munyaka discloses her experience with buying of water, water vendors and family needs laden with disabling conditions

Yes, there are. Sometimes I need much money to get much water for laundry. But when I go to the vendor, he says that my bill has become large, and thus it becomes difficult to get the water. Sometimes I can get money for food, but no money for water yet its needed for my family [MU-04]

Costs of water brings into light issues of affordability where according to the UNDP no household is supposed to spend above 3 percent of their total income on water expenses. Exorbitant water pricing stems from inflation by providers and the cycle of poverty due to insufficient income by PwD families. The key takeaway with costs is that water needs are deeply entangled with varied family needs and disability conditions. Urban families with disabled members needed plenty of water as compared to families with non-disabled members. This is directly cited by one household situation in Munyaka who complained of the inconsistent water supply from the municipality and how their disabled child needs plenty of water. Plentiful water is needed in disabling conditions such as those that make PwDs immobile making them either defecate or urinate in nearby living spaces, meaning a shortage

in the supply of water for cleaning soiled floors and bedding makes housing experiences unbearable to both themselves and their caregivers described in the previous chapter.

Traditional models of water provision in Eldoret through the county department of water or municipal agencies like ELDOWAS (Eldoret Water and Sanitation), have failed to meet the rising demand of water in the informal settlements. Because of that gap as witnessed in the study areas, residents of the informal settlements including PwDs engage in informal and at times formal practices to access water. It is well established in both research and practice inhabitants of informal settlements rely on varied water sources both formal and informal to fill the gap of the unreliable water supply or the inability to buy water from suppliers (Adam, 2018). In a previous study in Dar es Salaam's informal settlement, (Dakyaga et al, 2021:111) found that due to the failure of state actors to provide water, non-state actors self-mobilize themselves 'and develop low-cost water infrastructure systems' for a sustained supply. In Nairobi, Mudege and Zulu (2011) argue that problems about provisioning water in the city are less about scarcity of the water and more of marginalization of informal settlements in development planning. Both studies were consistent with Eldoret's case, where residents would depend on self-help initiatives and informal networks within communities which capitalize on the water scarcity to make a profit through supplying water as middlemen. Such 'clientelist' service networks although extortionist and run like a 'mafia' is an everyday practice that bridges the existing gap in water supply to residents thus can be termed as a necessary evil. This informal water practice is a testimony of the many ways communities within the settlements mobilised themselves with diverse resources to provide themselves with water. The arrangement allowed the communities to develop their own delivery mechanisms with or without the support of water utilities or the municipality. Three practices were common PwD homes, namely hand-dug wells, water-kiosks and private vendors all of which are briefly discussed and their relevance to disability evidenced through the various participant experiences.

Hand-dug water wells

When piped-public water is unavailable or intermittently supplied by mainstream agencies, folks in poor neighbourhoods turn to alternative means including constructing boreholes (Danert & Healy.,2021) and hand-dug wells for household uses. The hand-dug or self-provisioned water wells featured in most homes in the three informal settlements and were characterised by a shallowly dug pit (approx. 1meter in diameter) that was dangerously located next to houses and posed a great risk to vulnerable family members such as children, the elderly and PwDs since they can easily trip and fall inside the wells. The landlords of various properties had provided these wells but with no additional features that would aid PwDs in

drawing the water. Yet, to make matters worse, since most of these wells utilised a modified system of using a rope and a jerrycan to draw the water as seen in figure 21 in Munyaka and Langas, it was extremely difficult for a disabled person to use them. Tenants with physical impairments e.g wheelchair-users including [LA-03] and [LA-06] as discussed above, must recreate ways of accessing the service such as getting help from their relatives and neighbours.

The wells were seen as a cheaper option to machine drilled boreholes and despite posing as a danger to children and particularly those with disabilities, some were also dug not too far from pit latrines introducing further health hazards given the proximity. A participant from Langas describes this condition:

Then you might find someone who has a small housing plot in which the toilet is here, and the well is close by. For such cases, it wasn't wise to build that well. The person ought to have installed a tap [LA-04]



Figure 21: Hand-dug wells next to households in Munyaka & Langas respectively (Source: Author)

In addition, surface run-offs in many cases tend to contaminate the wells posing more risks. Intuitively, most of the residents, including [LA-03], reading from the descriptions of the situation that she finds herself, was cautious of the risk and only used the well water for household consumption rather than drinking and cooking, for instance washing clothes and general house cleaning. However, for some disabled residents without caregivers it was

difficult to distinguish the sources of water hence they were at risk of using contaminated water. A further issue is that the quality of the water can be distorted in the process adding another layer of risks for PwDs. Phiri (2016) who carried out extensive analysis about the state of groundwater in Makululu informal settlement in Zambia substantiates the finding on the risks that come with hand-dug shallow water wells. The study showcased that 90% of water that was consumed by residents had been polluted with toxic substances because of the proximity of the wells to sanitation facilities like pit latrines. The risks were higher during the rainy season as compared to drier periods further reifying the precarious connection between well water and pit latrines.

Depending on the season the wells do dry out because the ground water diminishes hence depicting that as a source of water, hand-dug wells were unreliable. A wheelchair-user in Langas acknowledged that

currently, our well has dried up. When you draw water, you get dirty muddy water. So, we get water from a neighbor's compound. My wife usually has a hard time because of the lack of water, but currently she is in the village with the children [LA-06]

This shows a confluence of services where on the one hand, residents use dubious and at times dangerous means to construct wells for domestic water consumption and on the other hand given the lack of sanitation services in informal settlements, landlords tend to provision shared pit-latrines that are in close proximity to wells with little understanding of the consequences.

The end results are mostly harmful to the disabled who find themselves struggling to access the water let alone the contamination it may have as evinced in the study areas. The relationship between disability and groundwater from hand-dug wells displays a conflicting situation within informal settlements whose local knowledge and understanding by both house providers and PwD tenants is sparse. Although groundwater supplied via hand-dug wells comes as a respite to PwDs by filling the existing gap in water supply in the informal settlements and therefore a critical source of non-piped water, accessing the ground water poses significant physical problems to PwDs while drawing the water for domestic use.

Water kiosks in informal settlements

In Eldoret's informal settlements, there were communal water kiosks that served residents as critical sources of water in various neighbourhoods. Residents considered water from the kiosks as clean for drinking, cooking or washing whilst water from hand-dug wells in household compounds and water bought from carts and *boda bodas* were seen to be of poorer quality hence only used for household cleaning and washing but hardly for drinking and cooking.

Generally, the water kiosk system is a formal to informal mode of supplying water in low-income neighbourhoods in many cities of the global South. It is operated by either groups or individuals who might be connected to the municipal supply (Akallah, 2020) system or rely on machine-sunk boreholes for reliable water. Community members mainly ran the water kiosks in Eldoret, for instance, Boma Turkana had a single kiosk, which was being operated by one of the residents, one participant explains

its someone from the village, we have put one of us from the village who used to be an elder in this village and also worked at the county, so when he retired, he put his child to be in charge of the water kiosk [BT-02]

Most of the water kiosks were set-up with the help of ELDOWAS; the state water company that is responsible for water supply in the city and were located in strategic places for ease of access and connection to the main water pipe system. As we will see, the ease of access was specifically for its functionality and not from the user's perspective, which was deemed challenging to some PwDs. Figure 22 below shows how location of the kiosks was key for service provision, both kiosks are sited next to the road where servicing them and connecting to the main pipe is easy.

Significantly as observed in the study areas, the physical access to the kiosks was an apparent problem for PwDs because of the steps that preclude their access,

'there were water kiosks in Munyaka and Boma Tukana but are not approachable for PwDs to draw water' [Field notes]

It was also evident that the ELDOWAS utility company, which is mandated to provide water for residents of Eldoret, plays a role in setting up of the water kiosks and even, supply the water at a cost for self-organised communities within informal settlements. That depicts how the government acknowledges the problem, sees kiosks as a means to bridge the gap in supply, and highlights the relationship between communities and the state. Relevant to such circumstance, [BT-02] explains

we do get water from the municipal, it is called ELDOWAS, they did build us a water kiosk and tank here, so we do buy a gallon at 5 shillings [BT-02]



Figure 22: Water kiosks in Munyaka and Boma Turkana respectively (Source: Author)

Looking at it from a disability perspective, it was unequivocal that water kiosks were vital to PwDs as they provided them with clean water for household use however because the kiosks mainly supply water through selling as noted by [BT-02] above, their non-negotiable costs (pay-as-you-go) reiterates how pricing water leads to expenses for families with disability needs. Since disabling conditions are often coupled with increase in water use, buying it in high volumes from kiosks is not sustainable to them. A respondent from Munyaka echoes this where she highlights a weekly demand for water in her house, which comes with high costs

on Saturdays I have to buy water at 5/- per container at the kiosk, so as to do laundry and that is very expensive for me [MU-07]

There were also cases of long-waiting periods while fetching water especially in particular times of the day and the multiple trips that are compounded by distance covered to the kiosks. For various households, fetching of water mostly by women, girls and sometimes children involves standing in long queues to fill water containers. Women have to carry the containers in their heads or backs without support from the men as underscored previously yet for a PwD with particular physical disabilities it can be impossible to carry the water. In addition, water kiosks were reported to being unreliable at times and may run out of water.

Informal water vending through private taps and mobile providers

In urban areas, water vending is ubiquitous; it fulfils a particular niche in the demand and supply of water (Kjellen & McGranahan, 2006). It was evidenced in Eldoret's informal

settlements through private taps and mobile/portable water vendors. Some individuals within communities who had networks to the municipality used political connections (as discussed in the next chapter) to acquire water for their households. They would in turn vend the water to their neighbours at a fee as noted by the interview excerpt below with a woman with a disabled child in Munyaka

‘ I usually buy water from outside my home...I get it from private taps and vendors’
[MU-04]

Equally, small-scale vendors used hand-pushed or donkey-drawn carts, motorbikes (popularly known as *boda boda*) or even bicycles to deliver water to various households at a cost. Often women and girls in households would call the local vendors for delivery of the water or instead carry the water where access is from a private tap. Where the latter is involved, carrying of the water on backs and heads mostly done by the women and girls was the norm and depending on the distance covered, the effects are varied and most significant for PwDs as underscored previously. According to participants, water from private taps and mobile vendors was the most expensive as compared to other sources. Yet, to some it was the only option to accessing clean water even if prices were inflated multiple times. A PwD resident from Langas recounted

‘we pay for our own water because we do not get any from the municipality, we get the water from vendors who at times charge us very high and inflated prices, the kiosk is too far and the water from the well is not fit for drinking’ [LA-09]

Apart from the high costs that mainly characterised informal water vending, one other striking issue about water prices that was indicated by many participants is that there was no consistent pricing with the 20-litre jerry can, which was the standard container used to vend the water, prices ranged between 5-20 KES. The main determining factor being the prevailing season where drier periods came with higher prices because of fewer alternatives, for instance the absence of rainwater. Just like any other business enterprise, informal water vendors especially mobile vendors, did provide incentives for households such as late payment after supply and flexibility in the time of delivering water.

Informal vending of water has been around since the onset of urbanisation (ibid) and just like hand-dug wells and water kiosks, they are a critical source to urban residents when options are limited and they become the most viable choice. Whereas water provided by kiosks is considered as vending (peddling/hawking) in other studies, this study does not classify it as an informal vending system since it was recognised in part as an extension of utility services in Eldoret (ELDOWAS). However, small-scale vendors were seen to buy water from kiosks at

a considerable cost and then redistributed it to residents at exorbitant profit margins. Large-scale vendors who use vehicle trucks were missing in Eldoret's informal vending system within informal settlements but were observable in high-income neighbourhoods delivering water to homes with large storage containers. The fact that some vendors depended on water-kiosks and at times piped municipal water demonstrated the overlap of the different modalities which when seen differently and in other contexts do compete.

As argued by Kjellen & McGranahan (2006) while water vendors are adorned for filling the water gap that exists within informal settlements, they are in many cases castigated for exploitative practices that thrive on top of people's absolute water needs. While their 'clientelistic' (through client politics) exchange of water for money was not as complex as in informal settlements of other larger cities such as Nairobi, water vendors in Eldoret had a strong relationship with their household customers and aimed to offer good and reliable services. However, that clientelism brought significant challenges to PwDs who lived in areas far from kiosks, which as already noted were the alternative for clean drinkable water.

Synthesis of water in disability spaces

There were instances where participants felt their houses needed to be connected with water infrastructure such as piping. A woman with a disabled daughter posited

I suggested to my husband that we should propose that water be connected to our house, by having a tap in the kitchen. But many of my previous proposals have not been acted upon him [MU-07]

She continues elsewhere and notes that

This issue of water has caused unpleasant friction between the landlord and my family. Sometimes I wonder whether I am looked down upon because I have a child with disability. I weep sometimes because of that...God will help me to one day have my own home [MU-07]

While some participants such as [MU-07] saw tap water as a solution to the water insecurity they face as PwDs, a majority admitted that costs that come with connecting and maintaining tap water from the municipal was the main reason. At the same time, others were not willing to buy the idea since they were renting their houses and so it was the landlord's duty to provide piped water.

In contrast, a small proportion of respondents felt that water was never a problem to them, for example a mother to a disabled child in Langas noted

water is not much of an issue because we have a water well and also there is tap water but I have not made the connection yet but it is just near... [LA-07]

The various accounts of PwD participants on water insecurity and how it affects their disability conditions in the study areas adds a different and significant dimension to existing evidence of knowledge about urban informality and disability through the daily struggles residents go through in seeking water. In the next section, urban sanitation issues and how they shape disability is explored.

Urban sanitation in 'informal disability spaces'

Enhanced sanitation facilities that cater for the needs of PwDs was difficult to come across in the study areas in part due to the inaction to implement disability-friendly facilities on the part of service providers both at the local household scale and to more advanced levels of the municipal and other governance structures. 'Human waste provides a powerful lens on a city' (McFarlane., 2019:1256) and was therefore a significant finding as spoken by the participants. This section highlights some of these lived sanitation experiences especially toilet use as a rich knowledge background which would aid informed decision-making for municipal services within Eldoret's informal settlements. The discussion revolves around how disabled persons negotiate the daily use of toilets as they struggle in conditions that are undesirable even to the able-bodied person.

Specifically, in the three informal shared pit latrines were the main sanitation facilities used by residents. Deficiency in sanitation facilities led to alternative and often undesired methods (degrading practices) which include 'openly defecation', using of 'buckets' or the use of paper 'flying toilets' (i.e using polythene bags and throwing faeces away) and sharing of facilities between households and to a lesser extent amongst the community/communities. Implicitly, for PwDs not to engage in such unsanitary practices, they had to fit into the prevailing conditions of the toilets most of which were unfit for PwD use. The forced and negotiated process is akin to survival for the fittest which as narrated by participants would at times entail clutching on dirty walls of the toilets and crawling on floors contaminated with faecal matter. An account by the coordinator of Association for the Physically Disabled of Kenya (APDK)- one of the key disability NGOs in Eldoret epitomizes the sanitation condition in informal settlements relative to disability needs

and for the sanitary facilities, and specifically the toilets, the toilets are pit latrines, if you look at the bathrooms, they are not supplied with water. So, you have to lift...I'm giving a typical description of the bathroom and the toilet in informal areas, you have to go to the bathroom, you're supposed to carry water with you. And when you get

there, you're supposed to...you're supposed to bend and draw water so that you can continue with the process. So, for a person with disability who cannot stand, that's a big challenge. An ideal situation will be maybe having a shower. But there are very few houses that have a shower, you will need to have a spacious place that has grab rails. The bathrooms and the toilets in those informal places will not have this. So, it's a really total mess. Some of them resort to showering in the house relying on a caregiver to assist them to do that [NGO-01]

The sanitation crisis was mostly reflected in PwDs perceptions, everyday practices and experiences with toilets, toilet-use and bathroom needs which tended to affect how they relate to each other and even to themselves in how they handled and treated their bodies. For instance, limited toilet facilities in some places forced disabled people, especially women to adjust their eating habits so that they do not often use shared toilets given the challenges that come with them such as privacy, cleanliness and the design of the toilets. As it will be revealed in the coming sections, 'fear of rape, especially at night, can lead to women not drinking fluids, chronic constipation, and using a bucket in their home as a toilet' (Coburn & Hildebrand, 2015:5). While changes in eating and drinking habits as mentioned was a major concern generally for occupants in informal settlements, for PwDs the process was extensively exacerbated since it adds another layer of a negotiated process on top of the already existing disabling situation that impede use of sanitation facilities. In a relatively similar context, Sharma et al (2015) have argued how women (both abled-bodied and disabled) in four urban slums of Delhi negotiate access to toilets. Their study corroborates the experience in Eldoret in that those who took part in their study revealed how they adjusted their eating habits by drinking less water and others skip meals so as not to urinate or defecate often hence negatively impacting on their health and well-being.

Equally, the struggles that come with sanitation was reported to the extent of using napkins as wrapping substances for adult PwDs who may not necessarily use toilets on their own, for instance a mother caregiving for her teenage daughter in Munyaka expressed the care experience she goes through and how she manages

she doesn't know how to use the toilet on her own. Sometimes I have to dress her with sanitary napkins. I wash her inside the house [MU-06]

Differently, others had to structurally devise makeshift bathrooms within their households as noted by MU-06 above and outside their houses for bathing and urinating when 'call of nature' happens as shown in figure 23 below- the same being enlightened by the APDK official. Observably, the main reasons for such adaptive mechanisms being inaccessibility and poorly

functioning sanitation facilities that are not conducive for disability needs. Therefore, an understanding on some of the realities about sanitation needs and challenges within PwDs everyday lives in informal settlements is essential towards making informed decisions in urban development trends.

This study fundamentally evidences PwDs as being at the margins on all aspects about toilets and toilet-use in informal settlements and are left out in precarious situations. A visually impaired woman in Boma Turkana stated of how she does not use some toilets, which were near where she lives because of their status

but I usually do not use them, I might step on faeces in case I use them [BT-01]

She instead opts for other alternatives that were far-off and locked to enable limited usage

For the ones that are locked, it is not easy for them to be dirtied, these ones here are normally the ones which are dirty [BT-01]



Figure 23: An elderly disabled woman outside her house with a *makeshift bathroom* alongside (Source: Author)

The Eldoret toilet practice was quite similar to the experience in Delhi and Nairobi however, no absolute acts of violence were evidenced but eating habits corresponded to some extent albeit indirectly where some respondents either preferred eating less themselves or caregivers

feeding disabled children less of something (e.g water) so that they often do not use the toilet. At the same time, unlike the two cities, which are morphologically complex and had communal toilets as the dominant sanitary facilities, in Eldoret the majority of the facilities were shared toilets among households with few cases of communal and private toilets. The shared pit latrines or toilets were used amongst five to twelve families, all in the same compound of households. Discernibly, toilets shared by two or three households in the same household compound were much cleaner, hygienically safer and had better safety and privacy features relative to shared toilets in a compound that exceeds four households. Although numerically few, communal toilets existed in some sections, for example in Boma Turkana, the Member of County Assembly (MCA) had constructed a community toilet but similar to a shared toilet among multiple households, it had issues meeting needs of PwDs because of poor maintenance. In the following sub-sections, the study briefly presents urban sanitation determinants as opined by participants in the study areas whilst linking the arguments with trends and studies in other relatively similar contexts.

Accessibility, availability and distance to toilets

Very few households had their own private latrines and in rare circumstances, some had adjusted their houses to accommodate toilets internally. PwDs found the private built pit latrines and toilets within houses as the most accessible and easy to use

In addition, as the disabled, we have a challenge in using public toilets. So, I request the landlords that the disabled should be provided with their own special toilets [LA-06]

Conversely, most compound households had shared pit latrines which were unusable for PwDs as they had features that rendered them inaccessible. A participant who is a wheelchair user from Langas captioned the feeling they go through with their shared toilet

You may at times find that a toilet has stairs at the entrance, but you know, as a disabled person, that will hinder me from getting in. But if they use a ramp, it suits everyone, including the disabled [LA-06]



Figure 24: A toilet block in a household compound in Langas (Source: Author)

Some of the features which made the shared pit latrines inaccessible for PwD as seen in figure 20 above are steps or a stair at the door front, small doors and small-sized cubicles with no support rails. LA-06 explains how he struggles and at times because of the limited choices given the design of the shared facility he is forced to use buckets for defecation and at times bathing within his house. He further explains how such a situation affects his well-being and relation with his neighbours as it is humiliating and uncomfortable as earlier alluded. Another respondent from the same neighbourhood decried of how they are troubled with their toilets and in as much as he wishes to have them inside the house, he is not in any position to ask the landlord to provide this:

that one does trouble us a lot, but the experience is just to persevere because you cannot ask someone to make for you a toilet... it would be suitable if it is inside the house, because as for me the way I am, supporting myself there, you know our backs and waists are weak, we cannot be able to use regular pit latrines like normal people [LA-03]

The observation by LA-03 showed that he struggles to use the shared toilets and the inability to squat makes him clutch on dirty walls and floors instead of rails as noted. As such, they end up being victims of chronic illness, as it will be expounded in the next section.

The distance between houses and the toilets was also highlighted as an issue to some of the PwDs. Such an experience was described by a visually impaired woman in Boma Turkana

They are a bit far, they are not close by, they are down there...they are the ones dug down...the difficulty mainly comes about when you want to visit them, I need to have someone who takes me up to there [BT-01]

Boma Turkana had a shared communal toilet, but its location nevertheless did not favour some community members such as BT-01 since they had to walk considerably long distances. That highlights why usage of communal facilities is directly related to distance and in many cases are suitable for passers-by instead of the intended users within communities. The same finding is reported in Kisumu, Kenya by Simiyu et al (2017) and by Adubofour et al (2013) in Kumasi, Ghana where both studies point to distance between households and toilets as a key determinant for scaled toilet use in informal settlements.

Some participants also experienced complete lack of toilet access

For us, we don't have a toilet within this compound. We use the neighbour's toilet. The landlord of this compound has turned a deaf ear to our plea for renovations and subsequent toilet provision... Yes, her condition makes her unfit to go to someone else's compound in order to use the toilet [MU-04]

There were instances where government intervention was reported to have happened in a bid to improve sanitation and particularly encourage house owners provide decent and accessible toilet facilities through incentives and plans. A community health worker explains

Initially, before we started going round, there was a problem because of toilets. But we organized for a meeting with the landlords, and as a result of the meeting they were given a deadline before which they had to have good toilets in their compounds. We worked together with the sanitation department of ELDOWAS (Eldoret Water and Sanitation) company to enforce this law... We gave the landlords architectural plans which they were supposed to use to build toilets. We gave them our plans for free. The rule was that if one builds according to our plan, we would then refund them the money used to build it [LA-08]

Unclean toilets leading to chronic illnesses in informal settlements

Since most toilets were pit latrines and were shallowly dug, the hygiene in spaces around them including households was always at stake. The design of the toilets, which was mainly characterised by a shallow pit, meant that they were filled up very fast. For house owners or landlords, the pit latrines provided in a shared manner were seen to be an easy solution to the needs of resident tenants as they require low maintenance (cleaning and refurbishing) and

were easy to construct. Tenants and particularly those with disabilities had serious issues with such toilets, a wheelchair user from Langas shed light on the situation

The toilet in that compound is a public one (shared between households). Sometimes you may go there and find that it is dirty...so when supporting yourself you at times touch the ground and walls [LA-06]

The shared toilets as described above pose various threats to PwDs including chronic illnesses like cholera and diarrhoea as they are the most susceptible to contaminated faecal substances. The toilets offer a limited sense of comfort, are attractive to flies and thus a haven for the spread of contagious diseases like cholera and diarrhoea. These toilets within the settlements were in most cases shared between five and twelve households living in the same compound (or plot as termed by many respondents). As enlightened by LA-06 above, the most basic characteristic of shared pit latrines in Eldoret's informal settlements and elsewhere was the distinct dirt and leftover faeces which made it difficult to use hence the discomfort. The situation becomes extremely problematic for PwDs as some reported touching floors and clutching on walls for support. Equally, others felt pain in different body parts especially since most had physical deformities.

Respondents alluded that the main reason for the unclean spaces was the unwillingness to shoulder the responsibility of cleaning something that is dirtied by other people. In ideal situations people using shared latrines share responsibilities of cleaning the facility by coming up with a rota as opposed to paying for cleaning services (O' Keefe et al, 2015). While some respondents were willing to maintain such a system, other users tend to be careless proving it considerably challenging. Such situations proved extremely difficult for PwD residents and in as much as they would wish to volunteer and clean them, their conditions would never allow. Women who had children seldomly volunteered to do the cleaning as they were afraid of their children falling sick.

The problem of shared pit latrines as agents of chronic illnesses is not limited to Eldoret's informal settlements, there have been several episodes of cholera outbreaks in Kenya especially in low-income settlements. For example, in a report by Gathura and Koross (2015) published through the Standard Newspaper, in 2015 sixty-five people died of cholera in Kenya most of whom were living in informal settlements like Kibera and Korogocho where sanitation is poor. Notably, such diseases which are highly contagious causes a higher frequency of toilet-use as outlined by one of the community health volunteers in Langas while describing the measures, they take to reduce effects of poor sanitation in informal settlements. For PwD groups living in informal settlements, such highly contagious disease outbreaks and a

subsequent increase in frequency of toilet use exacerbates the situation they find themselves as they may not be able to easily use the toilet since accessing it first-hand is a problem.

Cost implications of inadequate toilets

The other issue that was seen to influence PwDs lived experiences in informal settlements was cost that they incurred for toilet services. Toilet inadequacy in Eldoret results in economic burdens to families that may include additional costs for toilet provision, pay-per-use toilet charges, increase in medical expenditure due to chronic illnesses and a reduction in family income when women have to abscond work to give care to the sick. One woman in Munyaka who has a disabled child highlights a situation about her toilet condition

also, the toilet is a problem. The owner has stated that if we would like him to make necessary changes including house renovations and providing a toilet, we will have to start paying over 1,000/- for rent [MU-04]

Another woman, who has a physical impairment and is HIV+, suggested how at times she has to pay for it

at times we go to our neighbour here at the weighbridge for 10 shillings per session and that is just too much when one has stomach discomfort [BT-02]

Most of the residents in the three settlements who reported to use pay-per-use toilet services complained of an added economic expenditure that is made worse if they also pay for the service at their workplaces- a trend common in the Kenyan informal economic sectors like *jua kali* and hawking jobs, which offer informal employment opportunities for slum residents. This study established that those households, which use pay-per-use services, expend on average Kshs350 per month for toilet services, which represents a significant proportion of their monthly expenses. A further probe into the issue revealed that episodes of chronic illnesses like diarrhoea, which increased toilet use puts, a lot of pressure onto PwD families if other expenses of health and lost wages are considered. Interviewee [BT-02] above recounts how she often pays additional expenses and at times misses essential drugs for her HIV treatment on top of toilet services

yes I do miss at times, like now I lack Septrin, I just use one drug, those ARVs, I only use those ones and are the only ones I get, they have said they do not have so we have been told to go and buy, we usually buy that one packet for 100 Kshs [BT-02]

Safety and privacy for disabled women and girls in toilet spaces

Jenkins & Scott (2007), Simiyu (2015) and Winter et al. (2019) have explored the challenges women face while accessing and utilizing various sanitary alternatives at their disposal.

Inadequate, unsafe, and unhygienic toilet spaces results in multiple and overlapping health, economic, and social impacts that disproportionately impact women and girls living in urban informal settlements (Coburn & Hildebrand, 2015:1).

For disabled women in Eldoret informal settlements, two integral issues stood out, namely safety and privacy. Indeed, these issues among other key bodily processes such as menstruation make women and girls more vulnerable than men and boys (Chaplin 2017). Men tend to have more options at their disposal, where instances of peeing on the roadside or at the back of houses was seen as normal and convenient for them but for women it was an awkward practice if it happens. Therefore, a lack of toilet facilities that are functional turns women into victims as they have to queue for the available ones or rush their much-needed comfort while using loos. Such experiences intersect with other needs typical for women within contexts such as Kenya where they tend to be sole carers of children, older people and even the disabled.

Toilets with low and incomplete walls, missing doors, ununlockable doors (from the inside and outside), poor lighting and location are some of the distinct characteristics which were evident in the shared toilets placing the women at risk of lacking privacy. As seen in fig 25 below of a shared toilet facility in a compound comprising of households in Munyaka, in between two of the toilets a partitioning wall is lacking and doors were missing for both let alone the roof covering. Yet, as discerned, some households were using them despite the risk it poses for children and PwDs using crutches or a visually impaired resident. To this end, there was little or no considerations at all for disabled women's privacy when urinating or defecating, let alone physiological needs such as menstruation, menopause, pregnancy, incontinence etc that are coupled with care implications as noted above.

In the recent past, various organisations have been speaking against the lack of sanitation facilities arguing that they are drivers to the risk of women being assaulted both physically and sexually (Gonsalves et al.,2015). This is substantiated by an NGO participant in this research, he points out that toilet spaces are hot spots for both sexual and physical abuse

They (PwDs) become victims of all these social vices that are very high in informal areas. Especially the female people with disabilities. The cases of rape in those areas are quite high... Yes, so many instances of people with disabilities being assaulted, being raped in spaces such as toilets [NGO-01]



Figure 25: A sanitary facility in one of the PwD's homestead in Munyaka (Source: Author)

While there were no direct accounts of rape and violence relating to toilet spaces in this research (possibly because of fear to expose such incidences), the NGO official alluded to have had several reported cases which they have had them escalated into the judicial system as criminal matters. In their scholarship to investigate women sanitation experiences in Mathare informal settlement in Nairobi, Coburn and Hildebrand (2015) found that insecurity and the lack of dignity because of poor sanitary facilities was a fundamental concern for female residents revealing how several households within high-rise tenements share a single toilet and the distance covered to the toilet is approx. 52 meters. They highlight a preponderance of evidence which depict spaces in toilet facilities where women use them (including for menstrual calls) are havens for perpetuating sexual abuse and physical assaults leading to extreme anxiety, powerlessness, hopelessness, marginalization and stigmatisation. The data evincing toilets and their use in this study reifies their findings albeit with an understanding from disabled women. Overall, women and girls who are living with disability have more

compelling reasons for using toilets comfortably in informal settlements relative to any other social groups and the same has to be considered when implementing designs for toilet infrastructures in informal settlements. Finally, and in contrast to the majority of respondents, some PwD families were content with their toilet services and seemed satisfied with the existing conditions:

Wairimu doesn't have any problem in that line. She is very clean. Sometimes the neighbours commend her for washing the toilet [MU-07]

Similarly, a resident from the same settlement a woman describes her son who is mentally impaired

He doesn't have to be told what to do. He knows when he needs to take a bath, and he goes to fetch that water for a bath. He even comes and asks me where the soap is, so that he takes his bath [MU-08]

The discussions about toilets and toilet-use as presented in this section depicts how sanitation practices in the urban significantly shapes the lived experiences of the disabled in informal settlements. Critical toilet issues such as privacy, hygiene and cost implications causes miserable lives for PwDs living within the urban as they have the least options relative to other population groups.

Conclusion

This chapter explored how PwDs negotiate the spatial conditions within informal settlements. Whereas several spatial elements and characteristics affected the disabled living in Eldoret's urban informal areas, housing, water services and toilet facilities stood out as the most urgent and germane to their disabling conditions. Housing which the disabled inhabited was broadly categorized in the chapter into three main typologies: shared-rental housing, borrowed/caretaker housing and owner-occupied housing. The three types of housing uniquely shaped the lived experiences in varying ways and the disabled portrayed a blend of feelings that showcased both strengths and limitations for each of them. For example, while on the one hand shared houses were the least desirable in terms of size and quality, on the other hand they had stronger social networks since many residents lived on the same compound and could hence accommodate disability elements through offering care (as also discussed in the previous chapter). The idea of 'borrowed' housing also exhibited some challenges since PwDs had no freedom to make changes to suit their conditions, however this housing was often affordable. Whilst owner-occupied housing types had better features for instance ample outdoor spaces for privacy, they were expensive and therefore the least

common housing type for PwDs. The chapter also discusses some of the challenges PwDs must contend with while living informally where most of them encounter frequent evictions due to insecure housing tenure, live in small-sized houses that are crowded, have limited housing choices and lastly are rendered homeless in many instances. Importantly, although the chapter discusses these housing issues separately, they do impact on the disabled in a distinctive manner, for instance homelessness was often the product of evictions and PwDs in many cases have limited alternative housing solutions.

Water practices in informal settlements also had significant effects for PwDs and shaped their lived realities. The impracticality of accessing water, the gender dynamics, water conflicts and tensions and financial implications are the key issues discussed in the chapter. In multiple ways, the disabled in the research areas detailed situations of being unable to draw water from wells or carry water from its sources like taps. In such incidences they relied on caregivers or neighbours for help. At the same time, there was an extant gender dimension in water provision within disabled spaces. Compared to men, women were the most exposed to the effects of water scarcity in disabled households. They struggled and devoted their time to source water, thereby limiting their chances of engaging in other viable livelihood activities. As a result of the lack of water, both intrahousehold and interhousehold conflicts and tensions were heightened pitting the disabled in disadvantaged situations in case of violent altercations. Finally, the cost of buying water from vendors was a painstaking experience for the poor disabled who had to balance other household expenses with its exorbitant pricing. Further, the chapter also discusses water practices from the perspective and experience of a disabled person, the most common being hand-dug well, water kiosks and water vending practices. Overall, all the three water practices had unique and interlinked ways of shaping the lived realities of PwDs.

The last section of the chapter discussed toilet facilities and how they influenced disabled people's everyday lives particularly the dominant pit-latrines. Some of the key issues raised by participants and presented in the chapter include deficiency of sanitation facilities within the informal settlements, lifestyle changes as occasioned by the shortage of toilets and resorting to makeshift facilities as alternatives. More specifically, participants raised more subtle problems that affected them given the situation of toilet facilities in their neighbourhoods. First, was the average distance to the available toilets which was higher than desired meaning the disabled had extreme difficulties reaching them. Secondly, the available toilets facilities in the three informal settlements were mostly dirty thus made it hard for the disabled to use them as some complained of unconsciously stepping on faeces. Lastly, were problems around costs and privacy which made toilet access and use a constantly negotiated process. Given the distinctiveness of the spatial conditions of informal settlements in

secondary cities such as Eldoret, a southern theoretical approach as outlined in chapter 2 is key for better understanding of the lives of PwDs given its insistence on placing centre-stage the material contexts of Southern cities. Moving on, the chapter examines governance processes that shape disability.

Chapter 7: Urban governance responses to disability in Eldoret

The previous two chapters analysed thematic findings that depicted the lived experiences of PwDs, their social networks and relations, households and the informal settlements in which they live. This current and final empirical chapter transcends beyond the realities that PwDs undergo by looking at the political frameworks and the interpositions of state and non-state actors within the urban governance system of Eldoret. It responds to the third research question- How do urban governance structures shape and define PwDs everyday lives in informal settlements? The chapter offers a critical reflection on the existing relationships and attributes between the government, PwD individuals and the various community groups in informal settlements. The main argument in the chapter revolves around how the state, non-state actors and traditional authorities respond to disability issues in Eldoret and the challenges the disabled experience while accessing provisioned services. This was achieved through tracing how relevant policies address disability, the gaps that exist and the subsequent ramifications on PwDs in service delivery. By looking at the gaps within the governance framework, the experiences of PwDs when seeking services, this study situates disability within wider political debates for institutional changes and reform. The core thematic findings in the chapter were derived from document reviews of key secondary literature and analysis of interviews.

The analysis is premised on how actors involved in urban governance i.e., all relevant actors frame and conceptualize disability through policy and the resulting service delivery to PwD communities. As argued by Collord et al (2021) and Kelsall et al (2021) respectively, urban governance and development trends in African cities tends to be dictated and dominated by power and politics. While reflecting on the impasse around governance inequality and power relations, the chapter interrogates the existing disconnections between visions that exist in normative urban governance frameworks and the realities about disability on the one hand and the everyday disability politics on the other where such politics is driven by poor or the lack of key urban services that are necessary for PwD everyday life as seen in the previous two chapters of this study. The chapter is divided into two main sections. The first half discusses the existing governance frameworks which shape disability in Kenya and by extension Eldoret. It focuses on three forms of governance namely the state actors, non-state actors and traditional authorities. Significantly, the chapter highlights how the traditional authorities whose role in recent times according to Collord et al (2021) remain complex yet they are often the first contact in the governance chain and have extensive knowledge of heterogeneous populations including informal settlements. The second half of it deciphers generally the

governance challenges and failures in Kenya, which impact on delivery of services for the disabled especially those in informal settlements.

Overview of the urban governance structures that shape disability

Governance structures in Eldoret's informal settlements were broadly categorised into two main responses-formal structures and informal structures. The formal structures as initiated by the state or non-state actors and informal structures which were self-driven/styled organisations within communities aimed at settling conflicts and seeking their own political spaces and voices. A key highlight from this study with regard to governance is how most participants had a deeper affinity to informal forums as important democratic networks by using them for rewriting their disability situations. Here social transparency and visibility of issues (including disability) affecting communities in the informal settlements becomes an asset for political mileage as the most vulnerable issues are often able to be brought to light. Rohregger et al (2021) while describing how traditional authorities (chiefs, sub-chiefs and community elders) in Kenya are pivotal in the implementation of social policies point out the ambivalence of the process and how it involves 'multiple forms of interactions between 'formal' and 'informal' institutional structures' (2021:405). Drawing from such description this research explores the political interplay between the two domains, the formal and informal governance frameworks, and the position of disability within the context of Eldoret. Three forms of governance types derived from the interplay namely the state, non-state state actors and traditional authorities are discussed in the sections that follow.

The role of the state in shaping disability in informal spaces

The national government through the various state departments and county government of Uasin Gishu are integral to the disability agenda in Eldoret's informal settlements. This study found two key ways in which these state agencies influence PwDs lived experience in urban informal neighbourhoods. First are direct interventions where the state implements a number of socioeconomic protection schemes that are intended to be of direct benefit to the disabled and are only specific and tailored to their needs. These schemes include cash transfers, loans and giving of grants that empower PwDs economically. Also, as part of social protection initiatives, the national government deploys public works aimed at providing casual wages to Kenyans who live low-income settlements including PwDs. Secondly, are public services which PwDs are dependent on such as health services, land management services e.g titling services, educational facilities and energy needs such as electricity provision. While both the casualised works and the general services by the state are universal for everyone in the various communities, they were critically beneficial to PwDs. The two forms of public service provision are interconnected, and participants experiences are varied and are relative to their

disability conditions. For example, depending on one's disability some respondents stated they were ineligible for some specific state services meant for some category of PwDs. It is important to note that although some of these state policies were not purely tailored for the disabled, they indirectly had enormous effects on their lived experience. Therefore, the study seeks to explore such policies where the most germane and useful disability features are extracted and amplified. In the same manner, while acknowledging that there exist multiple services which the state engages that support the disabled either directly or indirectly, some of which are briefly discussed in chapter 3, this section of the research illuminates two state initiatives that directly relate to PwDs everyday lived realities- the *Kazi-Mtaani* initiative and the cash transfer initiative. The two will serve to portray the state's role in shaping disability in informal settlements.

'Kazi-mtaani' initiative- a stopgap or sustainable solution?

As an idea to provision vulnerable people in poor urban neighbourhoods with livelihood opportunities, the state fashioned an initiative dubbed *kazi-mtaani* a Swahili term which translates to 'jobs in the neighbourhood'. The initiative is an example of a state program which although is not specifically meant for PwDs, it was mentioned continuously by participants as a key source of income. The initiative according to an NGO official, started in 2020 after the outbreak of COVID-19 pandemic. Understandably, the nationwide program targets youths in dense urban settlements and has created a positive impact on their lives through reduced socio-economic vulnerability, enhanced social inclusivity and improved well-being (Kimotho, 2022). The program came as a safety net during lockdowns for those who not only lost job opportunities but had limited livelihood options like informal businesses. Due to COVID-19 the informal sector which is the lifeline of most people in cities was immensely affected because of the imposed restrictions, key being curfews which worsened poverty situations (Kimani et al, 2021). In other words, the initiative was meant to cushion the vulnerable individuals and households in informal settlements from the adverse effects of the pandemic. For example, a young disabled woman in Langas while sharing how her fruit vending business was affected by the pandemic expressed how the initiative has been her main livelihood source. She recounted

yes, sometimes things can be hard with what I earn from my job, but you just got to hustle hard and see that we get something to pay for rent, because you know fruit vending goes with the kind of weather and during COVID nothing was happening, Kazi-Mtaani was important and kept me going [LA-10]

The initiative is designed in such a way that youths are recruited to clean the environment within informal settlements and unclog drainage services and then get paid by the state on a

weekly basis. While the initiative was aimed at recruiting various youth categories, it was an essential way that PwDs supported themselves. A participant who lives with short stature and is one of the officials of the initiative in Langas shares her experience about the impact the program has had on PwDs

when the Kazi mtaani initiative was started, those disabled youths whom we saw were the idlest and would be roaming and begging in the neighbourhood were given priority over the others [LA-04]

The views above highlight how state initiatives at the local level have a direct impact on PwD lives since they provide a platform for them to engage in activities that are economically viable. As an affirmative measure, PwDs who are in a position to engage in the initiative are prioritized however she stated that some of them wanted to be competitively recruited like the rest of the youth. The initiative offers both an opportunity for a livelihood and a way to keep jobless PwDs engaged in communal service thus building a positive social experience with other residents. Therefore, in that sense, stigma and discrimination described in chapter 5 are to a certain extent reduced and PwDs develop a sense of community belonging. She goes on to highlight that 'when the youth are busy and get some earnings, they abandon the habit of theft' indicating that the social grants appear to shape and curb social ills. This corroborates findings from an unpublished social status report by Lijodi (2020) about the impact of *kazi-mtaani* in Mukuru slums in Nairobi which showcases that since the inception of the program fewer youth PwDs included have not only engaged in cases of drug and substance abuse and criminal gangs who terrorize residents have declined and overall crime rates have considerably reduced. Apart from the social and economic aspects about the *Kazi-Mtaani* initiative, some respondents alluded to its effect on housing as its income is used to pay for rent thus having a direct effect on shelter of PwDs discussed in the previous section.

Although the initiative comes with benefits to PwDs, a section of the respondents was critical of it in various ways. Apart from Langas, the other two settlements seemed not to feature any disability inclusive strategies in their *kazi -mtaani* initiatives. This means that from the national level the emphasis on integrating diverse youth has not been effective enough. As Kimotho (2022) notes that while the initiative is well intentioned since it generates viable income for the youth, PwDs are seldom integrated. Further, he argues that PwD youths could benefit more if they are facilitated with better welfarist initiatives such as the unconditional cash transfers as discussed in the next section. He continues to highlight that for *kazi-mtaani* to create a sustainable impact, it has to be integrated with other conscious efforts such as better working environment through working equipment for the disabled. As discussed in chapter 2, *jua kali* an informal economic practice is essential for livelihood opportunities in urban informalities

and thus training opportunities by the state may assist PwDs youth skilled to be self-employed within their neighbourhoods. A community health volunteer who also works for the disabled reveals more on how PwDs can be assisted by the state

The disabled need to be assisted with capital to start small businesses. 5,000/- can go a long way in kickstarting a good business. I am thankful to the County government because it allows the disabled to sell their goods near the edge of public roads. Examples of simple businesses for the disabled are shoe repair, shoe making or selling of second-hand goods... there is one disabled person whom I know. She is talented in hair dressing but doesn't have the necessary equipment to start up a salon business. She does her hair dressing business from house to house, and the pay is much lower this way [Community volunteer]

The intersecting identities discussed in chapter 2 explains how different social categories have to be taken into account for state programs to ensure inclusivity. Because disability differ some PwDs might not manage to engage in specific activities and therefore such dynamics must be accounted while framing the project. Another challenge about the initiative was illustrated by one of the NGO officials who support similar programs in informal settlements. He stated that

PwD youths from the poorer family backgrounds have to be discerned from their well off counterparts. Background checks by authorities like village heads and chiefs in charge are vital if the initiative is to be a success [NGO-01]

The official who works for an organization that helps PwDs argues that the existing design of the framework does not fully delineate the neediest in the communities, while it's a right for anyone to be employed by the state, his understanding of the Kazi-mtaani initiative is that its intention is to prevent poor youths who form the majority in the urban low-income neighbourhoods from further effects of poverty that came with the pandemic. Yet, the framing of the state initiative portends a dichotomy as to whether it's a universal scheme meant for anyone between the ages of 18 to 40 years and can be termed youthful or is it a tailored program that targets only poor and vulnerable youths. Accordingly, the initiative at the minute presumes all youth in urban informality live in poverty yet as we saw in previous discussions informal settlements are diverse and highly stratified. Therefore, he alludes that the initiative has to have an elaborate mechanism that distinguishes the various youths to ensure only the most deprived benefit thus expanding spaces that could involve more PwDs to be involved. Kimotho (2022) corroborates the arguments by the NGO official, he highlights that local-based knowledge is key if poverty levels are to be identified. Rather, instead of a blanket demographic targeting youth in urban informality other social dynamics such as disability and levels of disability is key and also factors such as orphanhood. In that light, a community-

based strategy that entails expansive local participatory processes is key to understand the most needful to be recruited and waged in the program. While it is difficult to create a flawless process that is indiscriminatory, grassroots organizations and traditional authorities covered in coming the ensuing sections are fundamental in adjudicating for the most deserving beneficiaries. Ultimately, a process that encompasses the participation of citizens as discussed in chapter 3 on better planning models in urban informality would be imperative by ensuring the resources from the state have optimal effects. While distributing entitlements to the vulnerable urban poor, transparency and accountability are also unequivocally vital and have to be strengthened for legitimate end products (Lines and Makau 2018).

Direct cash transfers- Inua jamii welfare program

Interviews carried out with several households in the three informal settlements alluded to depending on cash transfers as their main source of income. Increasingly, cash transfer policy has become a key poverty reduction and social safety strategy that has been adopted by most countries in the global South (Bastagli,2019). Two types of direct transfers are common in most countries, unconditional cash transfers which can be described as those universalized benefits for all citizens without any attached conditions, conditional cash transfers which are those benefits that are given with specific conditions and requirements for one to access them and are the most common and successful in emerging economy countries (Levasseur, 2018). In Eldoret, conditional cash transfer was the dominant and while many participants acknowledged their importance their criteria keep changing with implications for the recipients. This was mentioned by a disabled woman in Langas who decried of the process

They used to give all PwD, but nowadays they give only those who are most vulnerable. It is worth 2,000 shillings per month, if you have the card of PwD. This card is very useful [LA-04]

The cash transfers programmes in Kenya dubbed *Inua Jamii* (Swahili word meaning uplifting families) was extended to cover PwDs through the 'Persons with Severe Disability Cash Programme' (PWSD-CT). The upscaling was done in 2010 by the government after successfully rolling out two other social protection programs namely the Orphans and Vulnerable Children Cash Transfer Programme (OVC-CT) and the Older Persons Cash Transfer Programme (OPCT) in 2004 and 2006 respectively. According to the disability officer in Eldoret the aim of the programme is

To improve the lives of poor PwDs through the provision of a predictable cash and also empower the full-time caregivers of severely disabled persons who do not have other

livelihoods opportunities or rendered without a job given care responsibilities... for one to qualify for the grants one has to have a card which is acquired after a medical report administered by recommended and gazetted hospitals [GO-3]

According to the official who works for the National Council for People with Disabilities (NCPwD), the state is responsible to cater for the vulnerable including PwDs and therefore is tasked through its systems to have a welfare approach, in this case the *Inua Jamii*. As the custodian of welfare, the state officials have control and determine who qualifies for it and thus exposing the system to unfair and discriminative distribution. Where eligibility criteria is vague for example in terms of the qualification, officials such as medical officers who are tasked to assess and determine who fits the threshold are in many cases open to their own interpretations which might be unfavourable to some PwDs. For example, the case of medical officers being mandated to determine what really constitute disability where emphasis is probably placed on functionality and less of other factors such as the environment, family background, financial conditions and cultural beliefs which as explicated in the ICF definition earlier in chapter 2. This describes a fundamental issue since it determines how the grants can be distributed where on the one hand for one to be eligible a medical assessment has to be done and on the other, such legitimizes the medical model of disability where medical officers hold authority over the process. The officers' powerful positions tend to give them hegemony over other experts e.g social workers who could add a more elaborate and complete criteria for a just outcome. An NGO official interviewed alluded to various conflict of interests when serving the disabled in Kenya and puts the blame on the state if programs such as *Inua Jamii* fail. While responding to the eligibility criteria, he noted:

for PwDs it's not clear on who should be eligible and who is not eligible, so whoever is complaining I do not think they fall under that category of severely disabled but we have a very big number of people with severe disabilities who are not on the scheme, so we cannot blame them but we blame the government, am sorry to issue this statement the government has wronged people in offices especially in the line of PwD services, I am a trained medical practitioner and I only get to serve these people with disabilities one because of passion and two because of my personal abilities, otherwise if you take someone with my training and put them in the middle of service for people with disabilities they will restrict their services to what they are trained for because I am trained to provide devices but the fact that I can be able to argue out on their needs it's just an additional thing, the government has employed teachers, community development people and employed them as disability officers, these people have no knowledge of what is supposed to be done for people with disabilities [NGO-02]

While the *inua jamii* is done by the national government, the local or county government has a similar arrangement to support the initiative (no name to it was provided). The same NGO official above commented on the same by giving a description of how the county government has played a role in the process of cash transfers. He noted:

But the counties have been doing parallel cash transfers, not monthly, but seasonal cash transfers to people with disabilities. I'm not sure of any success stories, but I've seen families that have, through those monies have been able to put up maybe quality units, put up some small dairy unit for them. They're those little success stories however the two schemes (national and county) seem to work without any relation [NGO-02]

From the above the county government program targets PwDs who are fully dependent on caregivers (as the term severe implies) and in need of care on a day-to-day basis including provision of toiletry and protecting them from danger given their conditions. The officer emphasizes that for a caregiver to receive the funds one has to be offering full-time support which in turn makes the person unable to engage in other possible activities for income generation. As the official alludes one of the key issues that affects good governance in most countries is a lack of a working relation and integration between the various governance platforms. Meaning that there are teething problems and overlap of services because of the poor relationship between the county and the national government specifically affecting vital disability state policies like the cash transfers.

As discussed subsequently in this chapter, respondents argued that there is too much bureaucracy in the CCT process as a challenge and the state therefore needs to rethink offering UCTs to all PwDs. This is supported by Kimani et al (2021) who suggest that there is enough evidence which links the provision of UCTs or temporary basic income to people living in urban informal settlements and their potential to provide themselves with basic needs such as food and shelter. They further argue that beyond positively impacting on the provision of basic goods, UCTs are fundamental in people's wellbeing and leads to reduced social vices such as crime and gender-based violence. The same NGO expert above equally felt the CCT program is not ideal, he states

But I think the approach is not sustainable. That approach is not sustainable, from the national government, we have a monthly stipend for severe disabilities, they get 2000 shillings per month. But if you follow up to see the money has had an impact on them, it's not much, it's not much government needs to package something better for them [NGO-02]

Though the positive impact of the CCT program is undisputed to many in Eldoret, some participants who were less optimistic of it felt that the amount given was insufficient and therefore they have to depend on other mechanisms such as borrowing from their *chamas* as discussed in chapter 5. A physically disabled man from Langas gave such a revelation:

The big challenge is that the government only seems to offer help to the disabled, but in reality it hasn't disbursed enough money to help us.... I have friends who help me once in a while. But such help isn't dependable because the well-wishers give me such help at their own will and at their own time [LA-06]

Despite the challenges raised both *kazi-mtaani* and *inua jamii* initiatives there is clear evidence of how state responses do positively shape the lived experience of PwDs and how an improvement of the same could better their lives. The programs are vital since they serve as direct household income that reduce poverty by providing for basic needs. While the exact number of respondents on the scheme could not be determined, what was discernible was that some of them were fully dependent on the program and felt let down when the service run out or gets suspended, ultimately suggesting their importance. Critical funds such as those meant to cushion PwDs against the effects the COVID-19 were unfortunately short term measures and respondents described the state's short commitment into such initiatives. Moving on, the next section explores non-state actors which were equally if not more important than the state actions since they not only offered widespread services to the disabled poor but assisted the state to implement their policies.

Non-state actors and how they shape informal disability spaces

Non-state actors (NSAs) in the category of disabled people organisations (DPOs) and non-governmental organisations (NGOs) shaped the lives of PwDs in Eldoret's informal settlements. This section discusses DPOs and NGOs together as fundamental actors of urban governance. While it might be prudent to delineate the two and discuss them separately, it was observable that both DPOs and NGOs in their efforts work in tandem and therefore discussions herein will be done while referring to both but it will pick out specificities when necessary. Whether supporting state functions or filling gaps where the state does not reach, the NSAs in Eldoret were critical in the provisioning of services for PwDs including economic empowerment programs that cushion poverty, educational initiatives that improve literacy, health programs like rehabilitation services and even housing initiatives. In one of the interview sessions, a director of one of the NGOs sums up how their work shapes PwDs lives:

our work is about poverty eradication, through empowerment of the citizens. And also to bring sustainable change in the communities. In 2018, we started a new project, where we were targeting persons living with disabilities in Eldoret's poor settlements. And our work was, was covering the entire city reaching out to persons with disabilities from each and every ward with education for raising disability awareness. Basically teaching them about their rights, the laws, opportunities and privileges. And also we have income generation support program, whereby we are working with PwD groups to give them support in form of seed capital that they can be able to engage to, they can also be able to engage in the community whereby we are looking to achieve social participation and integration of persons with disabilities with others [NGO-01]

Apart from NGOs working across the city, within communities disabled people self-organized themselves into *chamas* as discussed in chapter 5. While most people saw grassroots DPOs as essential in their lives others did not see the benefits of being in such entities. In Eldoret self-organised *chamas* which were formal and duly registered had stronger mandates of promoting their members welfare. For example, through *chamas* members would access state benefits like grants and loans for businesses or equipment such as wheelchairs. Evidence gathered from the study areas depict that there exists a strong relationship between DPOs and NGOs since the latter support the former while keeping it independent for the benefit of both. One of the participants in Langas highlighted how their *chama* is a grassroots agent for an international organization-THIS ABILITY-which works for the inclusion of women and girls by amplifying their voices to be listened by the state. She noted:

Currently, there is this organization which deals with disability and whose name is "This ability." Our *chama* is its representative here in Langas. The support which they give us is like for example, if they hold an event here, we work as their agents and mobilizers. As a result they pay us some stipend as a group..we help them run their projects meant for the disabled [LA-04]

However, as argued by Bezzina (2017), NGOs especially the ones funded by international agencies tend to dictate the grassroots DPOs positioning them as puppets where the strings are pulled with a western perspective. According to her the NGOs do emphasize their own disability interpretation such as the social model thinking, rights-based or relational models yet these framings are not necessarily applicable and pertinent to PwDs realities in contexts such as Eldoret. Although such importation of knowledge and modern-day colonial processes exists and has been contested as discussed in chapter 2, an inevitable shift to the

understanding of disability from a Southern perspective has to encompass the roles played by NSAs as they are incredibly vital and instrumental in shaping the lived experience of PwDs.

Since the running and organization of NSAs in Eldoret is often done and comprises disabled members themselves, their work is usually better tailored and suited for PwD's particular needs. They therefore tend to spearhead development initiatives either by promoting state roles or entirely substituting the state as key providers of services as expressed by the NGO worker above. Since they tend to understand disabled needs better or are often closer to the people, a key function by NSAs is setting precedence for the government to emulate. While describing the impact of one of their projects, the NGO official recounts that

the first thing we noted when we started implementing our project was the feedback from the various existing stakeholders. For instance, the county government told us you guys are doing a good job...when we work and deliver our projects...the state is then be encouraged to help PwDs too [NGO-01]

The official's arguments elicit a situation where NSAs are seen to be pacesetters in delivering service for PwDs. He categorically places the stake on their organisation whose initiatives then ripples and triggers the state to act. Further he argues

and the biggest success that my organization has seen since the implementation of this project is on how we were able to influence the County Government to act, because previously before the project, they were not acting, but after our project of involving them in all activities, they have now been acting [NGO-01]

The official also argues that on top of pacesetting for the state to encourage them work for PwDs, they also lobby for PwDs to get opportunities such as jobs and government services e.g local purchase orders (LPOs). Through a report they conducted of the neglect of PwDs in workplaces and how they have limited access to job opportunities, he describes of an affirmative action they lobbied for by illustrating how the county government gave employment opportunities for PwDs. He noted that

for example, in 2018 they (local government) categorically advertised positions and employed around 52 persons with disabilities. Yes, the county government made a u-turn in their initial human resource way. Now if you go to the county government headquarters, the people who are cleaning the floors, there is a group of persons with a hearing impairment and so on [NGO-01]

When engaging the NSAs the state often has a mixed track record and do not necessarily lead the way for disability services. While stressing this point the official argues that the state does help those they see as worthy of investing for example the well-established and structured *chamas*, DPOs and other similar grassroots organisation. At the same time, he alludes that NSAs as part of the civil society directly lobbies for disability rights.

we've done lobbying in collaboration with the National Council for personal disabilities. We lobby by all means both legal and protests, we are lobbying for example for disability representation in various sectors including the buildings approval board in the county.... that is why you can see the new buildings in town are disability friendly, that there is a ramp, there is a lift coming up where it wasn't before [NGO-01]

Therefore, as it is the norm for NSAs especially the International Non-Governmental Organisations (INGOs) to support and promote thriving *chamas* and DPOs and technically lobby for them which in turn ripples the state to act and boost its public image to both the citizens and partners in development. The arguments by the official that they as NSAs on the one hand lead the way for government to follow via their projects and on the other hand lobby through protests and legal actions is a typical reflection of the reality about government's hesitant position on matters relating to disability in Kenya. However, as the official alludes there seems to be changes in the recent past as the state is bringing them on board together with representative of the disabled hence some of the mentioned physical changes in newer buildings within the city. This is corroborated by a government official who highlighted how the government when rolling out planning programs in informal settlements work closely with the information that NGOs share with them.

Normally we get accompanied by the various stakeholders....and normally the firms working in the specific neighbourhoods do harbour critical information which make our interventions easier. They also have vital ideas of the needs of vulnerable groups including PwDs [GO-01]

The interview with the planner highlights how NSAs are key for planning functions especially mainstreaming specific disability issues. In supporting the views of the junior planner, his counterpart who is the director of the department expresses of a change in attitude towards interventions that are disability friendly because of the effort put in by NSAs and the disability movement in the country. This reactive approach by the state is critiqued by another NGO official, who is the director of Association of the Physically Disabled in Kenya. He thinks that both state and non-state actors should be proactive instead of being reactive and that roles by either players have to be in equal measure. He states that

there is a wrong mentality from people that disability work is specialised for a few...and that only NSAs who work with disability have the outright mandate for the same. They do not see it as an issue which needs a wide spectrum of players and that as an issue it has to be integrated into policy from the start. The policies are crafted and then PwDs become an afterthought...so when it comes to implementing the issues and when they hit a dead end...the difficulties arise because we all have not thought of PwDs and their needs together [NGO-02]

The director's views tend to promote an all-inclusive approach of roles by both state and non-state actors and that disability thinking should be incorporated in projects from the beginning and responsibility has to be shared between actors. While sharing his experience of working with the state, he highlights that as an organization they are usually brought into projects when they have already been rolled out, yet they ought to be involved from the beginning for better approaches. In this case the role of NSAs would be better able to support and complement that of the state and not just set precedents. To this end, it is important to note that the study mainly draws insight from the NSAs staff behavior and attitude towards the state and the disabled people within communities.

On the one hand most participants saw NSAs as beneficial such as lobbying for their rights and implementation of local level projects for inclusivity meaning their working had a positive impact on their lives and that they were productive. On the other hand a minority viewed them in a negative manner and that not all of them are progressive and beneficial. They saw NSAs as taking advantage of their disabled situation to make profits from their funders and international donors. A subsequent section herein will highlight those NSAs that operate as charity but fail to adhere to the regulations. For example, a respondent from Munyaka while expressing how many agents of NSAs have visited them highlighted how potentially the organisations benefit themselves from disability imagery;

first let me appreciate what these organisations do, they do good stuff but honestly they will not help everyone, others come visiting for their own benefit, they come collect information which benefit because they get money from donors out of our images which is sickening to think about [MU-10]

The same narrative was mirrored in private caregiving homes within Eldoret who profit from donor funds, yet they expose PwDs especially children to dire conditions. This is a reflection of how disability as a social condition can be abused and misused to benefit elites in NSA firms through practices that can be classified as corruption-discussed in the second half of this chapter. According to Larsson (2018) private institutions in Kenya working as orphanages for abandoned disabled children thrive under the charity as an ostensible reason of helping yet

they place PwDs in life-threatening and deplorable conditions. Larsson reveals that hundreds of these NSAs, are potentially unlicensed to care for the disabled. Evidence suggests that they lock up children in confined rooms restraining them hours on end forcing the children to defecate and urinate within these spaces. These produces some of the challenging spatilities of disability discussed in the previous chapter. While this signifies the consequence of the charity model and how it defines the way disability is understood in the country, it showcases how informal institutions shape PwDs and how power relations manipulate the system allowing them to operate on the one hand gaining from donor funding and on the other exposing children to inhumane and poor conditions.

Traditional authorities and how they shape disability

Similar to state and non-state actors which are perceived as formal institutions of urban governance, there were traditional authorities and actors who were equally vital to shaping disability in Eldoret's informal settlements. They formed the lowest levels of governance and played a key role in rendering development solutions on behalf of the state or non-state actors by accounting for all living in communities including PwDs. Seen as informally constituted entities, these traditional actors facilitated policies and programs delegated to them by the formal actors. For instance, village elders would mediate between the people and the local authority on subtle issues such as state projects or functions that are contested. Traditional authorities in Eldoret's informal settlement included chiefs, sub-chiefs and village elders where the latter is the lowest level in terms of hierarchy. Accordingly, two levels of authorities are exhibited, the first one is the level of a dozen households and secondly the village level popularly known as the *nyumba-kumi* initiative and community *barazas* respectively. Details of these two power structures and how they shape disability is provided next.

The ten-household cluster initiative in Eldoret: *nyumba-kumi* initiative (NKI)

The *nyumba kumi* initiative (NKI) or ten-household cluster initiative in Eldoret was evidently the lowest level of governance which was directly in contact with the people and their households. It played a key role in rendering development solutions on behalf of the state as they possess local knowledge relevant to most if not all residents including PwDs in a given place. *Nyumba kumi* in Swahili means ten houses, therefore NKIs is a constitution of ten housing units which tend to cater for each other's needs. The need of the state to profile citizen's characters in various neighbourhoods necessitated the NKI system (Were and Opondo, 2021). Although criticized by some an intrusion of the private space, NKIs are aimed at providing informed solutions (ibid). The NKIs in Eldoret were organised into strong cohesive units cognizant of most of the needs of the citizens within their cells. For instance, NKIs are

critical in crime reduction, a woman who is a caregiver to her disabled son describes such a role of NKIs within Langas and how they promote secure spaces for her son:

Yes, through the *nyumba-kumi* initiative elders usually organise themselves when the situation escalates, for instance there was a time crime became serious until people were being lynched, even this year there is an old man who died just here, and it was just 8pm in the evening while going back to his home [LA-04]

NKIs are headed by a person nominated as an elder by a council of elders and reports to the *mzee wa mtaa* who is the head of the council of elders in an urban neighbourhood. According to Njenga (2017) the NKIs in Kenya started as a way to curb surging crime levels within communities through self-policing and 'knowing the next door neighbour'. Crime rates had soared in the country in the last few years and as a strategy the NKIs were introduced by authorities (ibid). NKIs are about citizens knowing each other as a principle of good neighbourliness. The system is premised on the understanding that locals have rich knowledge about their neighbourhoods and can spot unusual events that may be of risk to them (Njagi, 2020). In addition to enabling safe spaces, NKIs also build sustainable communities that are socially cohesive and well-integrated (ibid). While the concept started as a security enhancing technique or crime reduction model within communities it has since morphed to become one of the most fundamental units of governance that promotes social cohesion (Andhoga & Mavole, 2017) and inclusion of the vulnerable including the disabled in poor communities such as informal settlements of Eldoret. This is echoed by a mother to a disabled boy who described of how NKIs champion for the voiceless PwDs who as described in chapter 3 are within the Kenyan context often locked or tethered in homes. She notes

when the security is not good there is a way the elders have organised themselves and come out with viable solutions but the initiative has also been used to help lobby for the disabled needs and those locked up in known households here in Langas and kwa Mumbi [LA-04]

Whereas the initiative as a strategy is often assumed to have been adopted from Tanzania's *Ujamaa* policy (Ndono et al, 2019), a socialist political narrative, NKI concept has its origins from global household practices that tended to influence mobility, reduce crime, provide basic needs, assess socio-spatial and structural needs and impose political allegiance and elitism (Were and Opondo, 2021). NKIs are strongly linked to a particular *modus operandi* in a given context, for example the way politics is done and the economic situation. As mentioned above NKIs have evolved from being a crime reduction strategy through household registration to complex tools of civic engagement and community participation in activities that promote

social-political citizenship (ibid). In the African context, cultural traditions are key for regulating the lives and well-being of community members and social structures revolved around existing cultural tenets. Many countries have transformed these structures into NKIs as a leverage to curb social unrests key among them insecurity (ibid). While the realities within such contexts and the absence of public service create gaps and a breeding ground for crime, NKIs as a voluntarist approach not only provides stability through local knowledge, but they have also been transformed into mechanisms of mobilizing populations within these seemingly often-ungovernable neighbourhoods to partake in development activities.

Not everyone supported NKIs in Eldoret, other participants felt the concept was too intrusive and infringed on privacy levels as stated above while they saw *nyumba-kumi* volunteers to be wielding unnecessary power to individual who then tend to abuse that power. In light of that, Mwangi (2021) highlights how in Kirinyaga, Kenya, some NKIs roles exceeded their mandates and placed on themselves roles which were exclusive for the state. From Mwangi's report a government administrator in the same place stated

The role of the *nyumba-kumi* volunteers is to gather anything unusual and make a report to the chief or sub-chief who have the mechanism to escalate the matter to the concerned authority for action...I hear some are creating fear in communities for personal gain

However, most of the critiques from Eldoret were amenable to the benefits of NKIs although they alluded that the strategy has to be regularized through legislation. Were and Opondo (2021) argue that the NKI strategy was more of a reactionary approach 'and lacked an ideological backup that would have endeared it to the population and the implementers' (2021:13). Further they posit that in Tanzania for instance, the NKI model was more elaborate and controversial as a socialist process borrowed from Chinese Maoist socialist policy (Were and Opondo, 2021). The initiative in the 1960s became an effective political mobilization tool for the socialist ideology (ibid). Therefore, so as to give ardent solutions as intended of NKIs, they have to be organised into coherent and strong movements whose roles and mandates are clear and do not exceed what is expected from them. One of the key challenges of NKIs was in their composition and decision-making structures. Most were headed by the dominant ethnic groups and most decisions tended to incline towards male voices and less of female. Nevertheless, the arguments herein reflect on the working of NKIs as key promoters of development at the lowest scales and that collaboration of NKIs with the state is critical if solutions to disability challenges are to be achieved. Apart from social relations within NKIs, there was a tendency for inter-NKI relations which created a more complex form of traditional or informal NSAs which shaped PwDs lived experience as discussed next.

Community barazas in Eldoret

Narratives of community heads from the three informal settlements depicted *barazas* as a key planning platform where members of the community meet with or without the knowledge of the local administration to self-help themselves on pertinent community issues. A *baraza* literally translates to a gathering of people who meet for strategic planning especially for informal political engagements between elites and non-elites. The *baraza* is a reflection of neighbourhood planning associations (NSAs), a similar local planning conceptualization briefly highlighted in chapter 3 of this thesis. Borrowed from the colonial past, the *baraza* is one of the most enduring features that was bequeathed to the post-colonial administration (Omanga, 2015). In Eldoret, unlike the NKIs which are intended to be spontaneous, *barazas* are purposeful and planned, though less robust than formal political debates, they are usually triggered by an incident that happens and needs communal intervention. In the three study sites while the NKIs were headed by an elder as depicted above, the *barazas* are semi-official and conducted by chiefs or sub-chiefs who traditionally were the local representatives of the state. The *baraza* fora in Eldoret's informal settlements served PwDs with a space to engage with the rest of the community. A physically disabled person describes *barazas* as

such small organizations (*barazas*) exist here in Langas, they constitute several people from various neighbourhoods, we usually get important government information via the meetings [LA-06]

The *barazas* form a vital urban governance space where PwDs considered vulnerable and discriminated against gain vital fora to share their opinions on generic community decisions. Respondents from planning department attested to *barazas* as critical spaces where they interact with all groups of people for planning considerations. They mostly described *barazas* as interactive spaces where they meet communities' representatives including the disabled. One of the planners highlighted that while preparing for local physical plans, they ensure that in the committee *barazas* PwDs are fully involved. He states that

we ensure that at least we have one person representing the PwDs and so that at least they can give their input, they can give their comments and their proposal and their insights, the interventions they want. So that it can be incorporated in the plan [GO-1]

Some participants had challenges with *barazas* as modes of urban governance. The same participant MO above who had a physical disability state that they lose information if they do not attend *baraza* meetings. He decries that

sometimes, the village elder has information but he doesn't pass it on to us because we do not attend *barazas*. So, many remain in a state of ignorance [LA-06]

Such challenges have encouraged some to explore new ways of reinvigorating the ways in which the aging *baraza* model is conducted. As mentioned above, previously in the 1990s according to Omanga (2015) *barazas* in Kenya were ‘quasi-compulsory’ symbolic meetings that were ‘highly charged’ (Berman, 1997:346) and convened by the then powerful chiefs who had immense and legitimate authority to push for the state’s agenda and political narrative (Omanga, 2015). However, the influence *barazas* has waned in the run up to the 2010 constitution. Indeed, with changes in governance and the diminishing roles of traditional chiefs under the new legislative framework it was no longer possible to force people to attend *baraza* meetings. Furthermore, chiefs have historically been associated with coercion and brutal force and thus have commonly been perceived negatively. Such a perception affects *barazas* as they are usually the main convenors though not always the case. Due to the fading role of *barazas* and chiefs in modern Kenya, new forms of conducting *barazas* and chieftaincy have emerged recently. For instance, Omanga (2015) while working in one of Nakuru’s low-income settlement of Lanet explores how a new way of conducting *barazas* through social media mainly twitter has transformed its structure. The ‘new *baraza*’ model he argues creates a space for increased mediation and deliberation and thus complements and in a way tends to replace the aged colonial *baraza* practice in the country. At the heart of it is technology via twitter and mobile texting services whose popularity has grown fourfold in the country providing a deliberative platform for collective action in urban communities where mobile connectivity is universal. Presumably, the mode can be highly applicable in disabled spaces and prove effective for some physically disabled who ostensibly might not be able to attend conventional *baraza* model. This shift in form of *baraza* (to online) was however not evident from the data collected for this study, but can be identified as a key area for future research.

Table outlining the actors in governance, their current responses and the recommendations:

Governance actors	Responses	Policy Recommendations
State actors	<i>Kazi-mtaani</i> initiative: The state developed this initiative as an economic safety-net for the urban poor	Deliver PwDs tailor-specific programs within the initiative that would suit a diverse range of disability conditions

	including PwDs especially during COVID-19	
	<p>Direct cash transfers:</p> <p>The cash transfer policy is a state tool used to alleviate poverty through cash disbursement both conditionally and unconditionally for vulnerable people including PwDs</p>	Reduce the bureaucracies that is imposed by conditional cash transfers and instead offer unconditional cash to the disabled
Non-state actors	Services offered through disabled people's organisation (DPOs) and non-governmental organisations (NGOs)	Initiate a framework for a better working relationship between DPOs and NGOs so as to complement each other rather than compete to offer services for the disabled
Traditional actors	<p><i>Nyumba-kumi initiative:</i></p> <p>Indicating 10-house clusters, NKIs are the lowest forms of governance which provided the state with critical information for broader policy interventions</p>	Regulation of NKIs activities through policy legislation to define their roles in the governance structure

		Scaling up diversity in decision-making to include minority ethnic groups and women.
	<p><i>Barazas:</i></p> <p>A baraza translates to an ad hoc gathering of people who meet for local strategic planning</p>	Reinvigorating the role of barazas through adoption of modern modes of communication such as social media to disseminate information

Governance setbacks from a disability perspective

Building on the urban governance responses discussed in the previous sections, several participants highlighted aspects of poor governance as common themes which defined service provision and overall planning in Eldoret’s urban informal spaces. It was vital for this research to unearth some of these thematic challenges which had an effect on the urban lived experience of PwDs. Poor governance according to various scholars lead to non-compliance and the resulting failure to deliver on the planning mandates and an ultimate exclusion of sections of the urban populations key being the disabled (e.g Devas et al, 2004; Jenkins, 2000; Rakodi, 2001). Three of these themes generated from the empirical materials and discussed in the forthcoming sections include political disenfranchisement, mistrust and bureaucracy, corruption and bribery. These challenges to sound urban governance are enmeshed with urban informal politics that characterize a key component of urban informality as explicated in chapter 2. The shortcomings though defined here distinctively tend to intersect with each other and impact various PwD categories varyingly, for example, bureaucratic red tapes are often baits for mounting bribes to speed up government processes. Importantly, factors such as stigma and perceptions born from cultural beliefs as discussed in chapter 5 are triggers and drivers to these governance challenges.

Everyday politics of invisibility and disenfranchisement

While most participants in this study seemed to acknowledge the importance of being active in political processes, their participation and subsequent representation in urban politics was uncertain. Participation in political processes such as voting in municipal elections, representation via holding positions in the local assembly and budgeting processes are key to achieving democratic spaces and rights (Thu, 2016) in urban areas. As this research was

conducted in a time when politicians are bracing to woo urban residents to vote for them, PwDs felt that even with the seasonal excitement, they were being excluded or ignored yet whilst they form a legitimate constituency and an integral voting bloc they are often overlooked because their numbers seem nominal and insufficient. A PwD activist in Langas and an aspiring politician in the coming 2022 election cycle whose testimony and experience with local politics was useful narrates;

I have been interested in politics for a while now but opportunities for elective posts have been few, I know the weight politics has on decision making and budgeting of resources [LA-11]

As a person living with disability and a young politician, he explains how it is critical to be part of politics and/or political processes so as to ensure PwDs and other vulnerable groups in the society whose voices are hidden or co-opted get considered not just in *words but in deeds*. But the biggest challenge he posits is doing adequate representation once they plug themselves into active political positions hence influence on power. Political exclusion in this case is manifested in the actual lack of PwDs from being present and having representation in governance arenas such as the local county assembly. In an informal conversation with a disability activist in Eldoret, it was revealed that there was a glaring absence of the disabled in such spaces contravening the constitution which dictates inclusion of the disabled in governance structures. While it is debatable whether representation and presence in political platforms affects politics thereby reducing the power imbalance in communities, having PwDs share experiences of their own can enhance the potential to all-inclusive decisions. The scepticism of whether presence and representation in politics matters was witnessed in some participants perception and attitude towards those in political offices as expressed by a couple in Munyaka;

Someone like that Mr. Monzo (anonymised), does he represent us? But there are very few genuine advocates for the disabled all across the country. Disabled people from Central region of Kenya can cry out through Mr. Monzo and may be helped. How about this our region? Who represents us? Why does Mr. Monzo not fight for our issues while in the national assembly [MU-01]

Through his description of a parliamentarian in the country who lives with disability and is a known political figure in the local media, politics of representation is brought to the fore and is seen as an essentialist notion meaning the representation is just on record, but they do not feel much of it in terms of resources redistribution. In Kisumu, Walker and Butcher (2015) explore the extent to which representation addresses the problems of a particular group of people (subaltern groups) with the aim of reducing inequality and promoting inclusive

neighbourhood planning. Their findings suggest that politics of representation and presence (which is a crucial initial undertaking) if it is to promote needs of a particular group needs to go further into other dynamics which include gender planning methodologies and aspects of power relations and conflicts in the participatory process. Observably, the same applies to cases in Eldoret, where it is not all about having disabled representatives in governance frameworks as the ultimate solution but considering structural issues within disability politics such as ethicized norms, institutional cultures and power dynamics.

Indeed, the existing political frameworks have provisions that facilitate representation in political circles, for example the Constitution of Kenya on the one hand mandates the progressive inclusion of PwDs (five percent) in elective, nominative and appointive positions in both public and private positions. However, and on the other hand the law (such as electoral law) paradoxically impedes people with mental impairments from participating in political processes without the consideration that even in mental disability the severity in the disabling conditions varies. One of the DPO leaders (via an unrecorded interview) demonstrated a case where a disabled individual was barred from voting on the pretext that he was unsound mentally. Such an example illustrates the denial of disabled people of their right in a political process. Thuo (2016) sees this as a 'blanket exclusion' and an unjustified way of further rooting disabling environments in the political landscape. Whilst describing the conflation of various disability identities, she argues that we need to unmask the notion that all PwDs are unable to engage in public affairs and policy and always aim at integrating them into decision-making processes. The CRPD outrightly provides that PwDs participate in political activities and all manner of limiting conditions have to be minimised if not eradicated.

Despite their disabling conditions, PwDs also face financial constraints in representational politics since the ability to compete in political processes in Kenya is significantly hinged on financing campaigns for voter mobilisation. Most PwDs do not have those requisite financial flexes hence systemically end up being excluded from political processes, [LA-11] who failed in a previous electoral process recalls

I did organize for a campaign fund drive, but people never supported my call. I was insulted and the whole agenda was thrown out, unsurprisingly I lost because I could not compete [LA-11]

The above testimony relates to aspects around stigma and discrimination discussed in chapter 5 where the disabled are disparaged and less supported financially or otherwise for events such as participation in politics. Kanyiga and Mboya (2021) in their study show that that the higher the spending in Kenyan politics the greater the chances of winning elections. Even those who lose in the process have to contend with financial implications that come along with

the high costs of Kenyan politics. They further argue that female political figures tended to spend more than their male counterparts but are still outnumbered in the political structure of the country. While their work focusses on gender disparity, in this thesis the same applies to PwDs who are marginally positioned and less likely to engage in political processes. Female PwDs are likely to encounter further exclusion given the disability and gender dynamics as elaborated in chapter 2.

Apart from representational politics, some participants felt political decision-making processes excluded them both at the local and national levels especially during budgeting and planning for resources. A lady who is visually impaired in Boma Turkana recounts

People are usually negative when it comes to engaging the disabled in political issues and events-they never see us as equal citizens and have in turn limited our political lives and freedom- but we have learnt not to worry anymore, I never engage myself in political meetings so as to influence politics in this town [BT-01]

The lack of inclusion in processes of governance leads to poor service delivery, for instance, poor provision of housing or services that are not cognizant of disability needs. For example while referring to the KENSUP project in Kibera, Nairobi Yeboah et al (2021:7) notes that ‘the design and allocation of new housing structures however had no reflection of the diversity in the financial capabilities, disability, and use of space and economic activities of residents’ (2021:7). Several scholars have worked on various approaches to measure the decision-making diversity in urban interventions (e.g Checkoway, 2007; Levy, 2009). The ability to which people control their resources is an important indicator of improved living conditions of the underprivileged in the urban (Yeboah, 2021). In the Kenyan context, participatory budgeting as a policy tool is a requirement at both levels of government and all population groups have to be involved in the process. Yet, PwDs unlike other marginalized social constituency blocs such as the youth and women have not benefited enough to translate to their improved lived conditions across the country (Wampler, n.d:10). While intimating of recent improvement in the participatory processes at the local level of the county, the director in charge of planning in Eldoret echoes the following;

I must be honest with you, on aspects about PwDs participation on budgets and planning, we are performing poorly as a county but in recent cycles we have had significant progress, but we need to do more, and the governor is very keen on this issue [GO-02]

The legal and policy frameworks (Constitution in article 201 and Budget policy) on planning and budgeting in Kenya provides for the relevant entities (national and county legislature) to

do extensive public participation. Yet, from the opinion of the senior planner, the process falls short of encompassing PwDs and other social groups alike. Such a trend can be explained by the weaknesses and gaps in legislation that support an all-inclusive citizen participation as noted by Horn (2021) while describing Nairobi's citizen participation situation. He highlights how it is a limited process that excludes pertinent residents from the city's informal settlements at the expense of a few elites interested in profiteering through patronage opportunities.

A divergent opinion was evidenced by a junior planner in the same department who suggested that participation of all constituencies is an issue they focus on while carrying out planning within the county.

So in most cases in any integrated urban development plan or sectoral plans that we do, all urban plans that we do, and land use plans, we ensure that while forming such committees during the settlement stakeholder meetings, participant and public participation [GO-1]

Possibly, the reason for the difference in opinion about the process is that PwDs tend to be more involved at the initial stages of the planning where the junior planner is the key player but at the higher levels of crafting policy and implementing it, they are left out as alluded by the Director. This is however something that needs further probing to qualify their involvement in the various levels within the participatory planning process. In addition, institutions representing the disabled such as DPOs reinforced the aspect of political invisibility facing PwDs in Eldoret, a female DPO leader retorted

Let us not even mention national issues, even here at the county assembly, the events do not involve our organisation, yet we speak for disabled people who need support. When we confront them (county assembly), they tell us they would notify us when we are needed. Of course, they never do it. [DPO Leader]

The remark by the DPO leader sums up the obscurity PwDs face in political processes that lead to their exclusion and eventually their interests being co-opted or neglected altogether given the power imbalance. The lack of participation or one done limitedly as discussed happens in at least three ways. PwDs seeking to occupy political offices are subdued either directly or indirectly because of the existing barriers. It also happens when their agency and voice is not considered while planning and budgeting for public spending. Finally, even institutions such as their DPOs who happen to be a collective institution for PwDs are also prejudiced. The analysis in this section reflects on discussions on the social model of disability as conferred in chapter 2 where specific analyses around breaking social and environmental barriers which promote spaces that are representative of the disabled come to the fore.

Mistrust and bureaucratic fatigue in disabled informal spaces

After outlining the existing political ambiguity in community participation as an impediment to flawless institutional responses, there was also wide-ranging evidence of fatigue in the governance processes such as cash transfers and accessing public services, for example health and education which are specific to PwDs needs.

The interactions between citizens and bureaucrats—both the nature of the interactions themselves and their results—have consequences for mass political behaviour, trust in government, state legitimacy, and the functioning of bureaucracies (Pepinsky et al, 2017:250).

Most participants felt disillusioned and unhappy about the government elites and more so those that were bound to improve public service and governance processes. However, in as much as they criticized their political systems, they seemed reluctant to take up roles in the local politics, speak about their issues and even attend political events as detailed previously. As this thesis was interested in how governance practices at settlement scale impacted on the lived realities of PwDs, their perception about the existing system was significant if at all viable solutions are to be attained. Whereas mistrust and fatigue in governance procedures were highlighted as key setbacks which discourages PwDs from seeking services from state processes, most disabled participants were unable to seek services because they either could not afford it or stigma within social networks. This notion is supported by previous arguments in chapter 2 where poverty and disability are illustrated as entwined conceptual realities in informal spaces.

Mistrust in the working of either state or non-state actors is widespread globally and is caused by a number of reasons. Although a small number of PwD actors are actively involved in political activities, most of them prefer not to engage with state authorities and instead rely on other organizations mainly because of the lack of trust in the state processes and disbelief of any impactful changes. For instance, a mother of three children and living with a disability describes of how they were in favour of a medical facility being ran by a church organization and explains the role of the church which transcends beyond religious activities;

the community was asked to decide whether it should be put under the authority of the organization of churches or under the authority of the municipality. The community decided that it be given to the organization of churches [LA-03]

The essence of charity and how the model is depicted in chapter 2 signifies here how disability is understood both by the state and citizens. This is equally argued within religious activities discussed in the same chapter where fidelity to certain religious practices in African societies

is supreme. While the disabled themselves opt to fully depend on charitable services offered by international NGOs or well-wishers from within and beyond the community, the state seem not to instigate measures to protect the vulnerable PwDs from punitive services.

Another way which depicted mistrust in the state is how PwDs failed to attend *barazas* meant to discuss key community issues some of which directly affected them as explicated in the previous half of this chapter. In a conversation with one of the community leaders in Munyaka, he explains that PwDs hardly attend *barazas* which as described in the previous section are vital for governance and to communicate important issues;

people with disabilities are tired because of the unfulfilled promises they get from the leaders, they have been promised so many things in the past like special needs schools, hospitals because of their needs, roads, electricity and so on. I now see the same issue as they are completely doubtful if change will ever happen, so they give up and even do not attend *barazas* [Community leader]

While the leader's views highlights that there is mistrust in the governance system, this research also empathizes with the fact that PwDs in as much as they might be compelled to attend community meetings, they genuinely find it hard given their disabling conditions. That however does not explain the unfulfilled promises by the political elites during campaigns for elective seats which is the primary reason for the lost belief in systems of governance. The same mother of three from Langas brings to light how they were promised insurance cards and how the monthly remittances would be made affordable, she explains;

yes the insurance card, it is hard paying for it because you know I get very little income, so every month you cannot get 500 shillings, yet the governor and MCA and even the president promised that there will be universal health for poor people like us [LA-03]

Bureaucratic delays and other related processes are common features of urban governance in the African context (Wimpy, 2021) for so many obvious reasons, a common one as mentioned earlier is the nudge to make one give out a bribe as an incentive for a faster service delivery or exchange of goods. Bureaucracy as conceptualized by Weber (2016) a governance system which allows important decisions to be made by state officials, however, in common sense and though not always the case, when we speak about it, it alludes to the bad side of the state: excessive paper-work and unmatched requirements for services. The officials in charge of key disability functions intentionally delay processes to prompt bribing signifying a direct manifestation of corrupt practices as explored in the next section. Such processes further exacerbate the people's trust in the state, some PwDs complained and decried of such red tapes in service provision. One of them highlighted that

when we seek other services such as disability cards from National Council for PwDs (NCPwD) it takes ages for the process to be complete, they ask for a lot of requirements and conditions so we often give up the process [LA-03]

Similarly, a spouse to a visually impaired man in Munyaka complained how they were eligible for government cash transfer stipend, yet they had never accessed it due to the processes involved. While reflecting on the encounters they face, the following extract from her interview illustrates their disappointment and how they negotiate through the process:

What they usually say is that when they read the national budget, they will enter us into the system. But years come and go without any changes for the better... There was a time I went to the chief personally to ask about this matter. I talked about it with the village elder also, but they didn't help. I became angry and confronted them. The chief said that some people will come home to assess my condition. However, before I received the card, proper assessments had already been made. I asked them why it is that rich old men benefit from that fund while my husband doesn't [MU-01]

While such an experience articulates the woes by PwDs in the facets of governance from the top-levels of budgeting process to the lowest scales of household enumerators, importantly it showcases how street-level bureaucrats (Pepinsky et al, 2017) such as the chief and social workers who assess disability conditions are key to the implementation of policies since they are the final chain in service delivery. They are the de facto determinants of policy since beneficiary to state services such as CCTs above are at their disposal, they make on-site decisions and choose on how to conduct and enforce state policies (ibid). Therefore, for improved governance qualifying and training of frontline providers of services for PwDs is key as that equips them with necessary skills to fulfil specialized tasks in this case disability. Such frontline bureaucrats do possess extended and unregulated socio-political powers which is at times the genesis of ill practices such as corruption and ethnic nepotism. Such practices which mutilate governance are brought to the fore in the next discussion.

Corruption: an inevitability to PwDs?

Corruption is at the centre of service delivery for PwDs in Kenya and was evident as a common theme in this study just as it is an endemic issue in the country and one of the biggest setbacks sabotaging good governance. Kenyan politics is underlaid by corruption as it has been at the heart of political discourses since the end of Moi regime (Alexia, 2021) even dating back to the British history where loyal African leaders were corrupted to tow the lines of colonialists. In Kenya today, corruption is undoubtedly one of the greatest governance setbacks, it features

in the everyday life of Kenyans at all levels, from interacting with the police and other public servants to the patronage network of graft where state resources are embezzled and misappropriated (Harrington and Manji, 2013). Despite increasing public protests against wantaway corruption in public dockets and other related domains,

‘political leaders manage to maintain a strong electoral base by playing on ethnicity at election time...Daily experience of corruption in citizens’ interactions with frontline public officials contributes to some sort of integration of corruption into the Kenyan way of life, and even to its acceptance despite increasing mobilization by a part of society against the elite's corruption, there is a certain acceptance of the phenomenon among citizens’ (Alexia, 2021:28).

To understand the extent of the problem, this study sought to establish how the dynamics and complexities around corruption relate with the everyday lives of PwDs in Eldoret. The primary finding is that PwDs are not only more likely to be affected by corrupt practices but are prone themselves to corruption than other sets of population groups because of their often-vulnerable situations. According to Mugellini (2017), there are two main categories of corruption namely administrative and political corruption. Administration corruption refers to acts of intent that mutilate the implementation and of prescribed laws, rules and regulations within a public or private entity for the benefit of some actors. Examples of such corruption cases include bribing an official so as a minor or even major offense can be overlooked, bribing to get over a systematic procedure like acquiring a business license (World Bank, 200). Political corruption is about the formulation of policies and involves politicians and elites who as decision-makers distort the process to the own advantage in most cases to influence processes such as election outcome (Mugellini et al, 2021:7)..

Deeply rooted corruption featured in PwDs lives either directly or indirectly and can be attributable to a misconstrued interpretation of the strong African cultural traditions and their tenets of reciprocity. The missed interpretation being the thinking which requires one to satisfy their family before distributing to others and that probably would explain its omnipresent nature in most of the African states (Berghs, 2017). Defining corruption is not easy as it is a multifaceted phenomenon which is evolving and entails ‘various actors, behaviours and activities’ (Mugellini et al, 2021:7). Nonetheless, this study will adopt the definition provided by Transparency International (Transparency International, 2007), germane to disability corruption may be defined as power abuse for individual gain causing allotted resources to be misappropriated thereby making life-long suffering of PwDs. Corruption sources may entail preference to one’s ethnicity, the lack of patriotism and national interest and greed for self-enrichment and actualization (Wimpy, 2021).

Although corruption has expanded and contracted over time, it remains a concern of high priority for organizations who aim to measure good governance and scholars alike (ibid:2)

Direct corruption within the context of this research was most rampant and would characterize the everyday interaction with governance processes. It implies to the micro-level corrupt dealings between PwDs and service providers at the interface of face-to-face. Although usually generalized, disabled people interviewed in this study tend to feel the most from the often-trivialized acts of bribing municipal officials or for healthcare service. An illustration of how a disabled hawker is affected by a direct form of corrupt practices was brought to the fore by one of the NGO officials. He notes

There's a person with disability who sells clothes in the streets informally. And so, the county council police, the law enforcement department, mishandled him. So, you know, how they do, they went up there to go to his wares and beat him up and left because he cannot offer them anything. Luckily, somebody was recording that video. Okay, so persons with disabilities united and went, and complained. And action was taken on that particular officer was taken, you understand [NGO-1]

Such an occurrence describes how PwDs have to negotiate their lives thus are disproportionately affected by certain practices by those in power relative to other population groups. As the official interprets since the public was recording the ordeal, action was later taken on the county law enforcers. The hostile relationship that often exists between hawkers and municipal enforcement is not a new phenomenon within the Kenyan context. In Nairobi for instance Dragsted-Mutengwa (2018) sought out to understand this relationship where enforcement officers from the City of Nairobi are constantly on the attempt to get rid of hawkers or vendors to attain the idealist clean city since the latter are seen as unwelcome outsiders especially within the central business district (CBD). She depicts how crackdowns meted on the vendors provides a platform where bribery thrives through exchange and buy back for freedom and most of the times goods that have been confiscated get retrieved. Additionally, she showcases how urban politics play a part in the governance of hawking especially when electoral processes looms and the issue is used as a political bargaining for wooing votes. In such a case the crackdowns are suspended but reform promises become a wild goose chase and never implemented after elections. Finally, she shows how the exchange of bribes and other favours builds up a relationship between the officers and the vendors. Overall, she establishes how such a relationship marred with multi-levelled corruption is (re)created and (re)produced before, during and after the crackdowns and how urban governance relate to the process of informal trading. Disabled vendors in such cases face an even more complex

relation since their conditions would always position them as easier targets and victims of the crackdowns which happen most cities in Kenya.

Respondents also showcased indirect effects of corruption practices through various governance actions which although they did not have an instant correspondence with their lives, on a bigger picture those practices did affect them in one way or another. The meso-level punitive practices happen at a scale beyond the households of PwDs and are mostly embedded in public service which ostensibly is the channel to which the urban disabled poor rely on for the provision of basic needs. While highlighting how a certain piece of land was being converted for something else without involving the stakeholders who were DPO leaders in Eldoret, an NGO expert explains

Persons with disabilities in Uasin Gishu county have their own piece of land, the one I told you about that. Yeah. And so, one day, they just woke up and they saw development going on, on that piece of land. On checking with their leaders, they realized that the county government was using their land to put up a ward administrator office without their consent and the approval of their DPO leaders [NGO-1]

The above views highlight how corruption thrives in public administration through abuse and misappropriation of public goods and services. Activists and DPO leaders tend to develop coping strategies and ways to fighting corruption including publishing the practice for example the recording as earlier witnessed in the vending case. Equally, for this case the official explains how disability activists fought off the incident which would have led to the punitively taking away public assets meant for disability. He further notes

They called for a press conference, they gathered in town and condemned the action leading to a halt in the building process...what I saw is persons with disabilities came together and said no to the county government and construction was suspended. Yes, so I am saying the law is there but sometimes PwDs just do not know their enshrined rights [NGO-1]

While corruption was mainly evidenced through institutional action and agents in officials of either state or non-state actors, there were traces of PwD individuals who abused their disabling situations hence revealing inherent corrupt practices as illustrated by the next interview extract.

But just to just on the same point. On my part, I think that is fair. Because I know it's an injustice. It is unfair, it comes off as unfair. But you have to be aware, the county government observes that as soon as those stalls were allocated persons with

disabilities sold them. So, there is a group of them who get and sell. And now you have a person who's not with disability, conducting business freely without paying tax and licenses. So, the county government can't tell apart, who is this we didn't give you these. So that that is where the problem comes in. It is hard for the county government to tell because every day they come they find a person without disability there what's happening, you know, so it is a challenge [NGO-1]

Although the above instance of corruption would appear to be a survivalist mechanism where PwDs unable to run business sub-let to able-bodied persons, it is in essence a petty form of abusing a privilege and entitled powers. Since there is a serious shortfall in public support to curb poverty, such informal arrangements thrive. Such survivalist strategies to some extent are counted as lesser corruption practices. Despite this study simply categorizing corruption into two main facets i.e direct and indirect forms of corruption which happen at the individual and institutional levels respectively, corruption as mentioned is a complex concept that transcends nations, systems and infuses both public and private lives with far reaching ramifications on lives and livelihoods. Also, although the evidencing here so far has only highlighted public administration ways of corruption practices, the vice also breeds in non-state action as exhibited by the various agencies working for disability services. According to a published report by Mwambia and Wanuna (2012), in Kenya millions of shillings that is meant of PwDs is lost through massive corruption that swirls around DPOs that receive state funding for disability courses. Their findings highlight that the money which comes from a 3-year revolving fund ends up stolen and unaccounted through flawed processes of disbursement. More contentiously, government officials connive with the DPOs, and payment made to activities that are either non-existent or to 'ghost' recipients. This disadvantages disabled groups and PwDs at the grassroots who are the intended beneficiaries.

Apart from administrative corruption, political corruption through clientelism and patronage politics partly discussed in chapter 2 is also evidenced by participants of this study. It was extensively exhibited in the way recruitment and placing of personnel who work for the disabled at various levels shaped the governance of issues around disability. Such an act indirectly affects PwDs as noted by an NGO expert working closely with state agencies, he highlights that

the government has employed teachers, community development people and employed them as disability officers, these people have no knowledge of what is supposed to be done for people with disabilities, you will find someone in the national council office wanting to provide wheelchairs without the technical knowhow when in

essence they are supposed to focus on livelihood, but again even on the livelihood issues they are not aware of what is supposed to be done [NGO-2]

Clientelism and patronage politics is a pervasive and an embedded practice in many developing countries to control and influence power relations (Pepinsky et al, 2017). Local politicians use clientelistic mechanisms to gain state control so as to build lasting political relationships that can account for votes in electoral processes (ibid). Jobs in the public sector are the most common currencies used by political actors thus explaining the situation above. By abusing state resources, politicians exploit and control service delivery by effecting patronage jobs to supporters. On the one hand this happens at the detriment of efficiency of services for the disabled and on the other hand political elites gain political mileage by winning elections. Consequently, by embedding itself to service delivery, clientelism practices builds strong social relations that obscure accountability. In most cases misuse of such powers and hiring of the wrong individuals often leads to poor services as the extract below evidences the issue further;

So for us we give the technical advice but the implementation level are ignorant about what is supposed to be done...you will find a special needs education teacher posing as a physiotherapist, you will find a special needs education person posing as a social worker just because there is a vacuum no one knows who is supposed to do what [NGO-2]

To recap, corruption and other linked processes described here are generally depriving for societies and especially the marginalized groups such PwDs living in informal settlements. The vice exacerbates inequality and skews public resources to the benefit of a few powerful elites. The disabled minority often feel both direct and indirect effects of corruption because it not only impedes the provision of important devices such as wheelchairs for the physically impaired and sunscreens for people with albinism it also influences policies that affect their income through CCTs and grants. Often PwDs are the most vulnerable to engage in corruption because of their conditions which can easily be exploited for bribes. At the same time, corruption and discrimination tend to be closely linked since exposure to forms of corruption such as clientelism alienates particular groups from the state functioning. This is compounded by a lack of representation discussed in the previous section where the disabled constituency is disenfranchised politically. When PwDs are made invisible they either become less able to challenge corrupt practices or are unable to seek for recourse when they are unfairly accused of conniving in corruption. Such exclusion reproduces and recreates corruption practices since the disabled are excluded in decision-making process hence rendering them unable to demand for equality in public goods and services.

Conclusion

This chapter has explored urban governance frameworks and power relations in informal disability spaces. The chapter discusses both vertical and horizontal power relations as flagged in chapter 2, where both formal and informal governance dynamics come to play shaping PwDs lived realities. The arguments in the first half of the chapter explored the three main urban governance responses in Eldoret namely state actors, non-state actors and traditional authorities. Whilst in most cases these responses are distinct, often they inter-play (re)producing hybrid forms of governance. Using the *kazi-mtaani* initiative and the *inua-jamii* cash transfer program, the chapter showcases how state actors directly shape PwDs lives and livelihoods. The key argument being that state actors are critical for the disabled, yet interventions are not in part or fully streamlined and thus they have to be better structured to promote disability needs. Non-state actors in DPOs, NGOs and institutions which offer refuge for PwDs equally shape experiences of disability in urban areas. The grassroots DPOs are particularly vital as they offer spaces where PwDs meet, share and discuss common issues including pursuing their rights. The main challenge that plagues NSAs is balancing the interests of PwDs which in essence is their main mandate and competing interests of a few who are intended at benefiting from disability. This is particularly the case for NGOs who receive funding from international corporate bodies for disability agendas. Meanwhile, DPOs which foster western models tend to aggravate disabling conditions via misplaced solutions which do not conform to the dominant norms in the context of Kenya. Therefore, while the interventions of the organisations may be with good intent, the impacts are somewhat replicating colonial and exclusionary practices. Thus, it is imperative for PwDs to be empowered and their voices heard if institutions of governance are to make the desired changes and outcomes in disabled spaces. Traditional models of governance which comprise of the *nyumba-kumi* initiative and the *baraza* planning model have also been explicated as fundamental mechanisms through which urban governance shape disability in informal settlements.

The chapter in the second half looked at challenges that impede the functioning of governance structures and the factors making response to the needs of the disabled in urban informal settlements harder given the context. Three of these challenges although are universal are expounded and argued in tandem with participant experiences specific to Eldoret. The first is exclusion of PwDs from political processes such as participatory planning and budgeting processes and also representational politics which have been evidenced extensively to play a role through diversifying voices in decision-making. The mistrust and bureaucratic delays form the second strand of setbacks to governance witnessed in Eldoret. Here the key argument presented is on the relations of citizens and institutions and the superficially imposed

bottlenecks that sets back service delivery to PwDs. Corruption, which is the most rampant impediment that derails good governance in Kenya is presented as the last of the setbacks. The nature of corrupt practices categorized into administrative and political facets is depicted in how they get embedded in service delivery.

Beyond the notions shaping disability governance, in a nutshell the chapter examined the everyday experiences of PwDs in relation to frameworks of governance and how power manifests itself in that extant relationship. The arguments in the chapter highlight fundamental questions around the politics of disability in Kenya and how the future of PwDs in the country can possibly be enhanced by rethinking the existing approaches. For instance, when formulating anti-corruption strategies, issues of disability have to take centre-stage, a situation potentially overlooked in current trends. Importantly, the power play between various actors that shape governance in disability spaces is brought to the fore. The next chapter presents the conclusion of the research and possible areas of future research pursuit within disability and informality in the global South.

Chapter 8: Conclusion

The aim of this research has been to establish how informality (re) shapes and (re) defines the lives of PwDs within informal settlements in Eldoret, Kenya through an understanding of their spatial conditions and their everyday way of life and the links to urban governance. This has been explored through a conceptual framework, developed through a detailed literature review in chapter 2 and examined in relation to several key arguments. First, dominant western theorizations of disability are insufficient to provide meaningful interpretation of the interconnections between disability and informality in the Global South. The different theoretical approaches emanating from the North have traditionally conceived 'that cities everywhere follow a similar basic standardized template of development' (Wambui, 2020:32). Such a belief has resulted in governance structures in countries such as Kenya following western-derived frameworks which do not align with local disability and informal realities. Second, colonial legacies marginalize disability as a lived reality within post-colonial contexts, and especially in spaces which have become embedded in current efforts and responses to informality e.g. upgrading and 'sites and services' initiatives as mentioned in chapter 2. Third, the materiality of informalities and how they affect the disabled have been understudied especially in relation to secondary cities which as alluded earlier demonstrate distinct growth features. In that regard, this study has proposed a southern theory approach as a conceptual framework that is imperative if voices of the disabled in countries like Kenya are to be understood and epitomized. Against the backdrop of this conceptual framework and guided by the research aim and questions outlined in chapter 1, the study methodologically deployed a qualitative research approach by drawing on data from interviews, observations, transect walks/rides and document reviews so as to explore and understand the dynamics of disability and informality within the context of Eldoret.

This final chapter of the thesis revisits the research findings by providing a salient synthesis of the key arguments which have been broadly categorized into three thematic areas namely sociocultural realities, spatialities of disability and governance structures relevant to disability. All three themes have been examined from the perspective of engaging with people who live in three informal settlements in a secondary city whose growth is somewhat different from the often-emphasized primate cities such as Nairobi, Mombasa and Kisumu. So as to succinctly summarize arguments around these themes the chapter details how the research questions tying to these themes were answered given the empirical findings and the scholarly material reviewed in the first half of the thesis. As a general conclusion and a core argument of the thesis, the chapter spells out a critical review of the conceptual contributions used to relate and underpin the findings of this research, thus providing a nuanced comprehension and a

call for the relevance of looking at disability-informality through nexus thinking. It also posits how the findings of this research help to further develop specific concepts related to the nexus between disability and informality. Beyond that, the chapter also gives a brief presentation of possible areas of future research germane to the disability-informality nexus in secondary cities of the global South. Further, the chapter briefly discusses how the findings of this thesis might shape policy and responses to disability in the global South. Moving on, subsequent sections of this chapter present brief discussions of the thematic findings which culminate in an overview of both the conceptual and empirical contributions of this thesis.

Sociocultural processes in informal disabled spaces

The research in chapter 5 interrogated disabled people's social and cultural realities within the context of informality and examined how these realities shape their everyday lives. The chapter answers the first research question: How do sociocultural realities influence the everyday lives of PwDs in informal settlements? The thesis argues that the fight for PwDs' basic rights was significantly derailed by sociocultural marginalisation and the effects of living in informal settlements characterized by inequality and widespread poverty. Such realities meant that participating in campaigns and movements aimed at reducing and breaking extant disabling barriers was seldom a priority nor achievable for most disabled participants. The strategies available to PwDs to support their emancipation as they are currently structured seldom consider these realities since they are overly shaped by narrow Western thinking which tends to overlook or downplay important historical accounts such as the effects of colonial legacies and the diverse ethnic structures within populations in the global South, yet they shape current situations. In light of that, arguments in the chapter were framed from the understanding of a southern theorisation of disability which conceptually able to account for the way strong cultural traditions are co-opted to create meaning for disabling conditions.

This research confirms scholarly revelations of previous findings where disability as a construct is fraught with a lack of understanding and negative perceptions (misconceptions) that are not only difficult to overcome but keep changing and evolving over time (Rohwerder, 2018). The perceptions disempower PwDs leading to 'social exclusion and isolation' (Babik & Gardner, 2021:1). This is especially the case in an urban society like Eldoret where inequality and social oppression has been entrenched and can be traced back all the way to the colonial years. These perceptions defined through sociocultural realities resonate around four key issues namely stigma, social networks, care issues and cultural traditions which poignantly set the tone of how attitudinal differences to the disabled are inherited within communities living in informal settlements of secondary cities. A key finding from this section of the thesis is that these perceptions not only have negative effects to the disabled as presented in most literature

but also affect the disabled in a positive manner. For example, social networks such as *chamas* played key avenues for support against prevailing discriminative practices.

Evidence from this study is used to argue that secondary cities in Kenya such as Eldoret sit deep in historically determined stigmatising practices and overall prejudice for disability signifying how the disabled are viewed as lesser people and as objects to be eschewed. Overwhelmingly negative remarks are exemplified in discussions around the albino participant for instance who is seen to be an outcast and hardly relates with members of the community where he lives. Furthermore, negotiating stigma conditions is not merely a constant process which depends on the type of impairment as the albino case shows, it also depends on overlapping characteristics like age, space, ethnic background among others. This supports the work of Chatzitheochari & Butler-Rees (2022) who have recently argued that narratives of disability usually focus on monolithic disability interpretations and understandings while neglecting vital context-specific meanings and the intersections of inequalities which ideally expose disabled people to further stigma. This shows how a universal view of stigmatisation of PwDs is unproductive and intersectionality as highlighted throughout this thesis is critical. Demonstrably, discussions within the chapter shows how stigma happens at various levels starting from the individual to the family, the community and even the state. Whereas stigma at the individual level (self-perceived) is often the most overlooked it was evidenced as an important level driven by factors such as gender. Meanwhile stigma at the community level is the most common and widespread since the majority of non-disabled people in essence have limited understandings of the realities of living with a disability often seeing it as an abnormality as discussed in the social model approach. The study ultimately argues that the effect of stigma is exclusion and the feeling of being out of place, isolated from most of the social surroundings further entrenching and intensifying the effects of being impaired. This is exacerbated by living informally, which in itself is accompanied by marginalisation within the city as a whole although it often produces vital social networks.

Informal networks thus were used as an integral mechanism with which the disabled used to cope with the everyday forms of stigma or attitudinal differences alluded to above. Specifically, the *chama* ideology which is embraced by many offer a social, economic and political avenue to an ideal self-image and freedom from oppressive social norms and spaces. The study argues that while the *chamas* are vital for grassroots mobilisation and are critical non-state governance actors as explicated in chapter 7, they are even more important and instrumental in supporting the disabled who as noted in the literature face intractable barriers within communities. In addition, the *chamas* have been utilised by the disabled as local economic boosters where they make savings and loan themselves money thus improving their financial status while promoting a functional localised culture of fiscal integrity. The *chamas* also

enabled them to lobby for grants from various institutions which could be used to add to their savings. The understanding behind informal networks in the study has been inscribed theoretically using tenets that are extant within African cultures which emphasize togetherness and the need for people to coalesce local resources in support of each other. The *chamas* are a good example of how southern perspectives and understandings can surface key processes and practices often overlooked within dominant western theorisations of disability.

Care geographies proved to be equally vital for disabled social experiences as they not only strongly determined how one would cope with a disabling condition but also shaped daily relations with caregiving relatives, friends or neighbours within communities. The tension and stresses brought about by caring for a disabled family member affects relationships within households and can run the risk of the disabled being abandoned. The study presented and categorised care for the disabled into two main domains namely home-based care within households via the help of people close to the disabled and institutional-based care given through institutions such as schools and churches. The most significant factor with care issues for the disabled was its gendered nature and how this shapes disability. The study argued that while more women especially mothers and girls dominantly play out as the caregivers to the disabled, men (in) directly engaged for example providing money for the process. A key highlight that affected how men involved themselves in care issues was the deep patriarchal attitudes shaped by cultural traditions as articulated by the various ethnic communities within the study areas. This shows the complex intersection of care and culture-specific gender relations and thus reinforcing how care practices are conditioned by such social dynamics. The study also argued that vibrant and strong cultural traditions in Kenya influenced how the disabled perceived themselves and how others perceived them. The perceptions that were born out of cultural beliefs had significant effects to the disabled both positive and negative. On the one hand the ascription of disability to supernatural views was a consolation for some and positively gave hope to PwDs in their everyday struggles, on the other hand it was perceived that disabling conditions are as result of a curse or a sin committed by a disabled individual or his/her lineage further entrenching marginalisation.

The overall argument in the chapter is primarily centred on unpacking how disabled realities which are shaped by social and cultural processes are indeed critical to the southern approaches and interpretation of disability conditions. The discussion in the chapter also imposes the significance of context-specific notions and the importance of understanding and nuancing informal settlements not only as critical spatial entities for theorizing the urban south but as crucial social spaces with varying dynamics. Indeed, in using the nexus approach this study brings on board such social-cultural facets such as the *chama* ideology and sociocultural realities that otherwise are commonly overlooked so far in studies on disability in informal

settings. While these realities are partly influenced with how residents of informal settlements are perceived, it is their complex intersection and the dominance of cultural attitudes that shape how the disabled are treated both by society and state. For instance, how gender, class, ethnicity etc together shape how the disabled are perceived and treated. These realities alongside material-political dynamics if left untangled could in turn perpetuate oppressive and decayed social spaces. Therefore, an understanding of such experiences is profoundly critical when claiming PwD voices have to be listened to especially in the urban context where diversity is prevalent. The next section retraces chapter 6 and examines the spatial-material realities which shape disabled lived experience in Eldoret.

Adaptability and negotiability of various spatialities and materiality

The study answered the second research question: How do PwDs negotiate and adapt the various spatial conditions within urban informal settlements? Arguments centred on the extant relations between disability and the physical characteristics of informal settlements and were presented and discerned in chapter 6. This study focused particularly on housing conditions, water infrastructures and sanitation facilities as these turned out to be most pertinent in shaping the lived experience of a disabled person living informally in Eldoret. The analysis was framed from a southern urban theoretical approach where materiality of cities in the global South is closely embedded with informality and spaces that are not only dominated by poverty and insufficient services but also convey diversity and inequality. The findings revealed how PwD residents in informal settlements manoeuvred in creative and innovative ways the extant contours of city struggles. The analyses were guided by various concepts including intersectionality where the ultimate challenge was to portray representations of informality as diverse and critical spaces for urban theory. The study builds upon work that theorises urban informality as a contemporary urban identity especially in southern cities which to a large extent shapes urban practice (see Wambui, 2020). While mainstream urban theory does not necessarily take into account analyses of informality and risk producing 'one-size fit' solutions and piecemealed interventions in cities (as elaborated in chapter 2), southern urbanism considers informality as a way of life to be embellished and argues that solutions to persisting urban problems have to be found in collaborative and participatory ways where inhabitants of such spaces are extensively involved in the processes. To advance this southern urbanism approach, this study captures three typologies and modes of informal urbanism dominant in Eldoret and other urban areas alike (see Lombard and Meth, 2016), spatial informality has been presented both conceptually and through empirical observation as the most significant since the materiality of spaces in informal settlements directly shape the lived realities of PwDs through the three key spatial components as highlighted above.

Housing for the disabled as evidenced in the chapter was perceived as the most pivotal spatial component which forced PwDs to negotiate, cope, adapt and balance the nature of their disabilities and the existing housing conditions. The dynamics of informal housing and how they affected the disabled in Eldoret were broadly approached from three typologies: shared-rental housing, borrowed housing and owner-occupancy. The typologies manifested different characteristics which affect the disabled in multiple ways, for example while shared rental houses are cheap and affordable, they do possess strong neighbourhood relations which were beneficial for social networking such as home care discussed in chapter 5. At the same time, shared rental housing given the widespread violations of building standards by developers often had small-sized rooms which posed difficulties to the disabled. Although some of the respondents felt they were comfortable with the room sizes, a majority felt the smaller rooms exacerbated their disabling conditions. This was exemplified by how one of them who was blind struggled to store items within the house. These kinds of challenges tied to living spaces become further compounded when PwDs live in crowded homes with larger families especially when the disabling needs conflicted with other basic spatial uses. Caretaker or borrowed housing as discussed was problematic since the disabled had limited control as they could neither make retrofits to the house structures nor make new developments to suit the nature of their disability. Owner-occupied housing was the least common as few PwDs had the capacity or purchasing power to either own a parcel of land to build a house or indeed buy one, however such a category had the most salient features that accommodated disability. These characteristics around informal housing and how they affect the disabled in Eldoret have been built around a dearth in knowledge where calls for expanding the current debates on disability-informality nexus have been strongly advocated. Housing in informal settlements is usually characterised by poor quality housing structures, overcrowding and a lack security of tenure, all these features in part fervently define conditions witnessed in Eldoret. The empirical arguments in this chapter elaborate on existing housing dynamics, for example how disability models relate to design and the orientation of buildings and how that impacts on the day to day experience of the disabled and their caregivers. Beyond the household, the thesis has also exposed how complex housing processes involving actors in both the private and public domains play out while providing for shelter and the various consequences that has to the disabled. The findings herein generally reveal how housing quality and the consequent precariousness in informal settlements in Kenya and beyond as reviewed in the literature review shapes the lives of PwDs.

Access to water also shaped PwDs spatial relations within informal settlements since the extensive lack of it meant they had to devise strategies to cope. The research argued that whilst the lack of water in informal settlements affected most people, to some of the disabled

it was life-threatening given their various conditions which needed plenty of water. For example, cleaning the personal belongings of physically and mentally disabled participants was described by caregivers as a challenging experience if water is insufficient. The disabled experienced wide-ranging struggles which included physical difficulties while accessing water and the inability to carry water from its source. Further, the study also presented a gender dimension to disabled water conducts, the arguments reveal how for instance women struggle to access water while at the same time perform other household duties. The research also flagged the dynamics of water provision and how it sparks both intra-household and inter-household conflicts and tensions. In such cases the disabled are commonly the hardest hit since their relative vulnerability means the actual pushing and queuing menace in places such as water points awkwardly position them during the contestations. In addition, the study also highlights cost implications of water to the lives of the disabled. Arguably, discussions on water and the specific physical, health and financial consequences for the disabled are hardly reflected in literature, however testimonies from this study underscores water as a key spatial attribute which exposes PwDs to acute vulnerabilities. At the same time, such discourses often frame informality as homogeneously deficient while actually failing to appreciate the diversity of experiences within informal settlements and how they affect the disabled in varying ways depending on the nature of disability. Although it is true that informal settlements do exhibit deficiencies in basic services, portraying them in a wholly negative or singular manner accounts for only a portion of the urban narrative. The findings here in this thesis contribute to a wider body of scholarship which reveals that disabled people adapt to innovatively provide themselves with basic services such as water.

Poor sanitation as an incessant urban crisis in most cities in the global South was lastly presented in the study as an essential spatial component that shapes the disabled in contexts of urban informality. The core arguments presented resonate around issues of deficiencies, changes in lifestyle habits and makeshift strategies as a solution for the lack of sanitation facilities within disabled households. Whilst the sanitation configurations are commonly not ideal in southern cities, wider literature argue that new patterns of adjusting to existing conditions are always in the making (Lawhon et al, 2023) including the infamous 'flying toilets' a 'common scourge across low-income communities' (Thieme & DeKoszmovszky, 2012:80). However, while such habits were relatively widespread, the evidence suggested that for PwDs 'open defecation' and 'use of buckets' was also common as they had limited options and also weren't able to adjust to the realities. In addition, the disabled avoided making use of shared toilets since as a result of their physical impairments combined with the poor provisions of such facilities, being forced to crawl and clutch onto dirty walls mostly spewed with urine and faecal substance posed significant health risks. Such sanitation struggles in Eldoret entail

competing and dynamic socio-economic relations which tend to undermine the disabled in most cases. Meaning that while on the one hand the disabled spend more in both time and costs to access sanitation infrastructures, on the other hand their privacy and safety is nearly always compromised as they reluctantly made use of their nearest facilities irrespective of the physical conditions.

By recognising these kinds of challenges which have centred on housing, water and sanitation facilities, this study contributes to southern theorisation of cities (e.g Schindler, 2017) by placing materialities at the centre of analysis thus challenging dominant literature which tends to assume such infrastructures and services are readily available within the home confines. Specifically, it underwrites the already established debates on informality that contest assumptions on infrastructure/service availability by highlighting specific characteristics for the disabled. The recognition and analysis of the level and scale of negotiating, adapting and coping with these challenges within contexts of informality explicitly shapes disability and are invaluable additions to southern theory as it yields an understanding of the nexus between disability and informality, the central contribution of this thesis. The next section revisits how these services are offered in relation to that nexus through the various urban governance structures.

Governance structures shaping disability

The findings discussed in chapter 7 responded to the last research question- How do urban governance structures shape and define PwDs everyday lives in informal settlements? This section highlights a summary of core arguments and debates as presented in the chapter thus answering the research question. Discussions in the chapter mainly focussed on the various responses by the various governance structures namely state actors, non-state actors and traditional authorities. Accordingly, 'weak' governance processes in informal settlements are perceived in the chapter to be one of the key reasons why the urban disabled living at the city margins are left in poverty since initiatives are fragmented and lack a coordinated approach. That said, governance arrangements as expressed in the study are greatly influenced by local power dynamics where clientelist and patronage politics play out at the expense of the disabled poor. For example, within the everyday politics of informality rivalling gangs, dealmakers and brokers, self-appointed and elected leaders, religious leaders and businesspeople vie against each other to influence decisions (Amin and Cirolia, 2018). Such arrangements do not always go well with the neediest like the disabled.

In thinking how the state has responded to disability needs in Kenya, the study argued that although the existing interventions were vital for the disabled, they were also fraught with gaps key being corruption, unnecessary bureaucracy, poor relations etc. While the entry of state

action in the governance of informal settlements was scarce and often unexpected especially initiatives that are disability oriented, its relevance to the disabled was primarily featured in two main policy dimensions: *kazi-mtaani* and the cash transfer policies. The study argues that while these state programs are not entirely structured to solely meet the needs of the disabled, they were the most critical and influenced how they faced and negotiated both disabling social-cultural structures and spaces discussed in the preceding set of findings. *Kazi-mtaani* for instance was created during the tough COVID-19 times to provide generally those living in informal settlements with an income generating opportunity through engaging in daily public service provision such as unclogging drains and waste disposal activities. To the disabled however, while on the one hand the initiative was incredibly resourceful as it provided stable income especially when the effects of COVID restrictions were significant, on the other hand not all the projects were designed in such a way that they could participate. There was a strong feeling that such state initiatives were structured in ways that prohibit the disabled from participating and therefore there is a clear need for a holistic approach to encompass diversity in the urban poor.

Meanwhile, the study also argued that perceptions of disability in the context of government interventions were mixed and complex. This was evidenced by sections of PwDs who felt government initiatives should prioritise them in the recruitment process whereas others felt they should not be conceived to be disabled and instead they should competitively engage in the process. The study therefore argues that governance practices in the context of disability surface ambivalent claims since physical impairment restricted some from participating in the more overtly manual jobs. Besides *kazi-mtaani* policy, the state also has a cash transfer policy that specifically targets those that are severely disabled. However, the policy was contentious to many respondents as it was marred with extensive uncertainties of who exactly qualified under the category of being 'severe'. The chapter argues that power wielded through the medicalisation of disability tended to structure the process. That aside, the policy proved integral for supporting PwDs approached in this research with much-needed income for themselves and their family thus reducing the biting poverty that's prevalent in the lives of PwDs as demonstrated in the literature. The study highlights both as exemplars of state welfarism policies which are necessary for the disabled who reside at the margins of cities but where ideas and categorisations of what disability is are complex and potentially marginalising in themselves. Such a reflection provides knowledge insights into ways of not only entrenching further similar processes for the disabled within the urban but also involving them through participatory processes to advance transparency.

Despite state actions, the study also presented non-state actors (NSAs) which were broadly categorised as grassroots Disabled People Organisation (DPOs) and non-governmental

organisations (NGOs). The key argument presented in this section resonates within the existing relationship between the DPOs and NGOs and how that shapes PwDs. While the NGOs tended to support the DPOs through palpable initiatives, that support was often underpinned by and thus entrenched western ideologies in their working. This meant that, such knowledge foreignness created a disconnect between disability realities and proposed solutions to problems. That notwithstanding, the NSAs which as mentioned comprised of a tentative teamwork between DPOs and NGOs were evidenced as fundamental structural mechanisms which backed up or substituted state functions by provisioning relevant services which empower the disabled. This was achieved for example by boosting local economic scales through grants and loans. NSAs in this study were evidenced as fundamental in fragile spaces especially those that define and constitute the disability-informality nexus. Although a majority of the respondents in this study were appreciative of the work done by NSAs some had a resentful impression as they believed the NSAs bestowed services with hidden and unknown motives including setting out to profit from their conditions. Unsurprisingly, that was witnessed through private caregivers as NSAs who recklessly sought profits using disability as a leverage to pull resources from donors and philanthropy. Such institutions operate at the interface of formal and informal rules and without any particular structural organisation usually with the help of corrupt elite networks in state authorities. This risked exposing the disabled particularly vulnerable children with disabilities to inhumane and sometimes life-threatening conditions. Findings from this thesis complement other relevant studies where such public-private governance structures portend hybridisation of urban governance where mechanisms that are regulatory devote to deal-making that ultimately undermine the public good and interest (see Gibson et al, 2022).

Another hybrid form of governance, traditional authorities through chiefs, sub-chiefs and village heads were also critical additions to urban governance practices which shaped disability in Eldoret. The main arguments that were conferred resonated on generic and localised planning strategies around the *baraza* and *nyumba-kumi* initiatives. These governance efforts were presented as the closest to the disabled and comprised both state and non-state attributes hence their hybrid nature. While such authorities were key to the disabled as they helped in the mobilisation and the roll-out of state initiatives such as *kazi-mtaani* and cash-transfers, the chapter also argues that authoritative chiefs were conduits of power misuse whose history can be traced to their autocratic colonial past where the disabled and other minorities were most affected. The core argument in the last findings chapter brings to light the responses by three key governance structures which affect the disabled in informal spaces. While the services offered by these structures are supposed to be seamlessly provided to benefit them, they are usually overwhelmed with practices that are clientelist and

require deal-making and political brokerage which involve corruption and complex bureaucratic processes. That forms the conceptual underpinnings of governance processes within southern approaches where informal political connections reign and services provided are often based on reciprocation and favours (see Anyamba, 2011; Goodfellow, 2020). While on the one hand the disabled directly benefit in the sense that this is the only way they can access political channels and socio-economic services hence typifying urban informality in cities of the South, on the other hand evidence from this research illustrates that they are sidelined, and their voices hardly reflected in decision-making processes.

Knowledge contribution

To summarize the foregone discussion, the study while adopting a southern theory lens demonstrates how the specific materialities of place intersect with disability, how patterns of urban settlement tied to informality shape cultural and social relations and that informal spaces interconnect with governance practices in particular ways, with consequent impacts on PwDs living therein. It is against that backdrop that the study portends that adopting a nexus perspective is a new way of understanding the interconnections between disability and informality usually studied as separated concepts. This thesis illustrates that their interface matters for urban theory and practice in cities of the global South. In so doing, the thesis contributes to debates around southern disability and informal urbanism as vital reflections of a southern theory. Five key contributions have so far been covered. First, the study adds new dimensions to the southern disability theory by presenting extant realities and insightful empirical evidence through arguments including how multi-scaled urban informal networks (*chamas*) shape disability and how they are tactically utilised against oppressive attitudes and perceptions which (re) produce stigmatised territories of the disabled. Secondly, while adopting informal urbanism, the thesis foregrounds disabled material realities and the underlying socio-spatial implications to PwDs in informal spaces. Specifically, extensive conversations ranging from housing dynamics to water and toilet use are presented as an authentic version of how PwDs, manage, adapt, negotiate and fit into underlying processes of urbanisation which are greatly hampered by weak governance systems in most secondary cities of the global South. Thirdly, the study also contributes to scholarship on intersectionality, significantly producing a complex and a differentiated understanding of the nexus between disability and informality. Gender relations in particular (for example in relation to caring work) intersects with disability within the backdrop of informality thereby not only shaping other social constructs like ethnicity, religion, age and class but also shaping the material and political realities within the urban. Fourth, the study also contributes to an understanding of how disability must be understood in terms of cultural and post-colonial realities. Further, the study reveals how informal spaces are implicated as locations where migrants move to, and as

affordable sites in cities and that these spaces are frequently destinations for the disabled seeking an urban future. Finally, the study adds to new methodological knowledge through adapting existing research designs such as transect walking to collect key data. Also, by focusing on a secondary city to source data, this research contributes in a different manner to the existing methodological practices within urban studies and planning scholarship by placing understudied urban centres within the focus of a disability-informality nexus.

Possible areas for future research

This research has provided an insightful scholarly conversation of how the disabled in Eldoret experience urban informal processes and highlights particularities around socio-spatial realities and governance policies which shape disability. While the research gathered wide-ranging data on these conceptual particulates, it was necessarily limited and guided by the scope and extent of research questions. However, other significant issues arose especially in the process of data collection which if investigated further will usher in a wider understanding of the disability-informality nexus. First, is the relationship between the disability-informality nexus and specific disability geographies such as intellectual or cognitive disability, visual impairment and hearing impairment and how these relate to the disability-informality nexus. Whilst this research primarily focused on physical disabilities, the way cognitive and intellectual disabilities intersect within contexts of urban informality is largely absent. Secondly, the research also foreshadows scholarship on the effect of ethnicity, migration and conflict patterns in Kenya to geographies of disability and informality. This is particularly vital since evidence from this research suggested that some people were willing to migrate closer to their tribal kins so that their disabled family members can be taken of. Also, some participants alluded to ethnically motivated violence as a primary reason for their disabling conditions. Such conflicts in cities usually spark migration and displacement of populations where the disabled are potentially the most vulnerable. Lastly, while this research focused on the general population groups exploring the intersections of gender, disability and class, further intersectional approaches such as sexuality and age should be taken into account in literature.

Policy implications

Contingent on the discussions above, the findings of this thesis can be instrumental in shaping policy about disability and informality which in turn shapes development trajectories. The study speaks directly to policies that are driven towards inclusive housing spaces which enshrine the agency of PwDs such as slum upgrading initiatives and affordable housing programmes in Kenya. Although there have been outstanding policy initiatives that have tended to guide such programs in the country, evidence suggest that the disabled and their needs are not fully accounted for hence the need for better and more inclusive policies. Apart from spatial issues,

policies around social welfare by the state can benefit through some of the conceptual ideas that have been presented in this thesis. For example, the cash-transfer policy and the *kazi-mtaani* initiative which as analysed in this thesis are key for PwDs well-being can be improved to better capture the diversity of disabled people. Overall, the findings of this thesis argue that unless interventions related to disability and informality in the South are considered in entirety and in an integrated manner siloed and piecemealed accounts which focus on individual facets such as economic precarities without considering other vital tissues of the urban like material realities, social and cultural backgrounds are bound to have lesser impacts. Such policy interventions inadvertently perpetuate disabling conditions as opposed to improving their lived realities as envisaged. By using a nexus approach, this study brings together interpretive arguments from both disability and informality perspectives, thus, reversing or avoiding the often-narrow sectoral and segmented planning decisions which otherwise may result to unsustainable and inefficient resource allocation within cities (see Walker, 2020; Walker & Coles, 2022; Rees, 2013). In sum, this thesis offers a policy trajectory for the state in their role of framing and tailoring disability needs for enhanced PwD lived experiences particularly in poor informal urban spaces.

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Appendices

Appendix 1

Interview guides

- The interview to be conducted in an open space probably in an outdoor setting or a well-ventilated spacious room.
- This is a semi-structured interview and as such, the discussion may take many directions and the questions are designed as a guide rather than a definitive list of points.
- We can stop the interview at any time.
- Your responses are confidential and anonymous and will not be attributed to you at any point in transcription
- If permitted I shall audio-record the conversation for future reference
- Your name (anonymised where anonymity is needed), title, date/time of interview and your organization will be recorded

Name.....
.....

Organisation.....
.....

Title.....
.....

Date and
time.....

Audi
file.....

Interview questions for PwDs

BIODATA (maelezo ya kibinafsi)

- 1) Could you give a brief description of yourself in the form of...?
 - a) Your name (optional with anonymity preferences)?
 - b) Your age and sex?
 - c) Marital status?
 - d) Educational background/training?
 - e) The kind of work/job you do?
 - f) Health status/ nature of disability?

FAMILY SETUP (jamii)

- 2) Please describe your household composition?
 - a) Do you live alone or you stay with a family member?
 - b) If you stay alone, please explain how you manage yourself on a day to day basis?
 - c) If you are living with a family member/s, please describe the kind of relationship between yourself and him/her/them?
 - d) Do you have any support networks within the household, community or wider city? If, yes please describe them?

HOUSING DESCRIPTION (maelezo ya nyumba)

- 3) Could you please describe the housing arrangements and conditions where you stay?
 - a) Do you own or rent the house that you stay in?
 - b) If you are renting the house that you live, what kind of tenancy arrangement do you have with the owner?
 - c) If you own the house, please describe the process you underwent to acquire it?

- d) Can you give some details about the household in form of size, suitability, affordability, accessibility etc?
- e) Do you experience any housing challenges? If yes, please explain what these are. If no how can the current conditions be improved?

INFRASTRUCTURE SERVICES (miundomsingi)

- 4) What infrastructural services (e.g sewerage, water supply & garbage collection) do you consider of particular importance to meet your day-to-day needs?
 - a) Do you access these services?
 - b) If yes, please explain who is responsible for providing these services (i.e is the owner or municipality) and how do they do it?
 - c) Please explain the level of satisfaction from such services in terms of *quality, sufficiency and affordability*?
 - d) If you do not have these services in your home, how do you access them?
 - e) Are there challenges you experience while accessing these services either at the household/settlement or city level? If yes, please describe them?
 - f) Please describe how other infrastructure services that are vital in your day-to-day living?

ACCESS, MOVEMENT & TRANSPORT (upatikanaji, harakati na usafiri)

- 5) Please describe the nature of access roads in your neighbourhood?
 - a) Do you experience any challenges specific to accessibility at the household/settlement/city level?
 - b) How can accessibility services both for vehicles and pedestrians be improved within your neighbourhood?
 - c) Which transport modes do you commonly use to travel given your age and condition? How suitable are they?

ENERGY USE (nishati)

- 6) Please describe the kind and sources of energy you use in your house?
 - a) How efficient is that source of energy? Does it affect you in any way?

- b) Please describe whether or not you get any electricity services? How reliable is the supply?
- c) Are there incidences of illegal electricity connections? What are the effects of such connections?

HEALTH & SANITATION SERVICES (afya na usafi wa mazingira)

- 7) Please describe how you access health services in your neighbourhood?
 - a) Explain the ease of accessing these services both within your neighbourhood and beyond?
 - b) How affordable are these services to you?
 - c) Do you get any health benefits given your physical condition or age?
 - d) Please outline any particular challenges to health care service provision within and beyond your neighbourhood?
 - e) More specifically and on issues sanitation, what kind of toilet services do you have access to?
 - f) How does your age or condition affect your experience of toilet services?

SOCIO-ECONOMIC SERVICES (uchumi na jamii)

- 8) Please describe the kind of socio-economic services (e.g shops, schools, churches) you need/engage in your day to day living?
 - a) How accessible are some of these services?
 - b) Do you run any economic activities yourself? If yes, do you experience any challenges?
 - c) Do you have your own socio-economic support group e.g a self-help group? If yes, please explain how it is organized?
 - d) Do you receive any socio-economic support from the government or other organisations? Please explain how effective the support is?

RECREATION (burudani)

- 9) Please describe the kind of recreational activities you do and like to do?
 - a) Do you access these activities? If yes, how?

- b) Who provides for the recreational services in your neighbourhood and how effective is the provision?
- c) Please explain the effectiveness of these services in terms of being user-friendly to all categories of people?

SAFETY AND SECURITY (usalama)

- 10) Please describe the level of safety and security in your neighbourhood?
- a) Who provides security in your area? How is it effective?
 - b) Are there any community-based policing measures in your neighbourhood? Please explain?
 - c) Are there any safety measures put in place by the local authorities to reduce crime?
 - d) What particular security threats do you face as an elderly person/person with disability?
- 11) Are there any additional issues which you feel you experience as a person with disability/ an elderly person living in this neighbourhood? If yes, please explain?

Interview questions for agencies working for PwDs

1. Can you give a brief summary about your organization and its intended goals?
2. How has your organization been involved in championing the rights of PwDs in informal settlements?
3. What programs/projects do you undertake to support PwDs?
4. Is there any political/administrative influence(s)/dependence on the implementation of your projects?
5. How has your organization been successful on issues about PwDs and other disadvantaged groups?
6. What challenges do you encounter while running programs that support PwDs and the elderly?
7. How do you navigate through these challenges?
8. What do you think are the key challenges that PwDs face in relation to housing and living in informal settlements?
9. How do you incorporate housing and urban informality into your programs?

10. Apart from disability what other social categories within communities influence housing settlement patterns?
11. What is your opinion on the social inclusivity of different groups in the communities you work with?
12. Are decisions raised by the community considered by the relevant development implementing agencies?

Interview questions for government officials in the housing department (local/national level)

Overall housing practice:

1. Can you please tell me more about your position within the organization and your specific roles as a housing professional?
2. What legislative framework/ policy guideline (both local and national) informs your approach to housing in Eldoret municipality? (please if available provide copies)
3. Can you please in brief describe an overview of the state of housing in Eldoret in the form of housing typologies and settlement patterns/composition?

Disability integration

4. What is the position of disability in the current housing strategy in Eldoret municipality?
5. Are there any housing initiatives that are aimed at improving livelihoods of People with Disabilities (PwDs) in the slums of Eldoret? If yes, please highlight some examples?
6. To what extent are the PwDs living in informal settlements involved in these initiatives?

Housing in informal settlements

7. What is the current situation of housing in informal settlements in Eldoret municipality? Could you describe this by giving examples of existing slums?
8. Do you have any regulations/policies/legislations (locally/nationally) that support housing in the informal settlements? If yes, do you have any particular example of how they have been applied to specific informal settlements (such as Langas, Munyaka, Huruma and so on)?
9. How do these instruments (for instance legal instruments like evictions, sites and services or upgrading) relate with disability and ageing?
10. And if there are multiple instruments, do you see differences in their successes with addressing challenges facing PwDs?

11. Are there any other complimenting policies/ programs or institutions that support informal housing improvement meant for PwDs?
12. Do you encounter challenges while implementing housing programs for vulnerable groups like PwDs and the elderly in informal settlements within Eldoret? If yes, please explain these challenges and how you think they might be resolved?
13. In your opinion, apart from the provisioning of affordable housing, what other aspects can enhance the livelihoods of PwDs in Eldoret Municipality?
14. Do you know of any other relevant contacts that would be beneficial to this research work?

Interview questions for government officials in the planning department (local/national level)

Overall planning and practice in the municipality/city:

15. What is unique about Eldoret municipality in comparison to other cities in Kenya?
16. How do you plan for new and existing residential settlements? (planning approaches, land acquisition, methodology and so on)
17. Please highlight the current planning guidelines, development controls and standards (both national and local) that regulate residential areas in Eldoret municipality? (ask for these guidelines, building codes/standards)
18. Which target population within communities do you plan for?

Disability and aging integration:

19. What is the position of disability in the current planning frameworks in Eldoret municipality?
20. What planning needs would you associate with disability in Eldoret municipality?
21. From a city-wide level, are there any specific initiatives that have been targeted at improving urban functional spaces with regard to PwDs? If yes, please describe them?

Planning for informal settlements:

22. Are there planning initiatives that have been rolled out in informal settlements which are aimed at improving or coincidentally improve the lives of PwDs within Eldoret? If yes, please describe while giving examples.
23. How have these planning interventions in the informal settlements within Eldoret municipality transformed the lives of PwDs?

24. While making planning considerations for such special groups, do you involve them in the decision-making process? If yes, please elaborate while giving an example.
25. Do you experience any challenges while rolling out initiatives that are targeted at vulnerable communities (such as PwDs) living in informal settlements? If yes, please highlight these challenges and how they are/could be resolved?
26. Are there any other institutions/agencies or persons that you are aware of which/who do important work on issues about PwDs? If yes, please describe them.
27. Do you know of any other relevant contacts that would be beneficial to this research work?

Appendix 2

Participant Information Sheet

1. What is the project title?
Housing experiences of People with Disabilities (PwDs) in rapidly changing informal settlements of Eldoret, Kenya
2. Invitational paragraph
You are being invited to take part in a research study as part of a doctoral research. Prior to making any decision to partake, please take time to read the following information carefully and then decide whether or not you wish to take part.
3. What is the purpose of the project?
The project is out to explore informal housing experiences of people with disabilities (PwDs).
4. Why have I been chosen?
As a planning professional (or government official or person with disability) within Eldoret town and either living or involved in activities in the research sites, have a significant place in the housing industry and have been chosen to take part in this study.
5. Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep (and be asked to sign a consent form) and you can still withdraw at any time without any negative consequences.
6. What will happen to me if I take part? What do I have to do?
You are being asked to participate in answering a set of questions that intend to explore the housing experiences of PwDs in informal settlements. The aim of this interview is to assess your experience about housing challenges and opportunities especially with regard to disability. The interview will take approximately 45 minutes and will take place either face-to-face, on-line or telephone at a mutually convenient time. You have the right to see the collected data from you.

7. What are the possible disadvantages and risks of taking part?

There is a possibility of distress and discomfort therefore please be free and bring to my attention any unforeseen discomfort that arises either during or after the process.

8. What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will go a long way in highlighting housing experiences of PwDs which do not necessarily feature in housing plans either done by the state or private organisations.

9. Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team i.e myself as the lead researcher and my supervisors. You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. If you agree to us sharing the information you provide with other researchers (e.g. by making it available in a data archive) then your personal details will not be included unless you explicitly request this.

10. What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>. As we will be collecting some data that is defined in the legislation as more sensitive (information about your disability status), we also need to let you know that we are applying the following condition in law: that the use of your data is 'necessary for scientific or historical research purposes'

11. What will happen to the data collected, and the results of the research project?

Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions. We will ask for your explicit consent for your data to be shared in this way

12. Who is organising and funding the research?

This research is funded by the Commonwealth Scholarship Commission in the United Kingdom

13. Who is the Data Controller?

The University of Sheffield will act as the Data Controller for this study. This means that University of Sheffield is responsible for looking after your information and using it properly.

14. Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by the Department of Urban Studies and Planning.

15. What if something goes wrong and I wish to complain about the research?

If there are any issues regarding this research that you would prefer not to discuss with the research team in the field, please contact the research supervisor Dr Paula Meth email: p.j.meth@sheffield.ac.uk. However, if you feel your complaint has not been handled to your satisfaction by both the research team and the supervisor you can contact the Head of Department, Prof David Robinson email: david.robinson@sheffield.ac.uk who will then escalate the complaint through the appropriate channels.

16. Contact for further information

For further contact in case of additional information;

Lead researcher: Abraham Mariech email: ammariech1@sheffield.ac.uk

Research supervisor: Dr Paula Meth email: p.j.meth@sheffield.ac.uk.

As a participant to this research you will be given a copy of this information sheet to keep. Thank you for your time.

Consent Form

	Yes	No
Project title: Housing experiences of People with Disabilities (PwDs) and the elderly in rapidly changing informal settlements of Eldoret, Kenya <i>(Please tick the appropriate boxes)</i>		
Taking Part in the Project		
I have read and understood the project information sheet dated 16/11/2020 or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)	<input type="checkbox"/>	<input type="checkbox"/>
I have been given the opportunity to ask questions about the project.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to take part in the project. I understand that taking part in the project will include; being interviewed, being recorded (audio or video)	<input type="checkbox"/>	<input type="checkbox"/>
I understand that by choosing to participate as a volunteer in this research, this does not create a legally binding agreement nor is it intended to create an employment relationship with the University of Sheffield.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I can withdraw from the research/study, with or without notice, at any time. I understand that I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.	<input type="checkbox"/>	<input type="checkbox"/>
How my information will be used during and after the project		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.	<input type="checkbox"/>	<input type="checkbox"/>
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.	<input type="checkbox"/>	<input type="checkbox"/>
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	<input type="checkbox"/>	<input type="checkbox"/>

I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	<input type="checkbox"/>	<input type="checkbox"/>
I give permission for the audio recording that I provide to be deposited in storage device so it can be used for future research and learning	<input type="checkbox"/>	<input type="checkbox"/>
So that the information you provide can be used legally by the researchers		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.	<input type="checkbox"/>	<input type="checkbox"/>

Name of participant..... Signature Date
.....

Name of Researcher Abraham Mariech Signature Date

Project contact details for further information:

1. Lead researcher: Abraham Mariech, ammariech1@sheffield.ac.uk
2. Research supervisor: Dr Paula Meth, p.i.meth@sheffield.ac.uk
3. Head of Department, Urban Studies and Planning: Prof David Robinson, david.robinson@sheffield.ac.uk

Appendix 3
Research permit



REPUBLIC OF KENYA

Ref No: 462017

RESEARCH LICENSE



This is to Certify that Mr.. Abraham Mngat Mariech of University of Sheffield, has been licensed to conduct research in Uasin-Gishu on the topic: Housing experiences of People with Disabilities (PwD) and the elderly in rapidly changing informal settlements of Eldoret for the period ending : 13/November/2021.

License No: BAHAMAS ABS/P/20/7691

462017

Applicant Identification Number



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