Disability advocacy in Malawi: grassroots voices within the Federation of Disability Organizations in Malawi (FEDOMA)

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DEDICATION

To my grandmothers –

Saleha Huque (Didu), who believed in education,

and Francine Reillo (Grams), who dreamed of Scotland.

Neither is here to see this thesis, but it would never have existed without them.

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ABSTRACT

The Federation of Disability Organizations in Malawi (FEDOMA) engages in disability advocacy across all scales of Malawian society, including national lobbying and grassroots activism. Much of the literature to date on disability rights movements (DRMs) focuses on minority-world movements. Majority-world contexts are systemically different, with hybrid cultural and political structures which reflect the legacy of colonialism. Exploring these DRMs expands our thinking about social movements, contributing to broadening inclusivity in disability studies. This thesis explores the advocacy work and experiences of FEDOMA's grassroots advocates both within and outwith the organisation, focusing on voice as a resource. I investigate the internal dynamics of FEDOMA that effect members' motivation to activism and seek to understand the role of grassroots voices in reproducing and altering systemic structures. To achieve these aims, I devised a two-stage research project. In Stage 1, I conducted a "participatory design process" with FEDOMA, to develop the study. In Stage 2, I conducted interviews and participant observation with grassroots DDF members in four sites across Malawi and FEDOMA staff at national headquarters. I used structuration theory as a basis to develop a "hybrid disability studies" approach to data analysis, exploring the relationships between, and mutual constitution of, structures and agents. The discussion centres on (i) emotion, trust, and leadership as relational resources for advocacy, (ii) resource transference across scales and space-time, (iii) integration of hybrid structural schemas into advocacy work, and (iv) the importance of hearing and *listening* on the part of FEDOMA in sustaining an engaged grassroots base. The analysis finds that activists use the resources of global systems in combination with local knowledges to address the needs of modern, neo/post-colonial, hybrid societies. Developing hybrid, place-centric disability and social movement studies is one way to explore the complex, and sometimes contradictory, realities of social organising in majority-world contexts.

CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF IMAGES

All images were taken by the author, Sarah Huque, during fieldwork.

LIST OF ABBREVIATIONS

Area Disability Forum(s) (ADF(s))

Association of Persons with Albinism in Malawi (APAM)

Community-based Rehabilitation (CBR)

Disability Inclusive Disaster Risk Reduction (DIDRR)

Disability Rights Movement (DRM)

Disabled Persons’ Organisation(s) (DPO(s))

Disabled Women in Development (DIWODE)

District Disability Forum(s) (DDF(s))

District Education Manager (DEM)

District Health Officer (DHO)

Economic Empowerment Programme (EEP)

Federation of Disability Organizations in Malawi (FEDOMA)

FEDOMA Executive Director (ED)

FEDOMA General Assembly (GA)

FEDOMA Headquarters (HQ)

Head Teacher (HT)

International Day of Persons with Disabilities (IDoPD)

Malawi Council for the Handicapped (MACOHA)

Malawi Human Rights Commission (HRC)

Malawi News Agency (MANA)

Malawi Union of the Blind (MUB)

Monitoring & Evaluation (M&E)

Parents of Disabled Children Association of Malawi (PODCAM)

Project Coordinator(s) (PC(s))

Southern African Federation of the Disabled (SAFOD)

Village Development Committee(s) (VDC(s))

Village Savings and Loan (VSL)

UN Convention on the Rights of Persons with Disabilities (UNCRPD)

1 INTRODUCTION

My vision is low. Since Standard 1, up to my tertiary education, I used to only hear in class, as if… I am blind.

***

Where I'm coming from is poor. My father passed away. And before he passed away… The family divorced. Because of me.

***

We stand as a team with disabilities, saying "we are here!" We want our rights back. We have our friends here. Our relatives here.

***

We tell them… We as people with disabilities, we can get married. As I am a vivid example. I am a person with disabilities, and I am happily married. And these people with disabilities can get educated. I am a person with a disability, and I am now, a teacher.

The quotes above are excerpts from Mallory's life story, as she relayed it for this research project. Mallory is a Malawian woman with albinism. She is a member of the Federation of Disability Organizations in Malawi (FEDOMA) and the Association of Persons with Albinism in Malawi (APAM). Mallory is a grassroots advocate/activist[1] within Malawi's disability rights movement (DRM). The passages above hint at her journey, why she became an advocate, and what she has accomplished thus far personally, professionally, and as an advocate.

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[1] In this thesis, I use 'advocate/cy' and 'activist/m' interchangeably. While most FEDOMA members call themselves 'advocates', most of them are 'self-advocates', and their work is part of a larger disability rights (activist) movement in Malawi and internationally. My use of the terms falls in line with the work of Kimball et al. (2016) on disability self-advocates as activists.

In this thesis, I aim to understand the role of grassroots voices like Mallory's in reproducing and altering systemic structures both within Malawian society and FEDOMA as an organisation. In undertaking this research, I sought to learn from disability advocates in a majority-world context and to contribute to a growing literature on disability activism beyond minority-world perspectives. I designed the research project presented here with FEDOMA to incorporate a participatory ethos within the constraints of the project.

This thesis focuses on voice within the DRM, the ways in which voice is conceptualised, and how voice is used within and outwith organisational contexts. Drawing on structuration theory, I explore systemic structures which enable and constrain advocates' expressions of agency through voice. I also investigate the impacts of embodied and material conditions, such as physical or mental impairment and gender, on disability advocacy work in the Malawian setting.

A note on terminology: throughout most of this thesis, I use person-first language, i.e., 'persons with disabilities'. Person-first language is the preferred language of the Malawian disability advocates that participated in this research. The exceptions will be when presenting a direct quote from an individual or a text, or when I am discussing a different group and am aware of their alternative language preference. I also use 'non-disabled' persons throughout to indicate people without disabilities. This language aids in ease of understanding and was acceptable to participants in the research project.

1.1 SITUATING THE THESIS: TOWARDS (AND BEYOND) A HYBRID DISABILITY STUDIES

1.1.1 Theoretical perspectives and models of disability

Disability studies is "inextricably linked" with disability activism, as the work of academics and activists together in early DRMs is credited with the development of the field (Oliver and Barnes, 2010). As such, research on the evolving and growing movements for disability rights worldwide can contribute to a broader understanding and a complicating of disability studies. Most of the DRM literature has focused on movements within minority-world countries; the UK and US movements are particularly dominant. While these movements are credited with beginning both disability studies and 'the' DRM, newer movements have developed in the majority-world which can lend new insights, broader understanding, and new approaches to disability rights. This thesis contributes to the literature on disability by focusing on Malawi, a country for which most of the available academic literature still focuses on the medicalisation of disability. In addition, FEDOMA, a prominent umbrella organisation for disabled persons' organisations (DPOs) has not previously been studied. In this thesis, I argue the importance of a 'hybrid' approach to disability studies which incorporates notions of place-based context, an appreciation of national systemic and inter-systemic structures, and an evolving understanding of models of disability, including a move toward more "eclectic" (Gabel and Peters, 2004) approaches and new materialism in academic disability studies.

FEDOMA, through its organisational principles, claims to adhere to the social model of disability. The social model of disability arose from early disability civil rights activism, particularly in the UK, and it has been the backbone of 'the' DRM (in a collective, global sense) from its inception in the 1970s (Charlton, 1998; Shakespeare and Watson, 2001), to the present day. The social model offers an alternative to the previous hyper-medicalisation of disability of the past (the 'medical model'). Oliver and Barnes (2010) describe the social model as an approach which 'breaks the causal link between impairment and disability. The "reality" of impairment is not denied but… the emphasis shifts to how far, and in what ways society restricts their [disabled people's] opportunities…' (p. 548). The social model has been credited with beginning processes of consciousness raising and empowerment for disabled people/people with disabilities (Shakespeare and Watson, 2001). Over time though, some disability scholars have pointed out that a discounting, if not a complete disavowal, of materiality has arisen within the social model. Feely (2016) cites common critiques of the social model: "these approaches overlook the (often inaccessible) material world… they are unable to engage productively rather than critically with science and technology; and they discount the importance of embodied experience, including pain" (p. 865). Shakespeare and Watson (2001), argue that the success of the social model has simplified disability rights rhetoric in a way that is unrealistic to individuals' lived experiences, noting that "if the rhetoric says one thing, while everyone behaves privately in a more complex way, then perhaps it is time to re-examine rhetoric…" (p. 12). Shakespeare and Watson (2001) advocate a return to considering embodied experiences of disability, drawing on both disabled feminist critiques of the social model ignoring the personal and critiques of the "denial of difference" (p. 14) within the feminist movement. The importance of difference is central to the ethos of the DRM and should be part of evolving practice:

> Diversity is its [the DRM's] central characteristic. No one leader or organization can claim to speak for all disabled people. It is accepted… that members of the disability cause will hold shades of belief and not hew to an overriding orthodoxy… But by its acceptance of differences, the campaign for disability rights has forged a powerful coalition of millions of people with disabilities, their families, and those that work with them (Shapiro, 1993, p. 11).

Some disability scholars have advocated for new approaches which allow for a greater breadth of engagement with diverse theories and contexts within disability studies, for example the "eclectic" (Gabel and Peters, 1993) approach and new materialism. New materialism argues for a return to a consideration of the embodied, material, and personal, while simultaneously incorporating the strengths of the social model. As Feely (2016) put it: "there are ways to retain the radical potential of poststructuralism [and social models of disability] - the ability to contest oppressive identity categories - whilst also exploring the actual material world, the material sciences, and the visceral experience of having a body" (p. 867). Eclectic approaches also support a 'broadening' of disability studies, proposing to move beyond limiting models of disability, particularly through theoretical intersectionality (Gabel and Peters, 2004). Proposed by supporters of resistance theory as an evolution of disability studies opening to feminist, critical, queer, and race theories, this approach sees criticisms of the social model as "heralds [of] the beginning of a paradigm shift toward an eclectic 'model' (loosely defined) that welcomes diverse paradigmatic representations" (Ibid., p.586). New materialism and eclectic disability studies emphasise hybridity, an ethos which works for this thesis and developing an understanding of the complexity of experience within Malawi's DRM. Grech (2012) holds that hybridity can assist scholars in countering the "neocolonisation" of (global) Southern space through the transplantation of minority-world models of disability to majority-world contexts: "meaning is dependent on the hybrid contexts in which disability is placed, and any attempt to understand what disability means in specific spaces involves first engaging with what is valued in these same social, political, economic, cultural and ontological locations" (p. 58). While FEDOMA's advocacy work incorporates aspects of the social model, the approach utilised by Malawian activists (and arguably all activists in practice) goes beyond what can be comfortably encompassed within the social model developed within the minority-world. In this thesis, I discuss the crucial role of embodiment in experience and motivation for advocacy and activism, as well as considering the social constructions which constrain persons with disabilities from full engagement in social and community life. I discuss the physical 'realities' which impact activists' everyday lives. All these aspects are important to consider, supporting a hybrid approach to disability studies which focuses on the intersection of the 'social' and the 'material' in a particular context and the blurring of boundaries between the two. Structuration theory is useful for this, as it is concerned with the ways ('virtual') schemas and ('actual') resources mutually constitute one another.

1.1.2 A Malawian context

My 'eclectic' approach to disability studies in this thesis emphasises the importance of geographic and other contextual factors in developing a 'hybrid' disability studies which allows deeper exploration of the situational reality for Malawian advocates. It is necessary to consider diversity not just of experience of impairment but also in place, time, and systems - the experience of disability in Malawi is very different from the experience of disability in, for example, the UK. In the following section, I provide an overview of the specific context in which Malawi's disability activists organise. I begin with an overview of Malawi's history, then consider the Malawian context today both generally and regarding disability specifically.

1.1.2.1 History and Evolution of Structures: pre-colonial times - present day

In this brief discussion of Malawi's history, I explore the development of modern Malawian cultural, economic, and politico-legal structures. These structures are all related within the context of a system, constituting one another. I include disability history where possible, though academic sources on disability before the start of democratic governance are limited. Due to the dearth of historical information on disability, I focus on the evolution of a gendered division of labour and Malawi's changing political structures to anchor this overview. There are several reasons for this focus on changing gender divisions in particular:

(i) This approach provides background that will be especially relevant in Chapter 7's focus on intersectionality and the women of FEDOMA.

(ii) It enables discussion around the changes to both men's and women's roles during colonial and post-colonial times.

(iii) The gendered division of labour underscores the importance of socioeconomic status as a key intersectionality with disability; persons with disabilities are among the most socioeconomically disadvantaged in the world. A main focus for disability activism in Malawi is inclusion in evolving capitalist economic structures, but this affects men and women differently.

(iv) Cultural and legal schemas which relegate care work to women and the home, attempting to delineate home spaces as unimportant to (disability) governance, also work to side-line women from participation in governance. This effectively prevents the voices of those with lived experience of disability caring from contributing to the governance structures that impact them and those for whom they care. Added to the marginalisation of persons (and especially women) with disabilities more widely in Malawi, this stresses the need for disability advocates to find ways to have their voices heard.

1.1.2.1.1 Pre-colonial Malawi

There is little available information on pre-colonial disability in Malawi. There is evidence of community knowledge of infectious disease as well as a belief in illness caused by spirits or sorcery (Waite, 1987). This association between disability and sorcery endures to this day. There is considerably more scholarship on societal structures, in particular pre-colonial gender roles. It is important to note, however, that what the precolonial situation was is difficult to definitively say, because we can only access it via (i) colonial accounts, (ii) oral histories, or (iii) more recent accounts, all of which contain particular political biases[2].

Barry and Grady (2019) emphasise that in sub-Saharan African countries, including Malawi, “gender roles were atypical of Western context[s] prior to and during colonialism…” (p. 182). Notions of a “universal subordination of women” also do not suit explorations of pre-colonial African societies (Day, 2008, p. 496). This highlights a critical development within Malawian cultural schemas: new gender divisions introduced during colonialism, which differed from what gendered divisions existed during the pre-colonial era. Many of the cultural structures discussed here were reinforced through conversations with Malawian people during fieldwork, especially regarding how historical structures manifest today. Whether or not we consider descriptions of pre-colonial cultural structures ‘factual’, they are part of the belief system which underpins Malawi’s hybrid cultural structures today.

Pre-colonial ‘Malawi’ was made up of a wide variety of tribes with heterogeneous cultures and traditions; the nation of Malawi as we know it today did not exist. However disparate, in many societies, women held prominent roles, engaged in trade and agricultural production, and participated in village politics (Mandala, 1984). Chewa tribes were among the matrilineal societies found in the region (Ibid). Although there were patrilineal tribes in the region as well, Chewa societies became particularly important to the establishment

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[2] As do all qualitative accounts.

of ‘Malawian’ culture during the Banda era, discussed later. “The *mbumba*, the group of matrilineally related women, constituted the center of a village’s network of social relations” (Segal, 2008, p. 11). These matrilineal tribes had complex power relationships in which men would marry into a woman’s family, move to her village, and work her family’s land. Men were heads of households, but through kinship ties with women - fathers, uncles, and brothers as opposed to husbands (Kachapila, 2006; Peters, 2010). The power of women in these societies was counter-balanced by the role of the *nkhoswe* - the brother or uncle who led the family, as determined by matrilineal associations (Mandala, 1984). The *nkhoswe* “served primarily as a caretaker whose ultimate source of authority was the sorority group, led spiritually and sometimes politically by their eldest living sister” (Ibid., p. 139). Today, for many Malawians, “the kin group is defined as people related through female ancestors and relatives” (Segal, 2008, p. 6). This is particularly important in considering disability in Malawi, where the basic unit of society is the kinship group, and care work, including care for persons with disabilities who require it, is assigned within these groups.

During the transition from pre-colonial to colonial times, the onset of enslavement[3] in Malawi weakened the jurisdiction of village leaders “who were just as likely to be headwomen as headmen” (Davison, 1993, p. 408). In addition, drought impacted stability: “that village leaders could not ‘call down rain’ further weakened their authority” (Ibid., p. 408). Invasions by patrilineal warrior groups led to the deposition of village headwomen (Davison, 1993). These times of “generalized insecurity” resulted in increased power for the *nkhoswe* (Mandala, 1984). “As a result, by the time British missionaries gained a hold in the lower Shire Valley in the 1880s, other forces within southern Africa already were in place that contributed to the erosion of women’s authority and socioeconomic power” (Davison, 1993, p. 408). This increase in the prominence of men’s roles continued during the colonial era.

The impact of colonialism on women in Malawi[4] is well-documented in academic literature. “It was necessary for the advancement of a colonialist agenda to have gender-specificity to alienate African women

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[3] The global “slave trade”, though this language is considered inappropriate by anti-racist activists today.

[4] Known in colonial parlance as “Nyasaland”.

as they were seen as a threat to patriarchic ideals" (Barry and Grady, 2019, p. 184). The colonial government brought with them Christian patriarchal norms that soon infused throughout Malawian societal structures, altering schematic gender relations throughout, but especially in previously matrilineal societies, such as the Chewa tribes. Kachapila (2006) points out that "matrilocally married husbands" (p. 330) sometimes felt powerless in matrilineal communities[5]. This resentment enabled Christian missionaries to impact household structures during the colonial era. "The result is that…husbands… welcomed Christian teaching on marriage because it accorded them more control over their nuclear families than did the traditional matrilineal custom" (Kachapila, 2006, p. 330). This control often came through the development of economic structures which enabled men and constrained women. For example, Davison (1993) discusses the shifting of most household agricultural work to women due to men's colonial wage labour obligations. In addition, Church of England missionaries and authorities granted land to men, eroding the land transfer customs of matrilineal Malawian tribes (Davison, 1993).

Colonisers' desire to maintain the productivity of African workers - in order to profit from the "commoditisation of agriculture and labour" (Davison, 1993, p. 409) - led to the introduction of limited public health infrastructure in colonised lands like Malawi (Waite, 1987). However, "they did not include disability allowances, for only the productive periods of the colonized workers were of interest to the colonizers" (Waite, 1987, p. 205). Colonisers also actively undermined traditional medicinal practices, as part of a broader destruction of pre-colonial belief systems (Waite, 1987). Despite this, some aspects of witchcraft-based belief systems are still part of Malawi's cultural schemas. As Waite (1987) put it: "public control of sorcery… came to an end, but not the public's belief in the existence of sorcery" (p. 206).

Colonisers' focus on economic transformation and commoditisation also impacted gender roles in Malawi. Kachapila (2006) argues that "developments such as labour migration, cash crop production, mission education and the resultant employment of some educated Africans enabled Chewa men to transcend the

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[5] Matrilocally married men were expected to be subservient to their wives' male relatives and could not expect to become heads of households themselves (Kachapila, 2006).

context of matrilocal marriages" (Kachapila, 2006, p. 331). Waged labour such as tobacco crop production was open only to men, though they were often aided by their wives; towards the end of the colonial period some women engaged in waged labour independently of their husbands (Kachapila, 2006). At the same time, in addition to aiding their husbands in cash crop production, women worked brewing beer, processing food, and producing maize and groundnuts as ways to move toward economic security (Kachapila, 2006). These activities can be seen as forms of resistance through which women continued to engage in their roles as providers and stewards of kinship groups. The tension between 'culturally-appropriate' roles and survival continues to impact Malawians with disabilities and their (often women) caretakers as well. Malawian disability advocates, as will be discussed, use their 'ability' to engage in these roles and support arguments in favour of inclusion.

Further constraints on women's agency were established during the colonial era. For example, colonialists restricted schooling to boys (Barry and Grady, 2019). The erosion of women's position during this era also occurred through altered schemas in traditional spaces. In particular, the colonial era saw the ritual subjugation of women through the introduction of men's presence into traditionally women's spaces, such as c*hinamwali*, a girls' initiation ritual practiced in Chewa societies (Kachapila, 2006). While the practice of *chinamwali* could be seen as constraining women, as a way of training girls to please men, it was also a purely women's space prior to the colonial era. Additionally, *chinamwali* prepared women for their roles as producers, mothers, and contributors to their communities as well as wives. These examples disrupt tidy Western paradigms of traditional cultures as oppressive and of capitalism as liberating. In Chapter 7, I explore the role of traditionalism in women's approach to organising in more depth. Throughout the thesis, I discuss the ways in which all FEDOMA members navigate accepted or (neo)traditional schematic expectations in their advocacy activities, both reproducing and altering these schemas.

Colonialism led to changes in the ways African men viewed women: "Prior to colonialism Africana[6] men in many communities saw themselves as sons first (family-oriented-extension of their mothers), before their

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[6] Specific term employed by the authors and proponents of Africana womanism.

sex/gender identity as male/man (independent, autonomous being)” (Barry and Grady, 2019, p. 184). While some of Malawi’s traditional cultures were matrilineal, the legacy of colonialism and the rise of democracy and capitalism in Malawi’s system encouraged the development of what may be seen as a ‘new traditional’, Westernised division of labour: “colonialism created and reinforced crude dualistic understandings of social reality, with the effect that African women became associated with ‘tradition’ rather than ‘modernity’... Legacies of these ideas continue to influence popular discourses about social change...” (Riley and Dodson, 2016, p. 1050). These changes continued to evolve beyond the end of the colonial era. The post-colonial era saw the co-option of some concepts from matrilineal traditions into a new conceptualisation of ‘Malawian’ tradition, used by Dr Hastings Banda to establish himself as the leader of a united Malawi.

1.1.2.1.2 The Banda Era

After Malawi gained independence from British rule, Dr Hastings Banda came to power, ruling as an autocratic prime minister and then president from 1964 until he was defeated in Malawi’s first democratic elections in 1994. McCracken (1998) argues that “Malawi nationalism was a genuinely liberating force… in that it provided a stage on which previously marginalized groups, including some women… could perform” (p. 249). However, McCracken (1998) goes on to point out that “popular participation did not equal popular empowerment, nor… did it reflect that respect for individual rights and minority opinions on which democracy must be based” (p. 249). Banda’s ‘Malawian’ tradition-based independence movement appropriated matrilineal ideas from pre-colonial Chewa societies, altering them to empower Banda *without* (re)empowering women. Banda espoused the Chewa concept of *mbumba* as a *Malawian* concept, establishing himself as the *nkhoswe* for all of Malawi (Segal, 2008). Banda’s strategy included women members of the party as dancers (Tiessen, 2008) who embodied the concept of all Malawians as part of one *mbumba* (Segal, 2008). ‘Membership’ in the party was compulsory for all Malawians under Banda’s regime (Ibid.), highlighting the coercive nature of this participation. Banda altered traditional schemas and practices to portray himself as a leader who could ‘bring back’ ‘Malawian’ traditions, even though Malawi as a unified entity, and indeed, Banda's version of *mbumba/nkhoswe* likely never existed in the strictly hierarchical manner Banda promoted (Segal, 2008). "Traditional practices such as dance became a powerful tool for controlling and manipulating public support" (Tiessen, 2008, p. 202). Disability advocates who grew up with the legacy of these practices now use traditional practices themselves in their work.

The public support of women was also one form of patronage, widely practiced during the Banda regime, contributing to the development of Malawi into a neopatrimonial state. 'Big man syndrome' is a notable feature of African (including Malawian) neopatrimonialism, which compounds power within a central figure or figure(s) (Booth et al., 2006). Banda's claims of being *nkhoswe* for Malawi is one example of this. The cultural pervasiveness of neopatrimonialism, patronage, and 'big man syndrome' is reflected within other systems in Malawi, including FEDOMA, as will be discussed in this thesis.

The Banda regime's policies on women's roles demonstrated the conflict between a focus on traditionalism and 'modernising' and globalising influences in post-colonial Malawi. Despite the prominent visual position of women in the party, women held little actual political power within Banda's political circle or in Malawian society. Banda's new traditionalism continued colonial gender divisions; government training programmes aimed at women were highlighted as modernising, with a "homecraft curriculum" aimed at teaching women new ways to care for their husbands replacing traditional practices (Segal, 2008). In addition, Semu (2002) and Segal (2008) point out that these attempts at skills training did not address the real needs of women, most of whom did not lack knowledge but materials. The effect of this was the prevention of women from entering into spaces of development and waged work: "[women's] major role in the development process was to feed their husbands… to be domestic providers, doing what they were *said* to have always done… there is an identification of ordinary women with the traditional… the non-modern" (Segal, 2008, p. 16) [emphasis added]. Segal (2008) goes on to point out the contradiction and political importance of this association of women with Banda's new traditionalism: "this identification of women with tradition is important because tradition is described [by informants] as both a major support of and impediment to development" (p. 17). This ensured women were part of the consolidation of Banda's power with little actual empowerment of women within the societal schemas of Malawi. Banda used gendered divisions of labour to enable the political reconciliation of colonial schemas and post-colonial development within the new Malawi by taking personal credit for modernisation and 'resolving' contradictions between Malawi's past and present. This enmeshing of past and present is reflected in Malawi's hybrid structures today, which draw on pre-colonial, colonial, and 'new' Malawian practices, in addition to the neo-colonial influence of present-day global political and economic systems.

As a result of their exclusion from participation in economic and political development, women's roles in domestic spaces expanded (Sturges, 1998). This made "female-headed households… disproportionately important… due to such factors as migrant work by men. In addition, women make most of the decisions relating to farm activities in many male-headed households where the men are mainly concerned with non-farming economic activities" (Ibid., p. 200). Segal (2008) also highlights the importance of women's domestic roles, which "included provision of a substantial portion of subsistence, as well as maintenance of informal communal networks" (p. 23). Despite the Banda regime's attempts at reductionism, women's roles remain critically important to the survival of families, and many households are de facto headed by women. Today, this often translates to women engaging in waged labour or cash businesses to provide for their families (as they did during the colonial era and arguably never *really* stopped doing). While the gendered division of labour continues to be relevant in Malawi today, several decades into its democracy, poverty's blurring impact on these divisions is important to consider. Similarly, persons with disabilities seek to engage in waged labour for survival, despite cultural structures seeking to exclude them.

1.1.2.1.3 Malawi's Structures Today

Throughout the 'postcolonial' Banda era and the subsequent post-Banda turn towards democracy in Malawi, colonial structures were reproduced and altered in developing the structures of today. "When colonial rule ended in east-central Africa… European introductions remained" (Waite, 1987, p. 206). This includes the (still under-developed) public health system. Waite (1987) notes that the desire to marry the colonial and the ‘new’ traditional resulted in an emphasis on integrating both traditional and minority-world health systems. This is partially because “unlike the European colonists, post-colonial African rulers are interested in expanding health services to the rural areas” (Ibid., p. 206). However, there remains a large disparity of access to medical care and services, especially the specialised care, medications, and technologies needed by some persons with disabilities. In addition, the continued belief in witchcraft rituals impacts the inclusion and safety of persons with disabilities today.

Tiessen (2008) points out that “despite the shift to a democratic government, a culture of neopatrimonialism is pervasive in Malawi, thus limiting civil society reforms and prospects for gender equality” (p. 202). For example, women are still used in public displays of political support (as shown in Image 1[7] below), despite a belief in Malawi that “women’s exposure to public activities will lead to immoral behaviour” and that “political involvement will take women away from their responsibilities in the home” (Ibid., p. 205). This point can be extended to disability equality as well, including the barriers which constrain persons with disabilities from engaging in public and political life.

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[7] All images included in the thesis were taken by the author during fieldwork. All images containing identifiable aspects of people (e.g., faces) have been stylised as paintings to protect anonymity. All stylised images are photographs collected during fieldwork which were subsequently altered using photoshop to distort identifiable features.

Image 1. Women dressed in chitenje depicting the President's portrait wait to perform a traditional song and dance at the 2019 International Day of Persons with Disabilities celebrations in Salima, Malawi.

The perception of women needing to ‘stay in their place’ unless supporting men in politics reflects the power of the public/private divide in the lives of modern Malawian women, emphasised by the dualism of colonial and post-colonial gender divisions. Women continue to conduct the bulk of household and subsistence work; work which is belittled by dominant neopatrimonial narratives. For example, despite evidence that women are “more efficient farmers than men”, respondents in Segal’s (2008) study believed just the opposite, which “begins to explain why the position of women does not seem to have changed over the last 25 years” (p. 23). Tiessen (2008) also highlights that the continued pervasiveness of neopatrimonialism in Malawi means that national budgeting favours “powerful politicians”, and “prevents development assistance from being administered efficiently, equitably and to those who need it most” (Tiessen, 2008, p. 203). The use of “the budget for their [powerful politicians’] own ends” (Ibid., p. 203) impacts disability advocates’ ability to demand resources for implementation of legislation. For example, the

2012 Disability Act in Malawi promised the creation of a ‘disability trust fund’, which eight years later has not yet been established and implemented.

The lack of progress on government-funded programming for disability has contributed to a focus on economic inclusion in Malawi’s DRM. Most work in Malawi falls into the ‘informal sector’ (e.g., small unlicensed businesses selling anything from food to clothes); the majority of formal work is agricultural. Women are usually in charge of subsistence farming and domestic work (Pal et al., 2015). However, given the widespread poverty and unemployment across Malawi, men also engage in farming, including subsistence farming, especially when unemployed. Persons with disabilities are often excluded from farming assistance programmes by local authorities. This exclusion is technically unlawful but occurs as a result of persons with disabilities ostracization and perceived ‘inability’ to engage in farm work.

Increasingly, women have been the focus of economic development programmes, many of which emphasise entrepreneurship, often in the form of skills that can be utilised in the informal economy, such as sewing. For many women, economic security and the autonomy that comes with it are emphasised because it enables them to care for their families – reinvesting their economic success in “kinship and peer networks” (Harrison, 1991, p. 178). These skills development programmes reflect those of the Banda era, though often now with a message of ‘women’s empowerment’ as opposed to traditionalism. Though engaging in this type of skills training risks continuing to relegate women to particular industries and spaces, for women with disabilities, learning an ‘acceptable’ women’s trade can be transformative. However, women with disabilities are often left out of development and empowerment programmes aimed at women and girls (Malawi Human Rights Commission, n.d.). Pal et al. (2015) highlight that many women with disabilities struggle to gain employment (especially formal employment), even in jobs deemed ‘appropriate’ for women, such as teaching and nursing - facing even more limited choices than other women in their communities.

The struggle for livelihoods demonstrates the intersection of gender, disability, and social class (and other identities). Schriempf (2001) argues against viewing intersectionality in an “additive” way, however, which “presupposes a bio/cultural binary” (p. 65). This dichotomisation is “inaccurate” and “impedes the successful bridging of feminism and disability theory" (Ibid., 2001, p. 61). Schriempf (2001) argues for "the recognition that women with disabilities are not dually oppressed, doubly handicapped, or double whatever; instead they embody a complex of interwoven situations" (p. 67). This complex includes the constraining and enabling schemas that come with additional axes of intersectionality. It is important to keep in mind that these are only a subsection of the various factors that make up individuals' identity. For example, the role of race (as demonstrated by the impact of colonialism and neo-colonial development structures on Malawi today) and socioeconomic status as well as gender play a role in the lives of Malawian disability advocates.

Structures, as discussed in this section, are historical, malleable, and ever evolving. Cultural, political, governance, economic, and other structures are intertwined. This is particularly important in gaining insight into the political nature of the ways in which marginalised groups engage with culture, and 'tradition' as part of culture. Sharp (2013) highlights that Western perceptions of Africa are often apolitical, at least in that Western people tend not to consider the politics of individual African countries. Sharp (2013) describes this thinking as part of the West's focus on a "predominant and indeed overwhelming narrative… of lack" (p.4). Sharp (2013) connects this to "crisis images" and indeed, this is often the narrative around disability in Malawi. This enduring image makes 'African culture' seem ahistorical as opposed to evolving and hybridizing, and indeed this conceptualisation is sometimes reinforced by Africans' representations of their culture as ancient and unchanging instead of dynamic and evolving (see for example, Mwale, 2002). As a result, there is considerable emphasis on outside intervention through aid and charity, and less interest in the local social justice movements developing from the grassroots within majority-world nations. In particular, since majority-world disability studies of Malawi are often focused on attainment of basic needs, it is easy to underestimate the political statements made by Malawian women and persons with disabilities engaging in 'traditional' or 'everyday' roles in their communities. In fact, undertaking these roles is part of political consciousness and can be a radical act, as will be discussed throughout this thesis.

While the image of Malawi as a country in crisis can be damaging to outsiders' perceptions of Malawians' political capabilities, it does stem from a context of extreme poverty and deprivation. These circumstances are also important contextual grounding for an exploration of disability advocacy in Malawi. Malawi is classified as low income by the World Bank (2020), with a 51.5% national poverty rate. Malawi's population is very young - life expectancy is 63.7 years, and the median age is 17 years (National Statistical Office, 2019). 84% of Malawi's population live in rural areas (Ibid.). However, Malawi's four large cities all have a higher number of men than women, while there are more women than men in rural areas (Ibid.).

With this contextual information in mind, in the following sections, I discuss the specific circumstances of disability in Malawi. I present information on the types and prevalence of disabilities in Malawi today, an overview of key cultural beliefs about disability, and a brief introduction to Malawi's disability legislation. In Chapter 4, I provide further discussion of the development of this legislation.

1.1.2.2 Disability in Malawi Today

According to Malawi's 2018 census, "about 10.4 percent of the population aged 5 years and older... had at least one type of disability, [of this] 10 percent were males and 11 percent females" (National Statistical Office, 2019). This equates to 1,556,670 persons with at least one disability (Ibid.). Malawi's 2018 census report includes two measures of disability prevalence, the first inclusive of albinism and epilepsy, the second defined according to the Washington Group's more limited list of conditions and focus on "difficulty functioning" (Washington Group on Disability Statistics, 2016; National Statistical Office, 2019). These differences in defining disability emphasise the importance of focusing on national context and in-country understandings of and differences between types of impairments. For example, 647,450 Malawians with disabilities (15 years of age or older) were reported as employed, out of a total employed national labour force of 5,389,463 people(National Statistical Office, 2019). About 92% of these individuals have albinism or epilepsy (Ibid.). If we were to choose the more restrictive second definition of disability, which excludes albinism and epilepsy, the number of persons with disabilities in formal occupations reduces dramatically to 49,980 individuals (Ibid.). Albinism and epilepsy provide illustrative focal points for disability in Malawi. Albinism is among the most high-profile disabilities in Malawi, due in large part to extended media coverage of the violence committed against persons with albinism. According to the 2018 census, approximately 134,636 Malawians have albinism (Ibid.). Albinism as a disability highlights the nexus of beliefs and embodiment in defining disability in place: albinism is in part disabling due to the exclusion from society and violence committed against persons with albinism. At the same time, associated skin and vision problems constitute the embodied, material reality of albinism as impairment. The stigmatisation of persons with albinism is discussed in Section 1.1.2.2.2 – 'Beliefs about disability' in this introduction. On the other hand, epilepsy provides an example of a shifting conceptualisation of what 'disability' means in Malawi.

The recognition of epilepsy as a disability in Malawi is relatively recent and is just one indicator of changing, expanding conceptualisations of disability, particularly in the recognition of a range of neurological disabilities and disabling mental disorders. Communicable diseases, for example cerebral malaria, are among the reasons that Malawi has a high rate of children with "neurodisabilities" (Paget et al., 2016). From a medical standpoint, in Malawi the focus is on disease prevention (due to the extreme limitations of healthcare availability) as opposed to managing the long-term impairments that result when prevention fails (Paget et al., 2016). Most mental healthcare is done within primary care, as Malawi has very few psychiatrists and psychiatric nurses (Crabb et al., 2012). Many Malawians attribute disabling mental illnesses to drug use or supernatural causes, while at the same time there is widespread acceptance of "brain disease" as another cause (Ibid.). Kavinya (2011) notes that in Malawi:

> Psychiatric patients are often abandoned by their families because of the stigma attached to mental health. Mental illness... is still perceived as an indulgence, a sign of weakness. Self-stigmatisation has been described, and there are numerous personal accounts of psychiatric illness, where shame overrides even the most extreme of symptoms (p. 98).

The inclusion of 'intellectual difficulties' in the 2018 census was an indicator of some success toward destigmatising discussions of mental health and disability in Malawi; disability advocates who participated in my research noted this as an area for on-going work toward fuller recognition.

Women with disabilities face particularly severe marginalisation in Malawi. For example, “in much of Africa, women with disabilities are more likely to experience poverty, and have limited access to health care or companionship. They are more likely to experience stress related to social isolation, and are likelier, than blind men [for example], to marry another blind person” (Pal et al., 2015, n.p.). A survey by Disabled Women in Africa (DIWA), found that 64.7% of women and 56% of girls with disabilities have experienced “exploitation, violence and abuse” (p.1), but just 17.6% and 22% respectively said they had reported the abuse (Mkutumula, 2014). Women with disabilities are less likely to attend school than men with disabilities and non-disabled women (International Labour Organization, 2007a).

1.1.2.2.1 Disability Legislation in Malawi

In the years since independence, successive governments of Malawi have implemented increasingly progressive legislation aimed at promoting the inclusion of persons with disabilities. International legislation to which Malawi is a party, especially the UN Convention on the Rights of Persons with Disabilities (UNCRPD), provides important background for national-level legislation. Malawi’s 1971 Handicapped Person’s Act established the quasi-governmental Malawi Council for the Handicapped (MACOHA), in a first move toward acknowledging the role of the government in supporting persons with disabilities. The 2012 Disability Act was passed as result of international and local pressure and in conjunction with an evolving appreciation for the social aspects of disability in mainstream Malawian political discourse. There is currently a disability bill being reviewed in Parliament which would combine and update both the 1971 and 2012 legislation. In Chapter 4, I discuss the evolution of this legislation in conjunction with the work of activists.

1.1.2.2.2 Beliefs about Disability in Malawi

Despite the increasingly reformist legislative context of disability in Malawi, many persons with disabilities face a high level of social stigmatisation and ostracization. Engaging communities to alter stigmatising beliefs and the resultant exclusion is a major focus for FEDOMA's 'bottom-up' advocacy work. Booyens et al. (2015) argue: "the gap is indeed wide between the goals for the social inclusion of persons with disabilities, set by the Convention on the Rights of Persons with Disabilities (UN 2006) and the CBR [Community-based rehabilitation] Guidelines (WHO 2010) on the one hand, and the contextual realities of community disability practice in rural areas of developing countries on the other" (p.7). Part of addressing this gap means addressing cultural beliefs about the meaning of disability.

Disability is often seen as relating to witchcraft and/or superstition in Malawi. Disability can be viewed as punishment for a crime or sin committed by one or both parents. A child born with a disability might also be seen as cursed by society and thus someone to avoid. Disability is also sometimes viewed as contagious, which can lead to the ostracization of both persons with disabilities and their families. Health workers in Paget et al.'s (2016) study highlighted a lack of biomedical knowledge among parents and carers about long-term impairments caused by malaria and meningitis, turning instead to alternative explanations such as witchcraft. While there are broader superstitions about disability as a curse at any point in the life-course, many of the most dangerous are attached to individuals born with disabilities or those who acquire them in childhood, especially as it can be seen as an indictment of the parents, making the possible rejection or hiding of the child by families more likely.

Persons with albinism experience a particularly high level of social stigmatisation. The beliefs around witchcraft and superstition are especially potent regarding albinism (Rohwerder, 2018). Some Malawians believe that persons with albinism are not human and/or are 'magic'. Their bodies are used in rituals intended to help individuals gain money, status, or fame (Setume, 2016). These beliefs have made their way into the lexicon that people use when interacting with persons with albinism. In some cases, they taunt individuals, saying things like “there goes money” (FNs[8], 2018/19). This refers to the high price paid for the bodies of persons with albinism for rituals. As widely reported by news media in 2015-2016, this has led to a high level of violence against persons with albinism. This violence takes the shape of kidnapping, maiming, murder, and grave robbing. The supposedly magical nature of disability also means that they can be exploited in other ways by non-disabled individuals. For example, some believe that having sex with a person with a disability (especially albinism) can cure HIV/AIDs, leading to sexual assault against persons with disabilities (Setume, 2016). Banks et al. (2017) also highlight “stigmatising cultural beliefs” (p.11) around persons with disabilities, noting that perpetrators of violence against persons with disabilities may receive lighter punishments from authorities, especially in cases of domestic or household violence. Booyens et al. (2015) point out that superstition and stigma around disability is often internalised by persons with disabilities themselves.

A 2019 (UK) Telegraph article reported on increased kidnappings of persons with albinism (especially children) by mobs, noting that individuals interviewed in the story were especially fearful given that it was an election year and politicians were “reportedly in the market for albino body parts to use in witchcraft rituals meant to help them win their seats” (Blomfield and Mhango, 2019, n.p.). During the 2019 elections, multiple outlets reported that both the incumbent and at least one of the challenging parties were accused of engaging in these practices, which include dismemberment and disembowelling (Blomfield and Mhango, 2019; Economist, 2019). Groce and McGeown (2013), in their review of folk beliefs around disability in urban Africa, mention that children are seen as more “potent” and are thus increasingly prized for rituals. Blomfield and Mhango’s (2019) report continues, “the killings, it is widely believed, are done to order, carried out by an organised criminal network acting on behalf of rich clients willing to pay thousands of pounds for albino body parts believed to bring wealth and political good fortune” (n.p.). This adds another layer of complexity to the problem – wealthy families of children with disabilities are also seen as having made such deals, trading their children’s normative physical form for wealth and status (Groce and McGeown, 2013). In these cases,

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[8] Field notes

wealthy families try to hide their children for fear of being shamed by their neighbours for greed, ambition, and cruelty (Ibid.). There is also a belief that children with albinism are actually fathered by white men, prompting their actual fathers to abandon them (Blomfield and Mhango, 2019; see also Setume, 2016; Rohwerder, 2018). This belief may also be an explanation for Groce and McGeown's (2013) finding that "a disturbing number of killings have been reported by fathers or male relatives who hope to become rich" (n.p.). Abandonment of children with disabilities besides albinism, usually by the father, is also common (Rohwerder, 2018).

1.1.2.2.3 Accessibility in Malawi

Malawian society is often not adapted to be accessible for persons with disabilities, despite legislation requiring new building developments be "accessible" (Act No. 8 of 2012). This regulation is often not followed, and the majority of previously existing public infrastructure has not been redeveloped. Even if spaces have adaptations for some types of disabilities, many persons with disabilities lack mobility devices or other aids to help them navigate and engage in public places (Eide and Ingstad, 2013). While inclusive education has long-since been on both advocates' and politicians' platforms, access to schooling remains a challenge for persons with disabilities in Malawi. A 2004 nationally representative survey found that 53.5% of Malawians with disabilities had never attended school, compared to 25.7% of non-disabled Malawians (Eide et al., 2011).

The provision of services for persons with disabilities is also lacking, though this is certainly exacerbated by the dearth of public services in Malawi in general. Booyens et al. (2015) conducted a review of studies on disability in Southern African countries, including Malawi, which found:

> Individuals and households with a member with a disability experienced substantial gaps in access to services, social and economic status, access to information and to assistive devices and social participation (Eide and Ingstad 2013). Persons with a disability generally experience lower levels of living, particularly those in rural areas, and women with disabilities

> are worse off than their male counterparts. This translates into a denial of equal opportunities for persons with disabilities to participate and contribute in their community and society, which is a violation of their human rights (p.2).

This piece highlights the geographical divide in the experience of disability for Malawians, as those who live in rural areas have less access to services, support, specialised education, and health care (Eide and Ingstad, 2013). This is a critical point because most Malawians live in rural areas. Furthermore, (Banks et al., 2017) found that costs, including those for transport and missed work time, prevent individuals from accessing, for example, what child protection services *are* available to children with disabilities. Additionally, local leaders may ask for payment for services, despite their design as free services (Ibid.). Service providers said this was because of a lack of adequate and regular funding, necessitating payments from services users to fund follow-up (Ibid.). “Caregivers and other key informants not involved in service provision felt, however, that corruption may be more at the heart of this practice” (Banks et al., 2017, p. 10). Expectations of corruption are discussed within this thesis as a contributing factor to how disability advocates view not just Malawi’s government but the leadership of FEDOMA as well. In considering the disability context and lack of service provision, it is also important to consider how the scarcity of support impacts individual perceptions of social systems.

1.1.3 Introduction to FEDOMA

The Federation of Disability Organizations in Malawi (FEDOMA) was founded in 1999. The purpose of the organisation was to bring together disparate disabled persons organisations (DPOs) to engage in lobbying and advocacy as a collective. FEDOMA’s ideological foci are presented in Table 1:

Table 1. Table of FEDOMA ideological statements. Source: FEDOMA, 2019.

Vision Statement	**FEDOMA strives for an inclusive barrier free society where every individual is able to maximize their fullest potential.**
Mission Statement	FEDOMA is an umbrella of Disability Organisations which works to unify, coordinate efforts and strengthen the advocacy work of its affiliates for the well-being of Persons with Disabilities in Malawi.
Objectives	To promote and advocate for the rights of persons with disabilities. To advocate for and monitor the equalization of opportunities for people with disabilities as stipulated in the United Nation's Standard Rules. To coordinate the formation and strengthen the capacity of affiliated DPOs.
Values	Integrity; non-partisan[ship]; accountability and transparency; equality; participation; respect for human rights; tolerance; commitment; objectivity; equal opportunities (equity); flexibility; team work; honesty; gender sensitivity; good governance; belief in God.

The creation of FEDOMA was set against the background of a struggle for the passage of progressive disability legislation in Malawi. I explore this history in more detail throughout Chapter 4.

Throughout this thesis, I focus on the subset of FEDOMA's grassroots advocates who are part of its District Disability Forums (DDFs). Figure 1 shows FEDOMA's complex organisational structure, including the DDFs and the reciprocal relationship between FEDOMA and the DPOs.

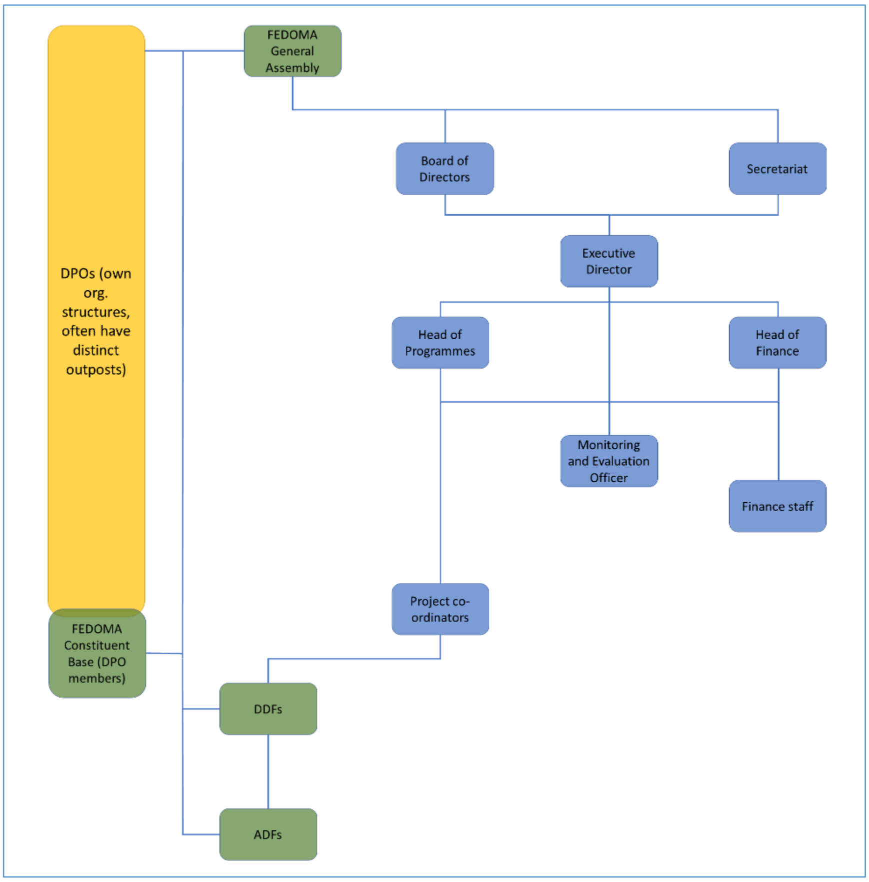

Figure 1. FEDOMA organisational chart showing relationships with DPOs. Original figure created by the author.

The DDFs were initially developed in 2015, in response to Malawi's decentralised approach to the implementation of national legislation. They are small collectives, intended to have at maximum two members representing each of FEDOMA's constituent DPOs, of which there were 12 at the time of the study. These grassroots outposts act as centres for FEDOMA activities in Malawi's districts. FEDOMA's understanding of, response to, and innovation around the changing place-based circumstances of 'achieving' implementation of codified disability rights indicates that their practice extends beyond a strong social model approach. Even though FEDOMA ideologically espouses the social model, this thesis set out to explore what they actually do in practice, using an eclectic, hybrid approach which draws on both the social and the material. Haang'andu (2020) highlights the need for an Afro-centric disability studies, which takes into consideration the unique contexts of post/neo-colonial Africa. Haang'andu (2020) argues that this is the necessary way forward for studying African DRMs. While I agree that an Afro- (or even Malawi-) centric approach to disability studies is important, I argue that Haang'andu misses the fact that groups like FEDOMA may already do this in practice. Haang'andu's (2020) point about the difficulties of achieving implementation of codified rights in countries with neopatrimonial governance systems is valid, but too narrowly focused on top-down approaches to activism. The establishment of the DDFs, the main grassroots outposts I discuss in this thesis, demonstrates that it is possible to work across and between scales at the same time. FEDOMA's approach is to work on the national legislative context *and* at the grassroots, building communities in which people with disabilities are included and feel safe. I will explore whether this approach can ensure that the embodied, everyday lives of grassroots advocates contribute to national-scale narratives about disability in Malawi. I investigate whether this hybrid approach can help to solve the problem of representation and 'real' change raised by Haang'andu (2020). I argue in this thesis that a hybrid disability studies that looks at context (including systemic structures and geography) and engages an eclectic, new materialist ethos may contribute to a broadening of the ways in which we think of DRMs around the world. To fully understand how disability groups worldwide can develop and share with one another, we must understand how as many national and local DRMs work as possible. This thesis also attempts to act as a platform for Malawi's DRM to share what they know internationally, especially since many of them do not personally have access to international forums. In a way, participating in this research is an act of transnational solidarity, while the project also emphasises studying the local, to gather a more complete picture of DRMs around the world.

1.2 RESEARCH QUESTIONS AND OBJECTIVES

In order to explore FEDOMA and Malawi's DRM, I conducted a two-stage research project. The first stage involved a participatory research design process with FEDOMA; the second stage involved data collection using qualitative research methods. Based on the participatory design process in Stage 1 (as will be discussed in more detail in Chapter 3), I developed a project that centred on the District Disability Forums (DDFs). The following research questions, derived through the participatory design process, provided direction for data collection and analysis, and the discussions in this thesis:

<u>Research Questions:</u>

1. Can participatory methods be an effective means by which to conduct research with activists in majority-world contexts, especially in the face of severely limited human, capital, and time resources?
2. What is the role of 'voice' within FEDOMA as an organisation and outwith FEDOMA in the broader Malawian disability rights movement?
    a. How do FEDOMA's members conceptualise voice?
    b. What voices do grassroots agents use, and in what circumstances?
    c. Do grassroots advocates feel their voice is 'heard' within FEDOMA and/or within their communities?
        i. Do grassroots volunteers at the local level feel that their experiences are understood and reflected in the broader objectives of the organisation and its national-level undertakings?
        ii. Whose voices are (or are not) heard, in what spaces, at what times?

3. How do disability advocates exercise their agency to reproduce and alter the structures within which they live?

   a. How does voice act as a resource for grassroots activism in Malawi?

   b. What (schematic) factors constrain and enable grassroots advocates' expressions of agency?

4. How do intersectional experiences of gender and disability impact women advocates' expressions and perceptions of voice and agency in Malawi?

1.3 THESIS OVERVIEW

In the next chapter, I conduct a broad literature review, which includes the theoretical foundations of the data analysis in this thesis. As disability is a cross-cutting issue, I draw on literatures from disciplines outside of geography and disability studies, particularly sociology, education, and management/organisational studies. In places where acknowledging other disciplinary inputs may be useful, the primary academic area of the authors is noted.

In Chapter 3, I discuss the methodology used in both Stages 1 and 2 of this research project. I review the results of Stage 1 and how they informed the development of Stage 2, through autoethnography. I also discuss the methodologies used in Stage 2's primary data collection - participant observation and in-depth interviewing.

Chapter 4 is the first findings chapter, in which I present a discussion of the development of Malawi's disability legislative context in parallel with FEDOMA's organisational development. I then use an extended example to explore the grassroots activism of FEDOMA's recent past and the development of organisational priorities. This will provide a contrast for FEDOMA's current grassroots advocacy and on-going focus on decentralising its activities.

Chapter 5 is the second findings chapter, in which I discuss the ways in which FEDOMA advocates engage in advocacy work across the scales of Malawian society.

By contrast, in Chapter 6 I discuss the internal dynamics of FEDOMA, including foci on emotion and activist motivation, trust, and leadership.

In Chapter 7, I use an intersectional lens to investigate the experiences of FEDOMA's women activists to further discussions of how gender intersects with disability and socioeconomic status over the life course (established in preceding chapters). Women with disabilities are among the most marginalised individuals within Malawian society and are arguably the most marginalised population represented in Malawi's DRM. Their experiences, motivations, and approaches to activism contribute a critical component to understanding the development of Malawi's DRM. In addition, exploring whether women's voices are heard within FEDOMA (given the organisation's stated value of "gender sensitivity") and how their voices do or do not impact organisational priorities, spaces, and activities can lend insight into the ways in which FEDOMA as a large organisation does or does not prioritise its most marginalised members.

Finally, Chapter 8 draws together the findings and insights across the entire thesis and provides conclusions, avenues for future research, and a post-script discussing developments after the completion of data collection.

2 LITERATURE REVIEW

Disability is a cross-cutting issue and as such is studied across a wide range of disciplines. Approaching this project with a goal toward developing a hybrid, eclectic approach to disability studies, as discussed in the introduction, required that I engage with the breadth of this literature. Later in this literature review, particularly in Section 2.3, I highlight some of the theorists who have advocated for this approach, which 'builds' theoretical grounding for academic disability studies that moves beyond rigid 'models' of disability. Engaging with this approach enabled me to incorporate works across diverse theoretical areas to develop a useful grounding for the analysis in this thesis – one that works *with* the data to apply and extend theory. This aided in my attempt to avoid re-shaping the data to suit a preconceived theoretical position before having the chance to fully engage with it during analysis. At the same time, I acknowledge that in the ultimate decision to apply even a variety of theoretical approaches to the data, I am shaping it. However, undertaking such a broad exploration of the literature helped me to see where surprising connections might be made and supported my attempts to be led by the data as much as possible. In this literature review, I first discuss structuration theory, which I have used as the basis for my analysis. I then discuss the approaches to theorising empowerment and relationality on which I draw and explore the evolution of geographical disability studies (including the development of new materialism) in particular. This leads into a discussion of 'relational resources' for activism – including voice, emotion, trust, and leadership. In the last section of this literature review, I discuss intersectionality and approaches from feminist studies that help develop the eclectic approach to disability studies outlined in the introduction and provide useful theoretical grounding for the discussion of gender in Chapter 7.

2.1 THEORETICAL FOUNDATIONS

I use Anthony Giddens' structuration theory as the foundation of my theoretical approach to data analysis. The basic premise of structuration theory is that systems are made up of structures and agents which mutually constitute one another over time and across spaces (Giddens, 1984). Structuration theory is implicitly concerned with relationships and processes, key reasons it is useful in exploring the research questions set out in the introduction, all of which involve the exploration of relationships within and outwith FEDOMA. From a geographical standpoint, structuration theory can be used to emphasise the importance of contextual - space, place, and time - impacts on interactions between structures and agents. It is also an approach which can integrate or act as a baseline for other theoretical approaches.

2.1.1 Structuration Theory

Giddens' (1984) structuration theory is based on the idea of systems as "reproduced relations between actors or collectivities, organized as regular social practices", which "comprise the situated activities of human agents, reproduced across time and space" (p. 25). In discussing structuration theory, both Whittington (2015), from a business studies perspective and Sewell Jr. (1992), in sociology, highlight the malleability of this approach, which emphasises systems' connection to people, existence across multiple levels, and interactions with other systems:

> Regular activities bring together people into social systems, which are reproduced over time through continued interaction. These social systems exist at various levels – a particular national society, an industry, organization or a strategy project team, for example. For Giddens (1984), it is important that these systems do not bind their members into some kind of deterministic homeostatic loop. Rather, systems are typically somewhat overlapping, contradictory and precarious (Whittington, 2015, p. 147).

Whittington's point about the levels of systems is important throughout this thesis, as activists engage within various systems at once in their daily lives and organising activities. Sewell Jr. (1992) also emphasises this point, noting that social systems can "also include social units greater (e.g. the capitalist world system)" (p. 6) than a national social system. The idea of systemic interactions as "contradictory and precarious"

(Whittington, 2015, p. 147) also emphasises the nuance possible within a structurationist approach, especially focusing on the situational as key to understanding individuals' actions. Precarity in particular is a useful consideration for the ways social systems are built and at what point they change; considering precarity connects systems' endurance and fragility to that of marginalised people. Social movement actors find themselves in precarious positions within their given social systems, but their endurance allows them to determine points of fragility in systemic structures to create change.

Across all levels, systems are produced, reproduced, and altered by actors engaged in processes of structuration. In this thesis, I define an 'actor' as a person or organisation of persons who does something. Depending on the scale and approach to a given analytical problem, FEDOMA can be considered both a system and an organisational actor. FEDOMA is an actor but *not* an agent. An agent is defined here as a *person* who perpetrates an action using their agency[9]. Organisational actors' actions are driven by members' combined agency. One of the objectives of this thesis is to explore the ways and extent to which different agents impact FEDOMA as a system and an actor. New materialist approaches, on which I also draw, situate human actors among non-human actors. As this thesis focuses on people as activists, the analysis may lean toward the anthropocentric. However, I note that human-environment interaction is also of critical importance for understanding social movements.

Agents and actors impact systems through their interaction with a given system's structures. For Giddens (1984), structures are comprised of "rules and resources, or sets of transformation relations, organized as properties of social systems" (p. 25). Giddens (1984) emphasises the relational basis of structures through the concept of the "duality of structure" (p.25), arguing that agents and structures must be thought of in relation to one another, as a 'dualism'. For Giddens (1984), "the structural properties of social systems are both medium and outcome of the practices they recursively organize" (p. 25). Of critical importance to this recursivity are "rules" and "resources", both of which constrain *and* enable agents' actions, leading to the

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[9] I discuss and define agency for the purposes of this thesis in Section 2.2 of this literature review.

production, reproduction, and alteration of both those same structures (comprised of rules and resources) and the broader social systems they constitute (Giddens, 1984).

While structuration theory is a useful starting point, the concept of ‘rules’ renders too black-and-white the cultures and social institutions which enable and constrain agents’ use of resources. In this case, Sewell Jr.’s (1992) approach to rules as “schemas” is more appropriate:

> “The rules of social life” should be thought of as including all the varieties of cultural schemas… not only the binary oppositions that make up a given society’s fundamental rules of thought, but also the various conventions, recipes, scenarios, principles of action, and habits of speech and gesture built up with these fundamental tools... What I mean to get at is not formally stated prescriptions but the informal and not always conscious schemas, metaphors, or assumptions presupposed by such formal statements (pp. 7-8).

Going forward, I use ‘schemas’ and ‘resources’ to describe the constitutive elements of structures. Giddens (1984) focuses on rules as “generalizable”, and Sewell Jr. (1992) applies this to schemas as well, noting that schemas can be “applied in or extended to a variety of contexts of interaction… not only [used] in the situation in which they are first learned or most conventionally applied” (p. 8). This to Sewell Jr. (1992), means that schemas must be virtual: “to say that schemas are virtual is to say that they cannot be reduced to their existence in… any particular location in space and time” (p. 8). The possibility of interacting with schemas in different ways within different contexts is critical for an analysis of the ways social movement actors engage with structures. It also allows for innovation in engagement with schemas and the possibility of intentional alteration of systems, an approach which is under-emphasised in Giddens’ work. Giddens’ (1984) approach to structure is preoccupied with the sub-conscious, habitual reproduction of systems by agents. Storper (1985) critiques Giddens’ “action theory” as “ambiguous” due to this focus on habit, and a lack of nuance and time-space distanciation built into his focus on structural reproduction over time. By contrast, this thesis is concerned with both the habitual and/or sub-conscious impact of agents on structures and the (arguably more important for social movement studies) conscious actions of agents within systems to enact change and the differentiation between how they conduct these actions in different spaces across time.

A focus on the actions of agents requires a concept of agency. Giddens (1984) defines agency as "events of which an individual is the perpetrator, in the sense that the individual could, at any phase in a given sequence of conduct, have acted differently" (p. 9). This approach holds that the potential for agency exists in all individuals but that the "action" of agency is constrained and enabled (constituted) by the structures an individual interacts with at a given point in time and space. In structuration theory, agency is in the action of doing, thus implying a certain amount of power (Giddens, 1984). Whittington (2015) highlights that this 'doing' is part of negotiating the contradictory and precarious, interacting systems of life:

> Indeed, it is this participation in plural social systems that underwrites the human potential for agency. System contradictions pose sometimes awkward, sometimes opportune choices for our conduct… it is important to recognize the potential for agency in just about everyone, by virtue of their participation in multiple social systems… Agency here is the capacity to do otherwise: to follow one system of practices and to refuse another… Such agency makes a difference to the world, in small ways or large, as it contributes to the reproduction or negation of each particular system (p. 147).

Whittington's point ties the potential for human agency to the complexity of systemic ways of organising society across multiple levels. Since we must live within multiple systems, we have opportunities to make decisions about which systems are reproduced and which are altered. This approach is important because it proclaims every person's access to some sort of resource within a social system, because resources are the medium through which agents impact schemas. Sewell Jr. (1992) points out that "part of what it means to conceive of human beings as agents is to conceive of them as empowered" (p. 10). This connection between agency and empowerment is critical to studying FEDOMA, as 'empowerment' forms a central pillar of their movement. For this thesis, I conceptualise agency as the 'external' expression of empowerment, encouraged by the 'internal' dimensions. I do this as part of an approach to empowerment as both process and outcome, occurring at various levels in individuals' internal self-perception and external actions. I draw particularly on the work of Sadan (1997) (on community organisation) and Kesby (2007) in this approach, as discussed in the next section.

2.2 EMPOWERMENT

Sadan's (1997) work on community planning draws on structuration theory to conceptualise empowerment as both process and outcome [or "effect" (Kesby, 2007)]. Sadan (1997) divides empowerment into three dimensions - individual, collective, and professional empowerment. In this thesis, I focus on individual and collective empowerment in the analysis. For Sadan (1997), individual empowerment as "process brings about an integration of self-acceptance and self-confidence, social and political understanding, and a personal ability to take a significant part in decision-making and in control over resources in the environment" (p. 76). The last section, ability to control resources, is agency. Sadan's (1997) conceptualisation of individual empowerment highlights the importance of both "internal and external change" (p. 76). For this reason, agency highlights points when internal change processes are reflected in individuals' actions and thus is useful in considering the changes agents undergo within empowerment processes. At the same time, the internal change in self-perception which enables agency is also empowerment as outcome.

Sadan's approach to collective empowerment is also helpful when considering the work of social movement actors, allowing for an analysis of the deliberate actions of collective actors in processes of structuration. Sadan (1997) defines collective empowerment as "the increased control of people as a collective over outcomes important to their lives" (p. 85). The differentiation between individual and collective empowerment helps us to consider the relationships between individuals' actions and the impact of groups on those actions. Storper (1985) highlights the importance of interaction in constituting motivation for human agency, again reflecting the relationality involved in empowerment processes. Sadan (1997) specifically discusses how these interactions can promote the evolution (and continued processes of empowerment) of social movements: “The group is the perfect environment for consciousness-raising, for mutual help, for developing social skills, for exercising problem-solving, and for experiencing inter-personal influence” (p. 81).

This approach also helps in exploring the ways individual and collective empowerment mutually constitute one another in social movements, and the ways collectives can motivate and demotivate, constrain, and enable their members. These relationships are the core focus of this thesis. Processes of empowerment change depending on time-space context. Kesby (2007) highlights the importance of spaces of empowerment and raises questions as to whether (and to what extent) empowerment (as effect) within a given space can be maintained in different spaces. Kesby (2007) also considers the internal schemas of collectives, emphasising that constraining and enabling schemas impact agency even within ostensibly ‘popular’ spaces. Beyond a given structure’s schemas, Kesby’s (2007) work lends itself to a consideration of inter-systemic impacts on agents as they navigate the various ‘levels’ of systems. The virtual schemas and ‘actual’ resources of one system may equip an individual agent differently as they move into another system. In this thesis, I address these questions within the context of FEDOMA. I examine processes of empowerment within the movement, the ways in which empowerment (as effect) may move within and between spaces, enabled and constrained by structures and relationships between individuals and collectives.

2.3 GEOGRAPHIES OF DISABILITY

As discussed in the introduction, I attempt to answer recent scholars’ calls for eclectic, hybrid disability studies, by drawing on a range of literatures, including new materialist ideas, that form a more recent part of the development of geographic disability studies. Early geographical work on disability involved the mapping of disability in conjunction with a medical, epidemiological approach to disability studies (Park, Radford and Vickers, 1998; Imrie and Edwards, 2007). Over time, geographers have contributed extensively to the evolution of disability studies away from purely quantitative, medicalised approaches, particularly through their work exploring the social and relational aspects of disability, as well as a more recent turn toward (re)considering materiality.

Geographers' focus on spatiality contributed to the evolution away from a strictly 'medical model' in disability studies to a consideration of the social and contextual (Murray, 2019; Wilton and Horton, 2020), including in the development of more "holistic" medical geographies (Park, Radford and Vickers, 1998). A geographic approach fills a gap in the development of the social model by considering what role "spatial or geographical points of reference" (Imrie and Edwards, 2007, p. 623) play in the construction of disability. Geographers have further contributed to the social model of disability through explorations of disabling environments, relationships and their context, and emotion/affect. Wilton and Horton (2020), in a review of geography's impact on disability studies, emphasise the contributions of geographers to "the careful spatial theorisation of the lived experiences of disabilities", "the shifting landscapes and politics of care and support" (p. 1021), and the continued evolution of geographic thinking in disability studies, including emphasising relationality and new (and/or 'new') materialisms. These critical contributions explore the context and lived experience of disability. Included in this are studies which consider experiences of home and decision-making around the home (Murray, 2019), experiences of 'disability spaces' (Morrison et al., 2020), and challenges to the ableist design of everyday spaces (see for example, Park, Radford and Vickers, 1998; Hall and Wilton, 2017; Morrison et al., 2020). While these studies have been concentrated in the minority-world (Imrie and Edwards, 2007; Wilton and Horton, 2020), especially the USA and UK, they highlight the necessity of studying disability in place, thus creating an argument for developing new, place-centric disability studies. This is particularly important in the study of disabilities in the majority-world, and the development of new conceptualisations of disability (and disability theorising). Geographic disability studies has been at the forefront of the fledgling movement to diversify disability studies, challenging minority-world definitions of and approaches to disability rights, including challenging the pre-eminence of independent living movements (Wilton and Horton, 2020).

Disability scholars have contributed to the use of emotion and affect, engaging with the experience of different places and spaces for persons with disabilities (Hall and Wilton, 2017; O'Dell, 2019). Morrison et al.'s (2020) research highlights the differential emotional, embodied experiences of 'disability spaces', challenging the assumption that these spaces are inherently positive spaces of belonging. This work reflects the emphasis of this thesis on DDF members' feelings about and embodied experience of FEDOMA spaces – spaces which are intended as empowering and inclusive, but which not all grassroots members experience positively. Geographers have also studied relationality and the ways in which it is entangled with identity, experience, emotion, affect, and interaction in different spaces (Imrie and Edwards, 2007; Hall and Wilton, 2017; Wilton and Horton, 2020). This relationality is also found in geographic disability studies of care, though in this the focus has again been on formal care systems in minority-world countries (Wilton and Horton, 2020). Further exploration is needed into how care is conceived and undertaken in other places around the world. For example, in Chapter 7, Section 7.2.2, I discuss the relationships between Malawian disability advocates and their families, exploring less formal caring relationships and their impact on the development of empowering identities, and consider the importance of 'caring' relationships between women within the organisation and the role this plays in creating strong disability communities.

Geographies of disability have also explored rights movements, including those which consider grassroots struggles and the impact of social hierarchies and intersectional identities (Wilton and Horton, 2020). In these studies, the impacts of structural violence, politics, and post/neo-colonialism on the lives of persons with disabilities contribute to the complexity of studying disability (Ibid.). This more recent work builds on foundations built by earlier geographers around the social production of space and power structures, and their impact on the exclusion of persons with disabilities from societal spaces (Imrie and Edwards, 2007). Geographers have studied disability and activism across a variety of spaces and scales, considering "the role of spatial scale in mediating and shaping political struggles between disabled people and the state" (Kitchin and Wilton, 2003, p. 98). Geographic disability studies considers scale to be socially produced and malleable over time, as well as focusing on the ways in which actors and "political gains" (resources) travel across scales (Ibid.) In part, this thesis considers how scalar politics impact disability advocacy in Malawi, including the work of FEDOM HQ staff and grassroots DDF members. Part of this consideration relies on the malleability of disability rights work in adjusting to shifts in scalar focus. For example, in Chapter 4, I explore the structural schemas which contributed to FEDOMA's shift in focus from the national scale to the grassroots. Throughout the rest of the thesis, I explore various scales of grassroots work, many of which overlap – combining concepts of scalar malleability with ideas of relationality not just between people but within groups, places, schemas, and resources.

More recently, geographers have been at the forefront of theorising that both challenges and answers challenges to a purely 'strong' social model of disability. These challenges hold that while society is disabling, some of the embodied aspects of disability are undeniably physical and material – for example, experiences of pain. A move away from a strong social model allows for exploration of these areas. Much recent work on the geographies of disability attempts to re-emphasise materiality without returning to a strictly medicalised view of disability. While materiality was never absent from geographies of disability, more theoretical and empirical work is being undertaken to specifically emphasise the complex interplay(s) between the material and the social. Much of this more recent work falls under the category of 'new materialism', much of which in turn is entangled with assemblage theory (Fox and Alldred, 2017).

Assemblage theory emphasises relationships, processes of becoming, and bodies defined by flows of interaction (Goodley, 2007; Dovey, Rao and Pafka, 2018; Cluley, Fyson and Pilnick, 2020). Assemblage theory creates space for a consideration of difference. It focuses on the *interactions* between differences of experience – an approach which can help to prioritise local scale, lived experiences and relationships (Dovey, Rao and Pafka, 2018). Goodley (2007) emphasises the use of assemblage theories in "reconsidering [bodies that refute normalisation] in terms of their resistant possibilities" (p. 327). Proponents of assemblage theory highlight that it "resists the hierarchy of identity over difference" (Dovey, Rao and Pafka, 2018, p. 266), in not accepting existing power structures as valid within its theoretical approach. Geographers of disability have begun to use this approach in decolonising disability studies, as a way of considering disability in ways that go beyond the minority-world models as "mandatory and inescapable", instead formulating new models from the ground-up (Araneda-Urrutia and Infante, 2020, p. 340). This "implies a radical openness to uncertainty and fluidity, assuming dis/ability as a biosocial assemblage" (Ibid., p. 340). Assemblage theory has been used in disability studies to explore, for example, constraints on the expression of 'othered' bodies (Araneda-Urrutia and Infante, 2020), social and care networks (Goodley, 2007), education (Goodley, Liddiard and Runswick-Cole, 2018), and conceptualisations of learning disability (Cluley, Fyson and Pilnick, 2020).

Some critiques of assemblage theory, however, highlight that its focus on difference can lead to a disregard for and over-abstraction of "identity" categories such as race, gender, and disability, which while socially produced and changeable, do impact the lives of (particularly marginalised) individuals in real ways (Kinkaid, 2020). This can result in a lack of emphasis on "social difference, power, positionality, and related epistemological problems" (Kinkaid, 2020, p. 458), despite their potential relevance to the areas under study. Furthermore, Kinkaid (2020) points out that:

> The idea [among some assemblage theorists] that social categories refer only to identities is reductive and oversimplifies poststructuralist critiques of identity (including Butler's). Indeed, we might consider how categories of 'race', 'gender', and 'sexuality' become perceived as identities through a particular operation of power when they in fact describe a set of social relations and transpersonal forces… We must resist the territorialization of these forces onto bodies marked by difference, yet we also cannot afford to fully dispense with the identities and categories that result from these territorializations (p. 460).

Kinkaid (2020) points out that assemblage thinking does allow for critique of "restrictive" social categories but cautions that "dismissing" them may inadvertently contribute to "further invisibilizing the production of social difference" (p. 460). The moral/philosophical position of invalidating existing power structures and "the hegemony of scale" (Dovey, Rao and Parse, 2018) is arguably less helpful in empirically considering how the virtual existence of structures impact individual lives than it is as a philosophical/moral position. These critiques may indicate that some instances of assemblage theory over-prioritise the material, without balancing it against thinking about the social and why/how social categories become entrenched across societies (Kinkaid, 2020). At the same time, Kinkaid (2020) notes that assemblage theory and related work within the “return” to materialism can incorporate feminist (and other, i.e., critical race theory) scholarship to ameliorate some of these concerns, again highlighting a need for hybridity in human geography, including geographies of disability.[10]

Closely related to assemblage theories and developed from similar philosophical traditions are the new materialisms discussed in the introduction. I draw on this emerging field as a guiding ethos for considering the material alongside the spatial and social, particularly within the social production of networks, relationships, and communities (Feely, 2016; Goodley, Liddiard and Runswick-Cole, 2018). New materialisms centre on disruption of dichotomies and exploring relationships between the material, social, and discursive (Fox and Alldred, 2017). While debate is on-going about the ‘new’ aspect of this turn, Fox and Alldred (2017) highlight that this approach contrasts earlier materialisms’ analysis of power as structural and “top-down”, instead incorporating feminist, queer theorist, and other critical theorists’ concerns, “which rejected economic and structuralist determinism as inadequate satisfactorily to critique patriarchy, rationalism, science and modernism, or to supply a critical and radical stance to underpin struggles for social justice and plurality” (n.p.). This analysis indicates that some new materialisms may answer critiques such as those levelled by Kinkaid (2020) through drawing on other forms of scholarship, which Fox and Alldred (2017) note has already been undertaken by the feminist, post-colonial, and queer theory traditions which aided in its evolution.

Proponents of assemblage theories and new materialisms portray them as ways of countering establishment models of disability, which is particularly important when researching disability in the majority-world. Araneda-Urrutia and Infante (2020) propose a “demodeling” approach, “as a collection of theoretical, methodological, and political gestures aimed at guaranteeing new ways of problematization of

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[10] There are also on-going debates as to the “true nature” of assemblage thinking, which can be difficult to parse due to its evolution from the philosophical works of Deleuze and Guattari, issues of translation of the original philosophical premise (Buchanan, 2017), and a tendency toward “incomprehensible and indeterminate” “jargon” (Dovey, Rao and Pafka, 2018, p. 266).

the ontological questions that hegemonic models of disability take for granted" (p. 340). This approach seeks to move beyond rigid models of disability toward an understanding that "emergent complexity and elusiveness are inexhaustible properties of (Southern) disabled bodies, making models dangerous essentializations. Instead of starting from models, we advocate for retheorizing dis/ability without returning to them" (p.340). My choice of a hybrid, eclectic approach to theorising in this thesis is an attempt to let theory emerge from the data as much as possible and respond to calls to shift disability studies away from rigid models. Keeping in mind the critiques of assemblage theory discussed above supports the need to draw on various literatures around voice and relationality which centre marginalised groups – something geographers of disability have also historically done in their work with the social model of disability (see for example, Wilton and Horton, 2020; Morrison et al., 2020). Drawing on critical race and feminist literatures as well as disability studies (discussed in the sections to follow), I incorporate an attention to social categorisations of power and politics into my approach to designing a hybrid, Afro-centric theoretical underpinning to this thesis.

2.4 RELATIONALITY

As is evident in the discussion thus far, relationality is a crucial aspect of the analysis in this thesis. While relationality is a broad term, it is well-suited to engagement with structuration theory, which is implicitly concerned with relationships. I have drawn philosophical inspiration from new materialism, as some of its specific tenants are well-suited to the recent changes in academic disability studies. Feely (2016) highlights the potential for new materialism in facilitating "a return to the material world and material bodies without a return to essentialism" (p.863). Like structuration theory, new materialism offers a 'middle ground', emphasising the role of social systems and their structures in constituting disability while still encouraging exploration of the material world and embodied experience. For disability studies, this can help to create an eclectic, hybrid approach to disability studies which recognises the social but also considers pain, physical environments, and technological innovation. In the next section, I explore some of the ‘relational resources’ used within Malawi’s disability rights movement. These resources reflect the importance of the material in impacting virtual schemas. These resources are concerned with the individual and their embodied experiences, but their development and use are impacted by particular schemas in particular spaces and times. They emphasise new materialism and structuration theory’s concern with the mutually constitutive relationships between people and structures.

2.4.1 Relational Resources for Social Movements: Voice, Emotion, Trust, & Leadership

The focal point of this thesis is voice as a resource for Malawi’s disability rights movement. The other resources discussed in this section all impact voice - they constrain and enable expressions of voice, highlighting the interaction between resources and the layering of (especially) embodied resources in an agent’s actions.

2.4.1.1 Voice

Voice as a concept for activism has been developed through various social action models, including “identity-oriented activism” (Pilisuk et al., 1996, p. 17). In much of the literature on social movements, characteristics that can be considered both embodied and socially constructed form the basis for oppression, and thus the basis for activism. Traditions such as feminist, critical race, and disability studies focus both on voice as a way of relaying the lived experiences of marginalised people and using expressions of voice to influence agents and make broader schematic change: ‘the “voice” component of CRT [critical race theory] provides a way to communicate the experience and realities of the oppressed, a first step in understanding the complexities of racism and beginning a process of judicial redress’ (Ladson-Billings, 1998, p. 14). These types of movements exemplify the power of voice as a resource when individuals express their experiences of oppression. From an educational sociology perspective, Clothey et al. (2016) pair “everyday resistance” with voice, highlighting the strength and resilience that can be found from sharing one’s personal life stories. Within the movement for immigrants’ rights in the USA, storytelling became a central strategy after undocumented youths themselves became more active in organising. This was a shift from the previous use of stories by ‘documented’ allies as simply a form of evidentiary support for policy changes (Swerts, 2015). Instead, the telling of personal experiences became integral to the movement, transforming it into a “safe space” for undocumented youths to be heard, emphasising the power of previously silenced individuals speaking their stories out loud within the movement, enabling them to gain in confidence (Ibid.). These gains in confidence resulted in youths gradually speaking publicly about their immigration status (Ibid.). Caldwell (2011) highlights a similar practice in DRMs via “open-mics” at movement meetings. In these examples, empowerment as both a process and effect, initiated internally to an individual and within a collective, is demonstrated. Storytelling, in both ‘public’ and ‘private’ spaces, was a way for participants to constitute and express their agency. The build-up in belief in one’s own agency during the ‘private’ storytelling was critical to their later use of voice as a resource to alter structures around them.

In the work discussed above, Swerts (2015) outlines a typology of “storytelling as social movement practice”, divided into “intraorganizational”, “intramovement”, and “extramovement” storytelling (p. 350). This typology outlines the importance of various considerations for social movement storytelling, including “context”, “audience”, “type of interaction”, and “purpose of interaction” (Ibid., p. 350). Swerts’ (2015) typology is arguably too clean, lacking an emphasis on interplay between the levels and blurring of boundaries between types of storytelling. However, the work is useful in underlining the importance of context and scale, as well as the political nature of social movement storytelling. This typology also helps to develop the idea of audience as an important consideration for voice in social movements. A particular voice is being expressed or *performed*, within particular situations, to achieve particular outcomes (see for example Butler, 1999). Whether those outcomes are achieved depends in part upon the audience of a given performance - their receptiveness to a particular expression of voice, and/or their personal power in turning their opinion into action. The particularity of a given voice is also important to consider, especially when looking at an 'activist voice'. An individual does not have a single 'voice', and the expression of voice to achieve social movement goals requires emphasis on the multiplicity of voice(s). In social work studies, McKay's (2010) "young [Black] scholar" character in a "playlet" on critical race theory also uses personal storytelling and emphasises the self as home to the tools of the oppressed: "If I do not explore and reclaim my own cultural capital[11], what tools will I use to dismantle an oppressive system that hides the tools in the first place?" (p. 31). These approaches use embodied and socially constructed identities as the basis for storytelling, and storytelling as a way of individual and collective empowerment.

The physical and material experiences of persons with disabilities in society play an integral role in informing advocates' storytelling. "Bodily memories" (Routledge, 2005) are part of the knowledge of individual agents about how virtual schemas are disabling for individuals with a particular impairment. Without these embodied experiences, there would be little grounding for the work of advocates; in FEDOMA and the DDFs' activities, they use these physical experiences in their quest for social change. One can argue that persons with disabilities should not have to explain their experiences to those who do not identify as disabled, and while valid, this argument ignores the on-the-ground reality of advocacy work with a goal toward changes in the physical environment and social world. Those who experience disabling environments are also those best poised to draw attention to them.

McKay (2010) gives the power of embodied knowledge more form, specifically calling on expressions of voice, for example "counternarratives", as acting like tools, highlighting voice's role in *building* narratives and counternarratives. McKay (2010) describes counternarratives as "challeng[ing] the perceived wisdom of subscribers of a dominant culture" and "open[ing] new windows into the reality of marginalized citizens by showing them possibilities beyond where they live, and the shared aims of their struggle" (p. 27). Counternarratives provide an alternative to the perspectives held within dominant schemas and are

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[11] In this thesis, I draw on the following definition of "cultural capital": "the non-financial assets of an individual used to position and forward that person within a social system of exchange" (Rogers et al., 2013, n.p.).

particularly useful for advocates who seek to make change via the ‘hearts and minds’ of people within their communities. In McKay’s descriptions above, counternarratives challenge what the general populace knows about a given group, as well as how that group sees themselves. Coming from a law, critical race theory, and social justice background, Delgado (1989) uses the term “counterstories” in a similar way, describing them as sometimes a force for destruction [of dominant culture, societal strictures]. These descriptions help us think of voice through the metaphor of a tool, with strength and form, which can alter structures. The strength of voice as a tool comes from the knowledge generated by embodied experiences, while the form (expression or performance) is purposefully designed to create the desired outcome. Activists shape their experiences into expressions of voice designed to stimulate a response in the recipient. However, unlike a tool wielded by an individual on a material object, expressions of voice involve another person and are to an extent dependent on the recipient (or the audience) to generate impact. Some of the power in a story is in the telling within a marginalised community’s internal ‘safe spaces’, but the importance of voice for social movements is also in the telling to others.

Different ways of performing voice, especially those non-vocal methods used by some persons with disabilities, can be constrained by existing schemas and resources. In rural villages where literacy levels are low and interpreters (e.g., for sign language) are not available, there may be some types of disabilities that render some individuals more ‘voice-less’ than others. For example, someone who is d/Deaf and does not speak vocally may still wish to relay their story at a village meeting. They may be able to, if there are sign language interpreters or many individuals at the meeting who can read. However, they may be constrained from doing so under different circumstances. Even in cases where an interpreter is available, there is an intermediary, complicating the notion of voice even further. Wickenden (2011), asks whether unconventional voices are “recognized and heard in the same way as others” (p. 3). Wickenden (2011) goes on to point out that unconventional voices have implications for how others perceive individuals and their circumstances. These discussions emphasise the relational nature of voice - it is not only important to consider the individual and the way(s) in which they perform voice but also the audience, and the context in which they hear and listen to others’ voices. As Delgado (1990) put it:

> heeding new voices can stir our imaginations, and let us begin to see life through the eyes of the outsider. Not only can it broaden our point of view; bringing to light the abuses and petty and major tyrannies that minority communities suffer can enable us to see and correct systemic injustices that might otherwise remain invisible (p. 109).

Delgado's point highlights the use of voice in generating awareness within the populace, which can lead to changes in agents' outlooks strong enough to affect their behaviour. This change to the exercise of agency by those outside of a given movement can help to alter broader systemic structures. This is a large part of FEDOMA's approach to advocacy - building awareness of disability rights at the local level to generate popular support for the implementation of changes to both behaviours and institutions.

Arguments in favour of considering both the individual and contextual elements of storytelling emphasise the importance of spatial thinking and temporal evolution in the use of voice in social movements, making them fundamental to a geographical understanding of social movements. These ideas speak to a virtual moment in our structuration timeline that will never be repeated the same way again and whose effects also depend on the contextual (schematic) factors at play throughout a given (and other) systems. Even within that particular moment, "we cannot assume that each voice has just one story to tell; voices may be multi-tonal and we need to think carefully about what methods we employ in order to be sensitive to each tone" (Seale, 2017, p. 160). Dependent on context, a particular expression of voice may play out in different ways. A given story, for example, may have a multitude of meanings and emotions and be expressed through speech, silence, physicality, movement, facial expression, etc. A presentation of facts about a group's rights may be specifically honed to focus on the relevant interests of a given audience. Each expression of voice's multi-tonal nature is a result of the interplay of schemas and exercises of agency, using the storyteller's embodied resources. Any given individual holds a wealth of experiences which can be expressed through different iterations of their voice.

Despite this multiplicity of voice, persons with a shared experience of oppression draw from a knowledge-base which has inherent commonalities based on marginalisation. Delgado (1990) phrased it thus in discussions around critical race theory: '...all people of color speak from a base of experience that in our society is deeply structured by racism. That structure gives their stories a commonality warranting the term "voice"' (p. 98). People with disabilities' "base" includes experiences of exclusion and marginalisation based on ableism, among other things. Using Delgado's approach, this is the 'voice' referred to when we think about the collective - the 'voice of the disabled', or the 'voice of the disability rights movement'. The shared experiences which create solidarity can help to direct a social movement's 'collective voice(s)'. Collective voice is "fashioned" based on the "discursive environment" (Finke, 1993, pp. 13-14) activist groups find themselves in, as are the individual voices which form the collective. Within collective organising, stories, narratives, and counternarratives contribute to a group's repertoire. A repertoire can be defined as "the whole set of means that a group has for making claims" (Tarrow, 1993, p. 283). Tilly (2005) connects repertoire to performances, arguing that we can "call the variable ensemble of performances the *social movement repertoire*" (p. 308) (emphasis in original). In governance studies, Tarrow (1993) connects performance or 'doing' to individuals' knowledge: "the repertoire is therefore not only what people *do* when they make a claim; it is what they *know how to do*..." (p. 283) (emphasis in original).

In a lot of participatory social movements, 'experience' as discussed above is considered synonymous with 'knowledge'. "As opposed to the objective, generalized 'knowledge' that is disconnected from the knower, feminists recognized and celebrated the subjective, personal, and situated 'voice'" (Krumer-Nevo, 2009, p. 290). In Krumer-Nevo's words, voice is a stand-in for experiential knowledge; voice is a way of expressing embodied, contextual knowledges. This is important, because "sociologists of knowledge know that knowledge is power, and power is something that people fight to obtain and struggle to avoid giving up" (Delgado, 1990, p. 110). This idea came up often during my fieldwork. DDF members spoke of their power coming from 'knowing' their rights. However, they also gained power from the legitimising of their experiences as important to the development of a just society; the advocates' use of their voice(s), telling their stories to make change, underscored their belief in their own experiential knowledge. The acknowledgement of embodied knowledge can also "function as personal rituals that serve to connect disabled people to each other" (Friedner and Osborne, 2013, p. 49). Krumer-Nevo (2009) highlights the "duallanguage" used to integrate experiential knowledge into more formal contexts in their study of participatory action research for anti-poverty activism in Israel. Framing their voices through the use of either "everyday" or "analytical" language, agents are able to ensure their audience believes that their experiences are knowledge:

> we heard personal stories as the product of narrativization of knowledge, narrativization of opinions and ideas, which characterize people's everyday talk… Instead of the people responding to an agenda set by others, more powerful, it was the people's experiences, attitudes, and recommendations that set the agenda for others (Ibid., p. 291).

This is the core principle behind "nothing about us without us" (Charlton, 1998) and the disability rights movement, prioritising embodied experiences as knowledge. This in turn reinforces the citizenship of marginalised groups, and their ability to contribute to society (Krumer-Nevo, 2009), advancing processes of social change and inclusion.

Postcolonial theorists have also contributed to academic discourse around voice and its relationship with the experiences of oppressed and/or marginalised groups. In particular, the work of Spivak (1988) questioned whether the "subaltern" can ever speak. The concept of the subaltern has evolved over time but is defined in *Disability and Social Theory* in two ways: (i) as a more general term for groups who lack access to "hegemonic" power, and (ii) by Spivak's work as a group "structurally written out of the capitalist bourgeois narrative" (Goodley, Hughes and Davis, 2012, p. 332). Spivak (1988) concludes that the subaltern cannot truly speak, pointing out the power differentials that suggest the subaltern must always speak in the language of the oppressor. However, critiques of Spivak's work point out the apolitical subject Spivak's notion of the "subaltern" may create: "the subaltern was defined by its exclusion from representation… in both political and aesthetic senses" (Thomas, 2018, p. 863). This interpretation of Spivak's work voids the subaltern of agency, citizenship, and participation in political structures. Alternatively, Spivak's work can be interpreted as pointing to the ways in which dominant, minority-world-derived discourse belittles and obscures majority-world ways of knowing (Briggs and Sharp, 2004), an inherently political reading of the work. This approach reflects the critique of the dominance of minority-world models of disability discussed previously. Barker and Murray (2010), in discussing the implications of Spivak's work for disability studies, suggest a "focus on situated experience" "which contribute[s] to the globalization of disability studies precisely through their understandings of specific localities" (p. 228). While the argument that the subaltern cannot ever speak is debatable and evolving, especially in contexts where subalternity could be defined along multiple axes, (including some that impact both a particular "subaltern" group and other groups which may be both "subaltern" and oppressor depending on the context), this theoretical approach highlights the power differentials to be found within discourse, as well as in the social and material worlds. Evolving scholarship, based both on critiques of the apolitical spectre of the "subaltern" as well as the usefulness of Spivak's conceptualisation of the subaltern for political theorising, has contributed to refiguring and reconsidering definitions of subalternity (see for example, Thomas, 2018). Ghai (2012) highlights work emphasising hybridity within an oppressor's language in the spaces of the subaltern disability community, indicating that there is space for the subaltern to speak in a language once derived from the oppressor, but now fundamentally changed by space, place, time, and its incorporation into the political manoeuvrings of marginalised groups. In this thesis, I explore the ways FEDOMA's grassroots advocates define voice, express voice as a resource through empowerment, and navigate and alter the discourse of oppressors – particularly in spaces where authority figures and accepted social schema constrain the language, content, and tone of their speech. This reflects the broader debates within and between academic literatures on the transformative potential of voice, as well as the limits of this potential. At the same time, Spivak's (1988) work serves as a reminder that minority-world researchers should seek not to represent an "authentic" voice of the other, but instead "examine how their unity and status as a group are manufactured" (Altermark, 2017, p. 1323). In other words, what unites members of a marginalised group within oppressive social structures, but – equally important in this thesis – what are the differences to be found within these groups? In considering the manufacturing of groups of disability advocates, we can see the evolution of, and challenges to, Malawi's disability rights movement, including challenges arising through an uncomplicated assumption of unity within a marginalised group.

2.4.1.2 Emotion

One of the important factors in individuals' performances of voice (and audiences' performances of hearing) is emotion. Emotion can be a resource for social movements. It can motivate and drive an individual to action – both as an expresser and a listener. Since schemas and resources mutually constitute one another, the development of, for example, positive emotional resources toward persons with disabilities within a community can indicate an alteration to schemas. Historically, however, emotion has been (i) feminised as 'irrational' and as belonging to the 'private' sphere in a masculinist world, despite its indication in all human action as an embodied resource, and (ii) ignored in most academic analysis[12] (Harding and Pribram, 2002; Bondi, 2005). More recently, feminist scholars have changed the discussion, generating a great deal of literature on the importance of emotion and subjective experience generally (Bondi, 2005). This work specifically considers the role of emotion in processes of decision-making and social life, blurring the boundaries between "public" and "private" spaces (Harding and Pribram, 2002). In a piece on the importance of "emotional relations" in academic geography, Anderson and Smith (2001) offer an indictment of a politics of marginalisation without consideration of emotion as also relevant to studies of activism: "performing the role of cool interpreter in the face of the displacement experience, or in instances where personal and collective hurt thoroughly infuse politics and memory… makes for an anaemic knowledges predicated on the artificial separations of private and public, body and citizen, domestic and global" (p. 9). While emotion has long been an element of the literature on empowerment, it's use in other academic fields, including geography, is more recent. Anderson and Smith (2001) also make the point that emotion is highly gendered and important to the shaping of space and social relations. This is particularly important when considering marginalised individuals who are constrained by particular social relations and excluded from particular

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[12] Significantly – partly for the same reasons.

spaces. Throughout this thesis, and especially in Chapter 7's spotlight on women with disabilities, I discuss the importance of emotion in the work of disability advocates.

Even in spaces where activists engage in 'rational' discourse with officials, as I discuss in Chapter 5, Section 5.3.4, their participation in that space is inevitably driven by subjective experiences. As Thien (2005), put it: "the world is mediated by feeling" (p. 451). Bondi's (2005) overview of the development of emotional geographies from humanistic, feminist, and non-representational theory (NRT) traditions, points out that these traditions centre the subjective individual, with NRT contributing a specific focus on non-verbal experiences which impact "affect". However, Bondi (2005) finds that the NRT approach risks returning to a separation between the "emotional" and the "rational" through the distancing of "affect" from "emotion". While I use 'emotion' in this thesis, NRT's focus on the non-verbal is a useful point to highlight, as emotion as a resource is expressed in both voice and action. In all three disciplinary approaches, Bondi (2005) highlights a lack of emphasis on the *relationality* of emotion. Bondi's (2005) position on emotion as "transpersonal and grounded in ordinary human experience" (p.442) is useful for thinking about the ways individuals' emotions affect a collective (and are shaped by interactions between different actors within that collective). In doing so:

> Feelings are not understood as uniquely mine [an individual's] but as providing some kind of insight or perspective on the betweenness that is constitutive of relationships. This is processual, as part of the movement or flow of emotions, between or among people (Ibid., p.442).

Bondi's conceptualisation of emotion as processual provides a helpful starting point for thinking about how emotions move between agents and impact action.

Within social movements, relational processes involving emotional resources can be engaged intentionally to generate a specific response from an audience. Bosco (2007), while also conceptualising emotions as relational, emphasises the use of "shared emotions of activism" (p. 546) in building social movements. In Chapter 5, I discuss the collective experience of marginalisation as forming part of the connectivity of agents throughout all scales of FEDOMA. Emotional reactions to these experiences form part of the motivation for an individual to engage with a social movement – and processes of individual and collective empowerment. Bosco (2007) points out that “activists’ mobilisation of reciprocal emotional bonds help build and sustain both local and geographically dispersed activists’ networks through physical, symbolic and virtual proximity” (p. 557). The emotions of individuals can help to create collective cohesion. Bosco (2007) highlights “strategic emotional labour[13]” (p. 547) within movements, focusing on its use in recruitment, forging connections, and working across scales. This labour seeks to induce an emotional response in the audience[14] and encourage them to act based on it. However, Bosco (2007) focuses mainly on “reciprocal” emotions generated between social movement agents, not on those generated between an expresser and an audience. The success of “strategic” emotional labour is to an extent dependent upon the “reactive” (Bosco, 2007) (externally directed) emotions of the audience. In turn, an audience’s emotional reaction can impact the original expresser, emphasising the relational nature of emotional processes. Successfully creating the desired emotional response in an audience can spur continued engagement on the part of an activist. At the same time, agents’ ‘reactive’ emotions can be just as strong a (de)motivator, which is somewhat neglected by Bosco’s (2007) piece. In Chapter 6, Section 6.3, I demonstrate that reactive emotions of DDF members inform their decisions to perform or not perform advocacy activities, including strategic emotional labour.

Bosco’s (2007) emphasis on going beyond reactive emotion as a force for building solidarity misses reactive emotions’ potential to *disrupt* solidarity. Representation is important within a social movement. Individuals’ feelings of not being represented can affect their participation in the group and the collectives to which they belong. Meyers (2014) points out that movements can struggle to mobilise membership if

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[13] One of the key differences between an NRT/affect approach and emotion as used here by Bosco is that affect tends to look at these phenomena as being before cognitive processes and therefore not something that can be “worked on” or used strategically.

[14] “Audience” may be used generically as any person to which voice is directed, and there may be unintended or unknowable impacts on individuals in a given audience. However, for social movements, the intended audience is often a particular group (i.e., other people with disabilities, activists, DPOs, non-disabled community members, etc.).

"frustrated membership… no longer believes it has a voice in decision-making processes" (p. 463). In this way, voice (or a perceived lack thereof) also impacts emotion. Shared emotions of helplessness, anger, and discontent can cause an advocacy group to stall, with or without intentionality on the part of the members. Bosco (2007) does acknowledge that it is difficult to mobilise a collective if there is a lot of variation in emotion toward activism, but *collective* negative emotion can also be a hindrance to action, as I discuss in Chapter 6, Section 6.3.

Negative emotional experiences, whether they be internal or external to movements, or generated by person-to-person or other forms of interaction, impact social movement actors. In social work studies, Brilliant (2000) expresses this idea in discussing "the loss of movement passion" (p. 555). This lack of passion is held by Brilliant (2000) as "inevitable" with the "formalization of social movements" (Ibid., p. 555). Meyers (2014) discusses the onset of "apathy" among members who joined a disability movement which did not ultimately transform to adjust to the needs and desires of its base. Meyers' (2014) and Brilliant's (2000) points both go to the importance of representation and participation in generating positive emotions, engaging a movement's base, and encouraging processes of empowerment. As discussed above, participation and representation are powerful resources for empowerment processes. I disagree that the loss of passion is inevitable. It may yet happen, but in Chapter 4, I discuss the formalisation of a large section of Malawi's disability rights movement under FEDOMA; my analysis suggests that this formalisation enabled the empowerment and development of passionate advocates in a much broader swath of Malawi's disability community than had previously been possible, through the greater access to monetary and physical resources afforded to formal organisations. However, formalisation may also lead to standardised procedures which alienate some members, resulting then in a loss of passion among individuals or local collectives. Far from being inevitable, this outcome is space and time-specific, as will be discussed in Chapter 6's comparison of different DDFs' feelings toward FEDOMA. Brilliant (2000) also suggests there has been a lack of research on the trade-offs between the necessities of organisational structure and passion, which this thesis in part addresses.

2.4.1.3 Trust

Closely related to emotion, and important for its impact within social movements, is trust. Trust, like emotion, is relational and often context specific. Trust can result from experiences with another party that generate positive emotional responses and feelings of security. In business and humanities, Moore (2006) discusses Giddens' (1984) work and defines trust as "part of the reflexive project of the self", which "helps people deal with abstract systems and disembedding mechanisms - the vast, complex and alienating scale of modernity" (p. 419). In a movement as geographically widespread as Malawi's disability rights movement, this second part is particularly important for maintaining connections. Purdue (2001) emphasises the personal nature of trust, while simultaneously emphasising relationality, viewing trust as "acceptance of risk and vulnerability deriving from the action of others and the expectation that the other will not exploit this vulnerability" (p. 2214). Without a positive (emotional) connection to another actor, placing oneself in a vulnerable position is difficult, making trust challenging to establish and maintain. Purdue (2001) uses the ideas of "morality" and "capability" as positive associations forming the belief system behind trust. Belief in an actor's morality and capability is based on experiences with that actor and the feelings that result from those experiences.

Social organising scholars highlight trust as important for building social movement cohesion, as it strengthens collective identity (McEvily, Perrone and Zaheer, 2003). McEvily, Perrone, and Zaheer (2003) also claim that trust "creates social stratification that produces differential status, power, and knowledge" (p. 94). In other words, the development of trust can 'create' leaders and followers within the collective. Trust is not static, however, and whether and to what extent an actor is considered trustworthy by another actor changes with input over time. McEvily, Perrone, and Zaheer (2003) note the importance of processing new information (experiences and associated emotions), as trust "is… intrinsically social" (p. 99). Continued trust in an organisation's mission and leaders is thus necessary to keep grassroots 'followers' engaged. We can think of trust within FEDOMA's organisational system as another resource, entangled with emotion, which in turn can motivate individuals' continued engagement with FEDOMA's structures. Trust, like emotion, is continuously changing within a group and must be performed and reproduced in order to maintain it. Trust is often considered a positive relational resource, though it can contribute to the development of internal schemas which encourage over-reliance on a trustworthy actor, as I discuss throughout Chapter 6. This is in part due to the construction of FEDOMA structures which reflect the broader neopatrimonial structures of Malawi's political system.

Trust helps to make an organisation more efficient, as it "shapes the relatively stable and enduring interaction patterns in and between organizations" (McEvily, Perrone and Zaheer, 2003, p. 93), which allow it to operate. Tilly (2010) notes that "trust networks rely heavily on commitment: operation of ties that facilitate mutual recognition and coordination" (p. 8). An organisation's success can be facilitated by the establishment of long-term trust through continued (processes of) 'doing' and renewing trust, to produce and maintain commitment from its members. Through this, Tilly (2010) states, "trust networks… have formed the basis for most weighty, high-risk, long-term collective enterprises" (p. 8). At the same time, the 'where' and 'how' of communication play a role in the durability of bonds of trust formed between actors. Remote interactions can play a role in building trust, especially in a minority-world context where infrastructure such as internet access is widespread. However, in-person interaction remains important in many majority-world contexts, including Malawi. The physical distance between FEDOMA Headquarters (HQ) and different DDFs, and the ability of actors from one space to interact with those in other spaces, is directly tied to the constitution of trust as a resource.

If trust can be built through positive experiences and emotions, mistrust can arise from the negative. Mistrust, resulting from negative experiences and emotions, can impact the work of individuals and groups and make collective action difficult. In addition to its effects on the movement, "mistrust can bring about a sense of disempowerment" (Della Porta, 2012, p. 39), in effect negating some of the empowering effects of association with a social movement for individuals. Trust and mistrust are thus resources produced by a system's schemas and in different spaces – trust is built within structures characterised by enabling schemas, safe spaces which encourage positive emotional interactions and engagement in empowerment processes. On the other hand, mistrust can also be a resource to those who want to alter a system, producing negative emotional reactions to constraining schemas and engaging agents in empowerment processes. For example, FEDOMA as an organisation seeks to encourage a level of trust of its internal system within its membership. At the same time, FEDOMA structures generate mistrust in the status quo of the broader Malawian societal system, encouraging members to seek change. Activist movements in general thus have a paradoxical relationship with trust, seeking to build it within internal spaces and undermine it more broadly at the same time. Questioning and beginning to mistrust normative schemas is for many the entry-point to activism.

2.4.1.4 Leadership

Trust is important in the development of leadership within social movements. Foster-Fishman et al. (2007) point out that disability movements need effective leaders at every scale to move forward. These leaders must generate support from other members, as human labour is arguably the most important resource for social movements (Martin, 2008). Those who emerge as leaders are trusted by members to enable their best chance at achieving movement goals. The leadership in turn must demonstrate their commitment to the needs and priorities of the membership, including through the evolution of collective movement ideology. Leaders can generate positive emotional responses by demonstrating their trustworthiness, in turn reinforcing that trust. They can achieve this through actions, and specifically performances of hearing and *listening* to other agents. Thus, leaders who can establish positive feelings and trust among their constituents are more likely to enable their movement to continue to exist. Foster-Fishman et al. (2007) emphasise the role of leaders in sustaining DRMs through "identifying and framing social and political issues for their constituency… and helping individuals see the importance of collective goals" (p. 342).

As sociologist Kelly (2010) points out, leaders become the voice(s) and symbol(s) of a movement (see also Herda-Rapp, 1998). This positioning of leaders raises concerns that a group might privilege the foci of the leaders while side-lining that of others. This is an especially important consideration given that leaders tend to be those who are already socially privileged (Nakano, 2013) and/or have more social capital[15] (Purdue, 2001). The establishment of leadership is an important factor in how individual identities can impact a local or movement collective. Caldwell's (2011) study of DRM leaders "emphasized the importance of gaining confidence, speaking out, finding a voice" (p. 319), tying leadership development to processes of empowerment and voice as a resource. Leaders' voices will often have an out-size effect on collectives, lending importance to considering *who* becomes a leader. Foster-Fishman et al. (2007) call for a diversity of disability categories to be represented in DRM leadership, as a way to enable more inclusive and participatory decision-making. They highlight that those excluded from these roles tend to be "people with more challenging disabilities" (Ibid., p.343), resulting in a negating of the diversity previously discussed as central to DRMs.

In addition to exploring individuals' DRM leadership, I discuss the DDF collectives themselves as leaders[16]. Foster-Fishman et al. (2007) suggest that "collective groups" as leaders may be particularly useful for disability rights movements:

> A collective… orientation to leadership provides a more inclusive framework for multiple types of people to be included as potential leaders. This… is particularly important within the disabilities arena, where people with disabilities are often perceived as not fitting the 'great leader' form and many disabilities cause health issues that require individuals to become less active as leaders for periods of time (p. 347).

Foster-Fishman et al.'s point emphasises the ways in which those at the margins can 'queer' the centre, making members of society question our conceptualisation of a 'normal 'leader'. The version of a great leader involved in all key leadership decisions described by Foster-Fishman et al. (2007) is ultimately unrealistic for the unpredictability of life. Disability movements offer a particularly illuminating example, given the need to

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[15] For the purposes of this thesis, I define "social capital" as resources constituted through relationships (Rogers et al., 2013).

[16] In this case, the DDFs can, like FEDOMA, be considered actors.

approach organising with respect to the physical demands and limitations associated with impairment. Emphasising a participatory ethos and collective leadership has ensured disability movements can continue to progress. In this case, the most ‘complete’ and ever-capable leader is in fact a collective, in which various members can support one another and contribute to key decisions. The organisation of persons with disabilities and their experiential and embodied knowledges into collectives may in this way create a more honest and ontologically real version of ‘great’ leadership.

Additionally, Foster-Fishman et al.’s (2007) focus on the embodied realities of impairment helps to ground the conceptualisation of individual social capital in materiality and privilege. Leadership groups may mitigate issues raised by movements’ focus on training leaders (Ibid.) versus participation and empowerment of the broader membership. On the other hand, peripheral groups ‘empowered’ by a central leader may struggle to take on a leadership role themselves, due to a perceived lack of qualification or ability on their part. Kesby (2007) explores this issue of authority: “considerable differences in status will often mean that participants defer… to the expertise of… facilitators… and concede authority to them *even if they do not claim it*” (p. 2817) (emphasis added). While Kesby (2007) is discussing a researcher-participant relationship, this concern is applicable to a broader consideration of imbalances in power and/or perceived or actual authority. No matter how participatory and empowering a collective may seek to be, individual agents’ circumstances, resources, embodied identities, and roles within the organisation (and society) will impact the collective. ‘Collective leaders’ thus, as organisational actors, are subject to the relationships of the agents that comprise it, at a multitude of interacting scales.

2.5 THEORISING ACTIVISM AND INTERSECTIONALITY: LESSONS FROM FEMINIST STUDIES AND WOMEN’S MOVEMENTS

In Chapter 7, I explore the ways identities beyond and in conjunction with disability impact individuals’ lives and advocacy work, through a spotlight on FEDOMA women. Women play a critical role in Malawi’s

DRM. As the most marginalised people with disabilities in Malawi, women's unique challenges are at the forefront of organisational activities. Women are also most often the caregivers of children with disabilities and adults who need continuous support. While there may be tensions between the advocacy of persons with disabilities and that of carers, within FEDOMA's system the two groups work both separately and together. At the same time, there are broader aspects of the feminist literature that can be applied to disability studies. DRMs make use of feminist approaches by 'publicising' and 'politicising' the private, i.e., leveraging embodied, everyday experiences as resources for activism. The importance of relational resources such as emotion and trust has been espoused within feminist studies since its inception. In addition, feminists have explored the ways women work within cultural structures to produce social change. This is important to developing an understanding of the ways FEDOMA advocates do the same. In this section, I explore feminist literature around activism to (i) explore lessons from women's activism that can enable an understanding of the complexity of identity within social movements and (ii) explore the literature on women's and women with disabilities' social roles and activism to inform the analysis in Chapter 7.

2.5.1 Feminist theory and intersectionality

For the purposes of this thesis, I define intersectionality as the intersection of various forms of identity-driven discrimination which "do not work independently but interact to produce particularized forms of social oppression" (Rogers et al., 2013, n.p.). Intersectionality is particularly important to consider within DRMs because the differing experiences of oppression can impact group focal points for activism, whose voices are heard, what actions are taken, and why. Feminist studies have long grappled with incorporating intersectionality into literature and practice. This section discusses some of this, focusing on the impact of race, gender, disability, and socioeconomic status, as these are of particular importance within a Malawian context.

Organising for women's rights can entail balancing and blurring the traditional with the emancipatory and facing "the tension between empowering women as women, and addressing the various ways women are oppressed as members of marginalized social groups" (Piedalue, 2016, p. 2). Piedalue's focus on specificity picks up an important critique of some feminist theory and movements – the focus on gender as the main avenue for marginalisation without considering the intersectional impacts of other marginalised identities which women may also possess. A consideration of the broader movement(s) for new paradigms of feminism and women's organising is appropriate to theorise majority-world social movements, including thinking about women in Malawi's disability rights movement.

Majority-world women and minority-world women of colour have critiqued liberal feminism as being narrow-minded and without consideration of intersectionality. bell hooks' (1984) scholarship, for example, emphasises the development of feminism in the United States as a movement of middle- and upper-class white women, whose struggles against the "leisure" of being a housewife eclipsed the experiences of other women, both in the United States and globally. Johnson-Odim (1991) provides an overview of efforts for change within feminist movements, addressing the problem that "taking the eradication of gender discrimination as the route to ending women's oppression, is insufficient to redress the oppression of Third World women" (p. 315), which is tied to gender but also to class, "race relations and often imperialism" (p. 314). Johnson-Odim (1991) also points to global inequality as an important consideration in the development of more nuanced, intersectional approaches to women's empowerment:

> In "underdeveloped" societies it is not just a question of internal redistribution of resources, but of their generation and control; not just equal opportunity between men and women, but the creation of opportunity itself; not only the position of women in society, but the position of the societies in which Third World women find themselves... Thus, Third World women cannot afford to embrace the notion that feminism seeks only to achieve equal treatment of men and women and equal access and opportunity for women, which often amounts to a formula for sharing poverty (p. 320).

Johnson-Odim's point emphasises the intersectionality found in Gidden's (1984) "duality of structure" (p. 25) as well as the interaction of different systems. Structuration theory maintains that structures and agency constitute one another, and structures are comprised of various, intersecting schemas. Johnson-Odim's point about intersectionality highlights the idea that multiple schema impact individuals at any given point in time. The duality of structures allows space to consider the intersection of multiple schemas – including those which govern disability, race, and socioeconomic status, etc. – in the experiences and actions of an individual agent. While Chapter 7 will look closely at work done at the grassroots by Malawian women disability activists, it is important to recognise this context and the ways in which global schemas of oppression, including racism and capitalism, are part of the interconnectedness of systems and schemas which impact the lives of women and persons with disabilities.

Day (2008) connects the problem with Western feminist interpretations of African spaces not just to a disregard for intersectionality but to a *misunderstanding* of culture and society through the imposition of a Western perspective. Day (2008) emphasises "the high importance" (p. 492) of motherhood, both within the family and in a broader socio-political sense, as well as African women as critical economic actors. Day (2008) also argues that historically, "female autonomy" has been an important concept in African communities which Western feminist movements overlook, and that African women possessed a "consciousness of their rights and responsibilities as women long before the influence of the Western feminist movement" (p. 497). Women's continued involvement in income-generating and subsistence activities during the colonial era, despite colonial leadership's attempt to enforce private/public and man/woman binaries through access to economic roles, is one example of the sustenance of this consciousness. This consciousness and assumption of rights reflects Kandiyoti's (1988) "bargaining with patriarchy" (p. 274), which focuses on the subtle engagement of women in activities *within* the constraints of a patriarchal society which may constitute resistance to oppression. This means that even in 'traditional' spaces, women can exercise agency and engage in resistance against their subjugation. For example, as discussed in Chapter 1, Section 1.1.2.1.2, in Malawi, men's participation in waged labour often entails travel and living away from home; women, by participating in their 'traditional' roles as wives left behind in home villages, become de facto heads of households, making decisions for their families, and engaging in labour in and around the home space. In contrast, as Mkandawire-Valhmu et al. (2013) point out, “the characterization of African women in the media as well as in the literature has been that of poor, illiterate women who lack agency and are victims of oppressive, patriarchal societies and traditions” (p. 333). This reflects global “Eurocentric and hegemonic discourse” (Ibid., p. 333). Mkandawire-Valhmu et al. (2013) highlight that this viewpoint “does not reflect the capacity that African women have historically demonstrated in surviving severe hardships and strategizing responses to difficult circumstances quite often while occupying spaces on the margins of society” (p. 334). They also note that their study findings “hardly suggest that [Malawian] women consider themselves victims. Rather… women [were] actively involved in shaping and determining their own destiny” (Ibid., p. 346). This focus on Malawian women’s perspectives on their own identities and positions is of particular importance for understanding their participation in social movements, and the sense of self-belief that constitutes part of Sadan’s (1997) definition of individual empowerment. This agency is also unfortunately often left out of research on the circumstances of African women. Westernised notions of powerless African women undermine their agency and the social movement work being undertaken in marginalised communities. It also deemphasises the propagation of patriarchal structures within which women are participants, subjugating other women for their own power. In Chapter 7, I explore the dynamics between women of differing status, which particularly affect women with disabilities. This is of particular importance for women with disabilities, who are even more infantilized and portrayed as ‘objects’ of pity as opposed to individuals who can express their own agency, and upon whom a ‘lower status’ among women is also often conferred.

Different theories of women’s empowerment have emerged which emphasise an intersectional approach, including Black feminism and African feminism (see for example hooks, 1984; Hudson-Weems, 1997). Some critique feminism itself as too Westernized and racist to truly create spaces of empowerment for non-white women. One of the resulting approaches to theorising women’s empowerment differently is African womanism, which “contends that in times of hostility, many Africana[17] women will highlight historical

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[17] Barry and Grady’s term

oppression (racism) before sexism; and community and family needs before individual needs, as individual needs are a colonial, patriarchal and westernized concept…" (Barry and Grady, 2019, p. 183). African womanists emphasise the needs of the community and understand the multiple axes of oppression which affect many African countries. This focus on community is important for understanding the motivations of Malawian women with disabilities who work as social activists. Barry and Grady (2019) argue that African women do not perceive the "institution of family" (p. 184) as oppressive in the same way as some white Western feminists. In contrast, the family is conceptualised as the original space of power for African women, which shifted during the colonial era. This is not to say that there are not gendered oppressions within the familial structures of Malawian households. It does however, (i) lend itself to an Afro-centric approach which seeks to assert the importance of indigenous cultural understandings and autonomy and (ii) emphasise that a hybrid approach which couples newer, individualistic, human-rights based discourses of 'modern' Africa with less-individualised and dichotomised approaches to thinking about women's power and oppression, is necessary to engage the full complexity of these spaces.

Some critics argue against the "Westernisation" of African womanists, saying women who follow a more Western or hybridised ethos would "not [be] seen as an authentic African woman by her fellow Africans" (Mwale, 2002, p. 118). Mwale's criticism speaks in favour of maintaining gender divisions in the name of the 'traditional' without considering the ways in which tradition can constrain women's participation in society and contribute to oppression. At the same time, this criticism points to on-going conversations around ways of thinking about women's empowerment and the maintenance of culture. Conflicting critiques point to the tension between African conceptualisations of society and gender roles and the influence of Western ideas (such as individualism and feminism) in African development today. Women, including those with disabilities, are caught up in these debates; through their participation in particular social movements, women help shape the direction of both discourse and action. Today, Barry and Grady (2019) argue, many "find themselves closer to a centric view between Africana womanism and feminism where African feminism and Black feminism lie" (p. 184).

2.5.2 Using cultural structures to 'do' activism

Culture in Malawi is a rich resource for making power claims that influence lives, as seen during the Banda era. The recreation of Malawian tradition in the post-colonial context means that there is now a fine line to tread between overly-Westernised, 'un-Malawian' actions and making meaningful social change. Thus, social movement actors must embrace some aspects of culture, though utilising it differently from conservative counterpoints. Piedalue (2016) highlights the way anti-gender-based violence movements in India used culture in their efforts: "rather than ceding the ground of culture or religion to conservative interpretations, [anti-GBV groups] work to re-educate those persuaded by some men's 'misuse' of religion to justify violence" (p. 10). In these cases, 'traditional' schemas can constitute resources for marginalised groups seeking to make change. Of course, there are beliefs about persons with disabilities that are held up as examples of cultural schemas' negative impacts on persons with disabilities, i.e., the killing of persons with albinism. However, other cultural structures, as will be discussed throughout this thesis, are sources of positivity for some persons with disabilities, i.e., song-writing traditions, religion. Tradition and community values can help to provide a "home place" for marginalised people, from which resistance can be built (hooks, 1990). Piedalue (2016) calls for a "reframing [which] acknowledges that historically and place-specific cultural practices intertwine with regional patriarchies and structural violence, but refuses the conflation of culture with gendered oppression among non-white, non-Western people and places" (p. 4).

Jackson and Kelly (2019) point out that creatively thinking about empowerment can help us to go beyond "widely shared opinions about women's submission and irrelevance in Africa" (p. 17), enabling us to consider the spaces in which women constitute and exercise their power. Piedalue (2016) discusses the problem of patriarchal Western morality and the ways in which it impacts international narratives of the 'right' kind of social change:

> While Western investments... presume the rational and moral superiority of purportedly universal notions of freedom, justice, and human rights, these ideas are themselves cultural productions... The supposition of a conflict between culture and rights, and

> particularly the gendered dynamics of this assumed clash... relies upon an understanding of patriarchy as singular across space (p. 4).

As demonstrated in the introduction's discussion of the historical complexities of African patriarchies, systems of domination are context-specific, not singular. In place of these assumptions, Piedalue (2016) emphasises "geographical specificity and variation" contributing to a "place-based understanding of patriarchal structures" (p. 4). This place-based specificity is important when considering the work of activists in communities. The particular patriarchies which constrain women, persons with disabilities, and/or women with disabilities are just part of the culture of a place. Activists use other aspects of culture, including the power within traditional roles, to make locally relevant change. As will be discussed throughout this thesis, different spaces require performances of different activist voices, altering schemas within "intersecting power structures at multiple scales" (Piedalue, 2016, p. 5).

Women's participation in Malawi's DRM can be transformative from disability, gender, and intersectional standpoints. Participation of women in social movements helps to normalise women as empowered actors across a multitude of spaces. Stephen (1993) found that "women's participation in grassroots organizations that offer a more egalitarian gender ideology can, over time, potentially transform women's visions of themselves as political actors" (p. 33). Stephen (1993) also argues that women's participation in social movements not specifically focused on 'women's issues' can facilitate the development of women's spaces within other movements. The development of women's spaces within DRMs can both help to avoid 'siloing' 'women's issues' and the exclusion of women from decision-making about 'non-women's issues', encouraging broad consideration of women's experience. Mkandawire-Valhmu et al. (2013) point out that "the African continent has more women's associations than any other continent, and informal women's groups have had important implications on social development since the era of independence" (p. 334). Asaki and Hayes (2011) argue that women's grassroots groups have the same aims as more "formal" social protection agencies, but their community structures and principals are the foundation of *sustainable* social change. They provide the example of a "collective kitchen", which addressed both survival needs and "offered women a space for political activism" (Ibid., p. 248), opening up new spaces for resistance. Similarly, Mkandawire-Valhmu et al. (2013) found women's collective organising empowered women living with HIV/AIDS, emphasising the collective in combatting stigma and encouraging local innovation. Mkandawire-Valmu et al. (2013) also found that women's "subaltern knowledge" was important in both a practical and an organisational sense, "demonstrated through women's ability to critically analyse their circumstances and collectively come up with plans of action" (p. 346).

2.5.2.1 Understandings of 'traditional' gender ideals and disability

Grassroots approaches, such as those used by FEDOMA, are intrinsically tied to everyday resistance (Clothey et al., 2016; Frederick, 2017), as they are developed with attention to lived realities and the ways in which everyday resistance can build sustainable movements (Frederick, 2017). 'Bottom-up' forms of organising can result in "decidedly beneficial outcomes directly for those women, as well as for their children, family and other dependents" (Asaki and Hayes, 2011 p. 244), appealing to women whose motivations for social change stem from an emphasis on community good and caregiving roles. Goss and Heaney (2010) point out that women's organising has come to embrace the variety in women's roles (whether by choice or otherwise):

> These organizations hybridize... they blend together discursive frames – "women as caregivers," "women as rights-bearers" – that many often consider separately and that some conservative ideologues have sought to cast as diametrically opposed. Their emergent hybrid forms represent adaptations to the changing environment of women's organizing (p. 29).

This can be a powerful strategy for women gaining entry to political spaces, as part of organising: "the organization played to cultural stereotypes of proper womanhood to ensure its credibility within the political and media realms, but it also represented the actual motivations of many women and certainly of its leaders"

(Goss and Heaney, 2010, p. 30). This way of organising can help women's voices be heard and reimagines the "traditional" roles of women as progressive, establishing a platform for issues of genuine concern for women.

The expectations of women regarding domestic roles, including motherhood, become particularly complex when considering the intersection of gender and disability. Literature on women with disabilities focuses on the ways in which they are denied participation in the gendered roles assigned to women. Schriempf (2001) provides an overview of women with disabilities' exclusion from conversations around sexuality, including those which occur within feminist and women's movements. Schriempf (2001) emphasises that women with disabilities must "prove" their womanhood, and that these struggles are largely ignored in mainstream women's movements. There are a number of paradoxes highlighted alongside this issue, which inform the constraints women with disabilities face: 'Because disabled women are seen as being helpless, childlike, or defenseless, they are denied the "choices" that trap able-bodied (white) women. Yet, paradoxically, they are viewed as "woman enough" to be sexually objectified...' (Schriempf, 2001, p. 60). Many women with disabilities are denied "sexual rights", including those related to reproduction: "since the majority culture values people based on their reproductive qualities… Sexual rights have always and only been awarded to those who are proclaimed to deliver quality offspring" (Fiduccia, 2000, p. 169). As will be discussed in Chapter 7, the negative perception of women with disabilities' capability as reproductive partners impacts their relationships. Frederick (2017) argues that women without disabilities "confront a moral imperative to become mothers" (p. 131) while the opposite is true of women with disabilities.

While they may be seen as unable or unlikely to produce 'quality offspring' or fulfil motherhood duties, pregnant women with disabilities in Malawi are often abandoned and left to raise their children on their own. "Mothers with disabilities face unique forms of stigma, generated by intersecting cultural beliefs about disability, gender, and motherhood" (Frederick, 2017, p. 131). These arguments reflect the criticisms found in the discussion of race in women's movements, again emphasising the importance of intersectional thinking. At the same time, the diversity of feminist approaches are connected through an emphasis on improving women's lives using 'whatever works' within a given context, according to the desired outcomes of individuals and collectives. Part of 'what works' is ensuring that the needs of a diverse subset of women are considered within social movements. Additionally, organisations can use this approach to politicise the status quo - the traditional - by applying it to the desires of marginalised groups for inclusion.

Men and boys with disabilities, as well as women and girls, are impacted by the view that "people with disabilities are… held to be asexual (or in some cases hypersexual), incapable of reproduction and unfit sexual/marriage partners or parents" (Addlakha et al., 2017, p. 4). However, boys' "gender services to balance many of the negativities carried by the girls that limit their dreams" (Ibid., p. 7). The perception of women with disabilities as 'incapable' caregivers extends to the economic aspects of caregiving, including limited access to work (both waged and subsistence/agricultural, in the case of Malawi). At the same time, women with disabilities' practical circumstances often mean that they do have experiences of caregiving, as do women who care for persons with disabilities. Engagement in caregiving is an important component of the resistance of women with disabilities. As I outline in the next section, motherhood and care work have critical implications for participation in social movements.

2.5.2.2 Motherhood and care work as a platform for activism

Sprague and Hayes (2000) state that "the work of meeting people's needs allows the potential to develop a notion of power as capacity or potential" (p. 674). This can be used to think about the ways in which women's domestic and kinship roles are enabling spaces of entry into social change-making. Women are found to have been motivated towards "leadership in critical areas for women's equity, a type of leadership that contributes to the general transformation of unequal societies and which starts with the 'basics', that is the needs of the most vulnerable" (Lalthapersad-Pillay, 2019, p. 104), including children and persons with disabilities. This has expanded into an opening of various issue-based spaces to women on the basis of their care work. The role of mothers in particular is well-established in the literature as critically important for the care of people with disabilities, and children in particular (see for example Lorenzo, 2003; Stace, 2013; Barlindhaug et al., 2016; Manda-Taylor et al., 2017).

Conradsen (2016) discusses the transformative potential of motherhood for activism: “motherhood has often radicalized women to fight for the welfare of their children and the betterment of their community, and these activists have frequently called upon the symbolic power of the mother identity for legitimacy and inspiration for others to join their cause” (p. 1). (It must be noted here that it is important that motherhood and caregiving roles are not seen as the *only* areas of activism relevant to women, legitimising women’s activism but also limiting their participation and burdening them with the expectation of engagement in caregiving roles.)

There are a variety of feminist theories around the social activism of mothers. Liberal feminism emphasises equity and justice, maternalism focuses on women as caregivers, duty, and love, and feminist care theory centres care for all as a collective responsibility and public good (Conradsen, 2016). Rather than choosing one of these approaches, Boris (2002) suggests motion in women’s organising, as “activism that moves back and forth between… survival needs based on women’s labor within families and communities and general demands for human emancipation and social justice” (pp. 140-141). This perspective, emphasising the contextual aspects of social movements, provides opportunities to think about the impact of space, place, cultural schemas, and resources on how and why women choose to engage in advocacy work. Mkandawire-Valhmu et al. (2013) highlight a recent example of the impact of context on women’s roles in Malawi - that of the HIV/AIDS epidemic, the loss of men in many households, and the impact of this loss on wives and mothers. HIV positive Malawian women “demonstrated resilience”, taking care of themselves in order to take care of their children (Mkandawire-Valhmu et al., 2013). Necessity can be a starting point for ‘everyday resistance’ and more formalised activism.

Conradsen (2016) highlights the need for a focus on “identity as a mother” as a “launching point for activism”, (p. 2), something relevant to many of the activist mothers of FEDOMA. Conradsen (2016) also argues that while motherhood “radicalises” women, this ‘has often been overlooked as activism and dismissed as “just mothers” performing their domestic responsibilities, protecting their children’ (p. 1). They go on to highlight the internalisation of this view by mothers: “this has been inadvertently reinforced by some mothers’… not viewing their own efforts for social change as social activism” (Ibid., p. 1). Landsman (2005) found that mothers of children with disabilities tended to think of their role “not in terms of political action” but focused on the “protection of their children from the discrimination they fear in the future” (p. 135). However, mothers of children with disabilities often ‘transform’ into activists through their advocacy work on behalf of their children (Heng-hao, 2009; Swanke et al., 2009; Carey et al., 2019).

2.5.2.3 Individual motivation and group solidarity in women’s organising

For the women who participated in this research project, disability as a component of identity was the central drive for their activism. However, womanhood was discussed by many of them, especially those belonging to DPOs that focused on women’s rights or the role of parents of children with disabilities. Even in cases where women did not particularly focus on women’s rights, their positions as women clearly affected their experiences and actions. Goss and Heaney (2010) discuss the struggle to reconcile multiple identities within the study of a particular social movement: “because the groups’ collective action frames centered on gender, with other identities secondary, the groups may have had difficulty resonating with diverse women who had complex feelings about gender solidarity” (p. 34). Similarly, gender’s complex resonance for advocates who view themselves primarily as disability activists is explored in Chapter 7. It also indicates the importance of considering different identity groups’ voices within any social movement, as I do throughout this thesis.

The women’s spaces within FEDOMA encourage consideration of women within the DRMs, developing ‘hybridity’ through intersectionality. Goss and Heaney (2010) found that “hybridity allowed women’s organizers to speak to different women’s constituencies simultaneously” (p. 44). FEDOMA claims to try to magnify the voices of women with disabilities and, often non-disabled, women as carers of persons with disabilities. Goss and Heaney’s (2010) work focuses on the collective action frames of entire movements, but intersectionality is highly personal and thus individual approaches are important to understand as well. The hybrid ways in which Malawian disability advocates approach their activism is unique to not just this movement but to them as individuals.

At the same time, group solidarity is just as important to advocacy work as individual motivation. Grassroots women in Kabeer's (2003) study emphasise the practicalities of group support: "when we five women stand together, then no man can get away with misbehaving with us. Because we have solidarity among ourselves, we will catch him and question him as to his misbehaviour. If it is one woman, anyone can insult her without fear" (p. 8). Women play important roles in a variety of advocacy spaces, and the connections forged in those spaces can also be important for individual women's identity development at the same time. Women gather together to combat injustices that have been committed against them. Jasper (2011) highlights the importance of women's collective action for "emotional repair of one's self-image" (p. 290). While Jasper's work focuses on "women's self-help movements", a similar process of "undo[ing]… damage by repairing women's emotional experience" (p. 290) can occur within other movements. Jasper's (2011) and Kabeer's (2003) pieces help to highlight the importance of groups of women in altering schematic constraints on their lives and sense(s) of self, a critical factor highlighted in the interviews I conducted. The emphasis on emotion and repairing damage caused by experience, however, is central to a variety of social movements for marginalised groups, including DRMs.

2.6 CONCLUSION

In this thesis, I use the literature presented here to explore the complex relational processes of structuration in which Malawi's disability advocates engage. In the 'Findings' chapters, I explore voice as it is conceptualised and used by advocates, learning from the ways in which it dovetails and differs from voice in the academic literature. I explore the way that relational resources, including voice, emotion, trust, and leadership, constitute the relationships between the DDFs and FEDOMA. These same resources are part of how disability advocates exercise their agency to reproduce and alter structures. In addition to exploring schemas and resources in the DRM more broadly, an intersectional perspective on women with disabilities' activism also opens space to consider the implications of differing aspects of identity on drivers for and experiences of oppression and activism. This interweaving of various forms of inequality help to develop a more nuanced understanding of Malawi’s disability rights movement.

3 METHODOLOGY

This project developed across two stages, a 'participatory research design' stage and a primary fieldwork stage. I attempted to work in participatory ways, in keeping with the DRM's philosophy of "nothing about us without us" (Charlton, 1998), while acknowledging that within the constraints of a PhD, undertaking a 'fully' participatory project would be challenging. In addition to considering the DRM's raison d'etre, participatory research can also be a methodology which prioritises social justice and local knowledge. I was interested in learning from experts in the Malawian context, as my own previous experience with disability was within a very different context; as such, focusing on local knowledge was a major aspect of developing this project. Participatory research as an overarching guide for my project made sense in meeting these goals and my development as a researcher, as:

> students who engage in community-driven action research can acquire the benefits of partnership and collaborating with the knowledge that the study can lead to valuable social, policy and/or organizational change. Since participatory research projects are based on community-identified needs with the goal of contributing to and expanding local knowledge and competencies, students can benefit from the research process while simultaneously assisting and supporting a local community (van der Meulen, 2011, p. 1291).

Complex ethical issues within the participatory design stage, which I will discuss in this chapter, impacted the work I undertook in the primary fieldwork stage. The process of developing and undertaking this research helps to answer RQ1, focusing on questions of how best to do research with activists in low-resource settings.

3.1 STAGE 1 - PARTICIPATORY RESEARCH DESIGN

I pursued a participatory approach in this project, particularly in the research design phase. Action Amos, the Executive Director (ED) of FEDOMA was my contact and FEDOMA counterpart in designing the project.

There were setbacks and delays during this stage, but they provided procedural experience and insight and encouraged creativity in the research design.

3.1.1 Development and scoping of the research project

It was important to me that FEDOMA benefit from the research, as an attempt to engage in “empowering professional practice” (Sadan, 1997, p. 13), which encourages professionals to strive to facilitate empowerment processes in their work with marginalised groups. When working with social movement organisations, one of the questions researchers must answer is: does this contribute to the achievement of this organisation’s goals? Depending on the organisation, the researcher, and the research project, the answer may be yes or no. In this case, I attempt to adhere to Stone and Priestley’s (1996) argument that “priorities for disability researchers must be… an overt political commitment to the development of the disabled people’s movement” (p. 715)[18]. Kesby (2005) also discusses the use of participatory approaches in facilitating empowerment: ‘by redistributing power and establishing more reciprocal relationships between “insiders” and “outsiders,” participatory approaches build ordinary people’s capacity to analyse and transform their lives and thus provide one practical means to facilitate empowerment’ (p. 2037). From FEDOMA leadership’s perspective, engaging an external researcher was an opportunity to undertake research that it did not have the resources to begin on its own at that time. FEDOMA was developing a new five-year organisational plan. FEDOMA leadership felt it was important to tap into the knowledge of its grassroots base and gain an understanding of grassroots advocates’ priorities for the future. To that end, they suggested that the research could focus on the DDFs, which FEDOMA had begun establishing in 2015. After a few months of initial discussions, we had a general framework for the research, but decided to

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[18] See Stone and Priestly (1996) for an in-depth discussion of the debates and challenges around non-disabled researchers working in disability studies.

undertake participatory pilot work in order to design a project that could contribute academically, as well as help FEDOMA prioritise grassroots groups.

3.1.2 Participatory action research

A good deal of research has been done emphasising the importance of participatory research in strengthening persons with disabilities’ calls for inclusion and in ensuring the applicability of such research to persons with disabilities’ own priorities. Participatory action research (PAR) can contribute to prioritising the voices of persons with disabilities in research, conducting research that is “grounded” in their “realities” (Asaba and Suarez-Balcazar, 2018). Academic geographers have challenged the prioritisation of professional and carer voices over those of persons with disabilities in research (Wilton and Horton, 2020), highlighting a need to disrupt the power differentials which lead to the silencing of persons with disabilities in favour of experts talking ‘about’ persons with disabilities. Powers (2017) highlights the growth in various forms of action research in disability studies as demonstrative of growth in *respect* for the voices of community members in research development. The establishment of communities as partners in research can disrupt traditional power differentials in research relationships, contribute to participant well-being, and reduce the risk of researchers taking advantage of participants and offering nothing in return (Powers, 2017; Asaba and Suarez-Balcazar, 2018; Tanabe, Pearce and Krause, 2018). PAR in majority-world settings can also help to methodologically incorporate the eclectic, hybridity, and contextual sensitivity discussed in the literature review. The involvement of communities in setting research agendas can demonstrate gaps in minority-world understandings – for example, the ways in which disability and disability-rights organising are conceptualised and conducted differently in majority-world settings. This highlights the importance of local and contextual knowledges in contributing to the development of academic disability studies beyond the minority-world. Altermark (2017), speaking about research with individuals with intellectual disabilities, highlights their potential as “knowledge producers” that “show contrasting descriptions and add depth and nuance” (p. 1328), connecting this approach to Spivak’s (1999) “counter-strategy as a process where the people of the

West must 'learn how to learn from the subaltern' by unlearning their privileged modes of knowledge production" (p. 1328). In this project, I set out to learn from Malawian disability advocates, attempting to 'assume my own ignorance' to enable as open-minded an approach to project development, fieldwork, and analysis as possible.

To further explore the use of participatory action research (PAR) in disability studies, I developed a systematic review protocol[19] to survey the wide range of fields engaged in disability research. 342 full papers were ultimately included. Of these papers, nine involved research in an African context; none of these studies were undertaken in Malawi. This finding indicated that the use of PAR for disability studies in Malawi has not been widely explored, something which this thesis attempts to work towards. Six of the studies done in an African country mentioned working with an organisation active in that setting[20]; this indicated that organisations play a key role in researchers' accessing communities, ensuring representation of group/community interests, helping to set research agendas, and in providing knowledge of local contexts. I attempted to work with FEDOMA in a similar manner.

During project development, it became clear that it would be difficult to engage participants as co-researchers during the primary data collection. For FEDOMA, the draw of engaging in this research was essentially to do research which did not come with a cost to the organisation; co-researching within this context proved to be beyond time, funding, and other resource constraints. However, FEDOMA as a disability-rights organisation is committed to the ethos of "nothing about us without us" (Charlton, 1998) and to participatory research, making attempts to build participation into the project critically important. Spending time at FEDOMA and discussing what issues activists were interested in learning more about lent itself to a 'participatory design process', with mutually beneficial outputs. One of the critiques of

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[19] See Appendix A for protocol and bibliography of included studies: African context. Also included in Appendix A is the ethical approval for a Delphi study. This study was conducted to develop the COREQ checklist for writing qualitative research (Tong, Sainsbury and Craig, 2007) into a tool for assessing qualitative research. This tool was used in assessing the quality of included studies for the systematic review.

[20] Works cited: Chivandikwa, 2013; de Clerck, 2011; Greenwood et al., 2016; Lorenzo, 2003; Lorenzo et al., 2007; van Niekerk et al., 2006

participatory action research, as highlighted by van der Meulen (2011), is an "over-reliance on ideology rather than methodology" (p.1292). A participatory design process is an innately practical endeavour, which acknowledges that we cannot always achieve 'full' participation (and we may not always want to). Designing a project collaboratively can help incorporate a participatory ethos into different aspects of 'doing' research and help translate the ideal into the practical. Asaba and Suarez-Balcazar (2018) note that PAR occurs across a continuum and "community participation in research needs to be meaningful and substantial; desires of the participants should drive the research process" (p. 310). In engaging in a participatory design process, I sought a research design that was driven by the needs and desires of Malawian disability advocates. At the same time, I also acknowledge that although my project aims to highlight voices from grassroots - participants who are generally 'on the periphery' – the project materials and structure were primarily designed with those who occupy more powerful positions within the organisation. The centring in the project of more marginal grassroots voices benefited from (and in some ways was dependent upon) the willingness of organisational leadership to focus on them and aid me in accessing grassroots groups. In this, FEDOMA's grassroots history, current attempts to become as democratic as is realistic, complicated governance structure, and on-going focus on decentralisation of activities created an atmosphere amenable to participation both by an external researcher and peripheral actors. This project contributes one example of 'filling the gap' in academic disability studies as to the practicalities of and challenges to conducting PAR with persons with disabilities in "resource-limited" settings, as highlighted by Tanabe, Pearce and Krause (2018).

3.1.3 Ethics 1: Institutional ethics

A research agreement between the University of St Andrews and FEDOMA was developed and signed by all parties. We applied for and received ethical approval from the University of St Andrews for the 'participatory design process' and the primary data collection. Initially, both stages would have included in-depth interviewing and participant observation: the first stage of interviews and participant observation were intended to set the agenda for the second stage. We also needed ethical approval from the government of Malawi. Since I am the researcher for this project, I travelled to Malawi to finalise the application with FEDOMA management and staff and submit it to the Malawi ethical board. Stage 1 fieldwork was conducted from 29 September through 17 November 2017.

The Malawi government was less convinced of the participatory nature of our project, given that we were dealing with individuals legally classified as 'vulnerable', despite the input from members of Malawi's disability advocacy community in designing the project and FEDOMA's commitment to ensuring that the interests and safety of persons with disabilities were considered in the research. The application was initially rejected and sent back to us with requirements for changes not just to the project plan but to the legal research agreement between the University of St Andrews and FEDOMA. While this was a set-back, it (i) gave me some insight into frustrations and delays commonly experienced by my participants and (ii) forced innovation, encouraging me to attempt new methods in order to use my first visit to Malawi productively.

The initial rejection of the ethics application by the Malawian government impacted the timeline of the project. Given the existing resource constraints, particularly available funding for the research, we decided to conduct a less formal 'participatory research design' process, with me embedded within FEDOMA but not undertaking formal interviews or participant observation. In place of this, I conducted an autoethnography of my experiences within FEDOMA, developing an understanding of members' priorities for the research through informal conversations and participation with the organisation. This experience enabled the best use of the first stage trip to Malawi while maintaining a participatory ethos, if less of a participatory methodological approach. The autoethnography also allowed me to interrogate my positionality during fieldwork and analysis, contributing to a depth of reflexivity also emphasised by proponents of participatory research (see for example, Pain, 2003). These changes also meant that the participatory research design phase had to be guided by a participatory ethos to which myself and the FEDOMA representatives adhered in our practice, without the formal data gathering for the research design which could have held us more externally accountable. It is reasonable that some may challenge the true depth of the participatory research undertaken in this project, despite our best attempts (within the constraints of this project).

The change to the timeline also presented new challenges in the administrative aspects of the project. I developed skills in responding to government priorities for research and learned about differences between the stated ideals of an ethics committee and their duty of care to citizens. For example, Malawi's national social science research guidelines declare the importance of ensuring research is participatory, but in our case required a much more structured approach to the research than we had initially planned. While many academics may see this as overly bureaucratic, it also reflects the challenges faced by majority-world governments around protecting citizens from abuse and exploitation by (especially minority-world) researchers. In reviewing the research agreement between the university and FEDOMA with the perspective of the Malawi government's comments, I was able to see what items caused concern and, in some cases, agreed that the university's standard protocols and intellectual property rules are designed primarily to benefit the university, and could in some ways undermine the ethos of participatory research and mutual benefit. On the other hand, I came to understand some of the frustration felt by persons with disabilities whose 'capability' is challenged and who are automatically rendered as 'vulnerable' when attempting to engage in research activities. This experience provided valuable insight into this fine balancing act, and in the end, we were successful in obtaining ethical approval for our second submission. However, the process of renegotiating the research agreement proved to be a lengthy one, pushing the timeline for the research project back further. Ultimately, this meant the project was nearing completion during the Covid-19 pandemic, and the combination of these two events meant that a final planned participatory fieldwork stage – data validation and feedback with participants in Malawi, had to be cancelled.

3.1.4 Autoethnography

Autoethnography falls between ethnography and autobiography, shifting the focus of the research from 'other people' to the self (Ellis et al., 2011). "When researchers do autoethnography, they retrospectively and selectively write about epiphanies that stem from, or are made possible by, being part of a culture and/or by possessing a particular cultural identity" (Ibid., p. 276). As I did not have ethical approval to engage in participant observation or in-depth interviews, I took detailed and personal notes on my own experience and reflections during my first trip to Malawi, in order to construct an autoethnography. This approach was practical in that it yielded useful data from the trip and enabled me to engage in a process of empathising with and relating to Malawi's disability advocates. 'Being part of' the culture of FEDOMA during this visit helped me to blur the boundaries of difference between myself and my participants. For the purposes of this project, my positionality included my status as a 'professional' researcher from a minority-world country, who does not currently identify as disabled. I have experienced chronic disabling conditions in the past and have been a caretaker to loved ones with disabilities. However, while these aspects of my experience informed my interest in disability studies, this would not have been as clear to participants as my differences to them, impacting the relationships I was able to form. While I was an outsider, through autoethnography I also became a participant in the research project and subjected myself to a similar analysis as other participants' contributions.

I went to 'work' each day as if I were a FEDOMA staffer (with some restrictions) and was invited on various projects to get a sense of what the broader work of the organisation entailed. These projects ranged in type, though most were located in the area of Headquarters (HQ), as districts further away were serviced either by staff who stayed in those districts for extended periods, or through longer trips by HQ-based staff. After an initial meeting with FEDOMA staff and management, I was granted access to participate in any activities that were going on while I was there, with the exception of FEDOMA's General Assembly (GA) meeting, in which only members are permitted to participate. Upon my return to Scotland, I worked with my notes to code the different experiences and used these to construct and analyse an autoethnography, excerpts from which are included here.

3.1.4.1 Authoethnography Part 1: Positionality and voice

During my initial visit to Malawi, I engaged in a process of gaining awareness of my positionality and expanding my understanding of and empathy for my participants. I faced challenges that acted as parallel experiences through which I could begin to understand some of what my research participants are faced with as persons with disabilities. Through my own encounters in the field, I developed an understanding of what it feels like to lack a voice and struggle to communicate; this underscored the struggle to be heard that forms a large part of the disability advocacy work happening in Malawi. For example, one of the main barriers I had to overcome revolved around my ability to communicate across both language and impairment barriers, as I discuss in the following vignettes based on my field journal.

> *The DDF meeting was just getting into swing, and I was told by Nora[21] to introduce myself to the crowd. I stood up at the front of the room and, knowing that many of the attendees wouldn't understand me, nervously launched into as brief an explanation of who I was as possible. In a moment that seemed straight out of a B-movie comedy, there was a long, awkward pause, before Nora translated for me. The interaction gave everyone a laugh and eased some of the formality and nervous tension in the room. I noticed that there was no single interpreter at this meeting for the deaf participants - some had a volunteer or caretaker with them to help them follow along. I was in a similar-but-different position without a formal interpreter to deaf attendees, as the meeting continued in Chichewa and I followed along only by the good graces of Eva*, who translated for me. (Autoethnography FNs, 2017)*
>
> ***
>
> *One of the main ways I communicated with the deaf staff members in FEDOMA's offices was through passing notes. The limited space offered by a note required the writer to really think about what they want to say, and these were some of my favourite experiences in the office. I was surprised to learn how much communication there is through miming, eye contact, and*

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[21] Pseudonym

> *writing. I did more laughing and felt more comfortable in these silent, makeshift conversations than almost anywhere else – maybe because my own embodied experience in Malawi consisted of a lot of hearing without understanding. In these conversations, we made our own understanding. With two of the deaf staffers, I discussed school and work, conducted exchanges in the field, and joked, all without physically saying a word. Their joy and humour, communicated through paper and largely silent laughter, was infectious. Communication was the key, and in a lot of ways, that sums up what this project became about. Communication, and performing voice, through bodies as well as vocal cords (Autoethnography, 2017).*

My experience as an outsider in both the disability community and the broader Malawian community brought me some level of understanding of the embodied experience of being an outsider in this place. (Though my experience was differentiated by my obvious non-Malawian status.) It was not an unfamiliar feeling but felt more relevant than my past experiences because this was within the socio-spatial context of my research project. I was able to use my particular experiences on this visit to try to overcome challenges with communication, which in turn allowed me some insight into navigating a world in which you are the other, as my participants do. Crucially, though, there was always someone willing to translate for me, which is not the case for all persons with disabilities who need these services. The depth of reflection central to autoethnography was a part of the methodology that helped me to effectively conduct research in resource and time poor settings. I was able to use the time I had in the best way I could, and I was able to develop a project that spoke to critical issues in the lives of disability activists within this context.

This experience also helped me to develop questions about whose voices might be lost, even in an organisation with strong democratic principles. In the development of new grassroots outposts through the DDFs, communication and the role of voice were not fully explored as important aspects for the evolution of these groups. The questions that FEDOMA's management have about the effectiveness of the DDFs are really questions that scratch at the surface of conceptualising what the DDFs need to succeed. The key to finding that out is to ask, and let people voice their understandings. In particular, the positionality of grassroots advocates, physically and hierarchically distant from the central organisation, was something I identified as a critical area for investigation. Did FEDOMA manage to integrate those who were physically distant from HQ through the approaches to advocacy they utilised? I became interested in researching how those on the periphery of the organisation felt about their role in the movement and how they developed those perspectives.

The advice and supported provided by FEDOMA HQ to grassroots advocates focused on people with disabilities 'speaking up' and 'sensitising the community'. They focused on 'voice' as a key resource and the ways in which people with disabilities could use voice to engage their communities. However, throughout my first visit, there was little discussion of the impact of grassroots voices on the central organisation's activities, despite the claim that FEDOMA priorities were set based on the felt and expressed needs of the broader disability community. I began to question whether FEDOMA was also listening to grassroots voices, while helping grassroots advocates express their voices in their communities. In this questioning, the autoethnographic exercise emphasises my own voice in shaping the project. As an external researcher, I was free to challenge the statements of the central organisation, and through this my explorations of the relationship between FEDOMA and its grassroots outposts developed. My voice is found in the creation of questions which question the unity of the organisation and seek to investigate the potential reasons for any dis-unity.

3.1.4.2 Autoethnography – Section 2: Setting the research agenda

Based on the experiences I had during Stage 1, I engaged in discussions with FEDOMA management around what issues seemed the most critical. The idea of better, more frequent communication had come up often, so that was where we decided to concentrate the next phase of the research. The differences, conflicts, and sheer organisational complexity of FEDOMA and its grassroots outposts also stood out to me, and raised questions about the setting of advocacy agendas, and the ability of the grassroots forums to act independently. In addition to my academic interest in the DDFs, FEDOMA sought to ‘evaluate’ the DDFs, in order to decide how to incorporate them into the new five-year plan. We decided to focus on the DDFs, as the established grassroots forums, whose members now held varying degrees of experience with local organising, though with a ‘softer’ approach than a formalised evaluation.

Engaging with autoethnography offered me a clearer insight into the practicalities of developing research in partnership with an organisation, by writing about the process as it was occurring. This allowed me to locate my voice as the researcher in shaping the project. Although I committed to developing a project that focused on the needs and priorities of the organisation, my position as an external researcher also enabled me to question the organisation’s approach. My focus on emphasising the stories of grassroots agents through engagement in-depth qualitative research was integrated with FEDOMA management’s desire to ‘evaluate’ the DDFs in the shaping of the research project.

At FEDOMA HQ, questions were raised about the future of the DDFs as a focal point for the continued decentralisation and grassroots expansion of FEDOMA. The answer to how much independence the DDFs should have and how they should be integrated into the overall organisational structure is a conversation that needs to start with how the DDF members perceive their role. I realised that during my time in Malawi, the people I had heard from the least were grassroots advocates, since I was shadowing professional staff members. It seemed necessary to investigate how district-level advocates feel about how the organisation should move forward, especially given the inherent conflicts that arise when discussing grassroots organising and institutional hierarchies. In a complex disability organisation like FEDOMA with both a hierarchical structure and a desire to diversify and decentralise its operations, whose voices are heard and why, and how does that impact the process of communication throughout the organisation?

At the end of my Stage 1 visit, I learned that FEDOMA hoped to establish a reporting system using mobile phones to effectively channel information between the levels of the organisation. The next phase of my project included a brief ‘pre-pilot’ of this idea, asking grassroots advocates their opinions about the usefulness and feasibility of such a system as part of longer interviews. This is a practical idea intimately connected to voice; how the DDF members feel about representation within the organisation's hierarchy will ultimately play a role in whether a mobile-phone reporting system could be successful.

Throughout Stage 1, I had discussions with Action Amos about the things I was observing and the analysis I was developing. Action was interested in ensuring that the felt and expressed needs of grassroots advocates were incorporated into the development of FEDOMA's five-year plan. We decided the research project would focus on grassroots advocates' use of voice, both in trying to make change in their communities and in communicating what was happening at the grassroots to the central organisation. These two concepts are connected, as a lot of what grassroots advocates raise to the central organisation is based on their experiences within their community. FEDOMA in turn relies on this information to ensure that the knowledge base from which it draws in national-level campaigning, project design, and fundraising is relevant to the people 'on the ground'. From this I developed the research questions laid out in the introduction. Autoethnography aided me in bringing together what I was told by FEDOMA management, what I learned from participating in events, and what I was questioning as a researcher. Including the autoethnography in this thesis sets the findings around grassroots actors' voices and agency against the backdrop of a project developed with the perspective on an external researcher. As a result, the DDF 'voices' presented in this thesis are those which ultimately were expressed in response to my own voice, through research design, interview questions, and analysis.

3.2 STAGE 2 - PRIMARY FIELDWORK: IN-DEPTH INTERVIEWS AND PARTICIPANT OBSERVATION

Stage 2 of the project commenced once the revised project received ethical clearance[22] from both the University of St Andrews and Malawi's National Committee on Research in the Social Science and Humanities, with adjustments to the study timeline and approach based on the delay. Stage 2 fieldwork was conducted

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[22] See Appendix B for Stage 2 data collection ethical approvals.

from 11 November 2018 through 17 January 2019[23]. In this stage, I decided to use in-depth interviews and participant observation. I continued to undertake the research with a participatory, scholar-activist ethos, but I employed more traditional approaches and gathered the data myself. This approach allowed my work to be of use to the organisation without taking valuable human (and thus financial) resources away from FEDOMA.

I decided to use qualitative methods, in the form of participant observation and in-depth interviews, as methodologies for investigating grassroots advocates' felt and expressed needs, inviting them to express their voices and tell their own stories. Since this thesis is focused on storytelling and voice, this felt especially appropriate, as Warren (2004) describes interviewing as a "special kind of conversation" (p. 521). Arguably, special forms of conversation are exactly what advocates engage in when they use voice as a resource in movement activities. Wilton and Horton (2020) also emphasise autoethnography and qualitative methods as contributing to "rich empirical-theoretical consideration(s) of diverse, lived disabling and enabling geographies" (p. 1022). Qualitative research is useful in engaging the multiplicity of situated 'truths', experiences, and knowledges of individuals, highlighting the importance of context and culture (Hartley and Muhit, 2003). Qualitative methods can be useful in engaging with disability beyond medical diagnoses and statistical research, particularly in the majority-world, where such research is particularly scarce (Ibid.).

3.2.1 Research sites

I conducted participant observation and interviews with grassroots advocates in 4 districts, one in each region and the last in one of Malawi's urban centres. The research sites were chosen in consultation with

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[23] Throughout this thesis, I cite Field Notes as 'FN' plus the year – 2017 for Stage 1 and 2018/19 for Stage 2. Exact dates for field diary entries are not provided as part of an effort to avoid identification of participants who requested a pseudonym, who participated in non-public participant observation events, and/or who provided sensitive information about the internal workings of FEDOMA (especially members of HQ staff). Specific dates may increase the likelihood of individuals being made identifiable to other participants in those settings on those dates, or who have access to attendance lists for activities during which I conducted participant observation.

Action Amos. The selection of the sites was based on Action's suggestion that I visit (i) DDFs which were well-established as well as newer ones, (ii) DDFs perceived as 'successful' and others perceived as less successful by staff at HQ, and (iii) a DDF which represented each region of Malawi to capture any regional differences. The selected DDFs also differ in level of financial support received from FEDOMA. Information about fieldwork sites is in Table 2 below.

Table 2. Information about study sites and sample size from each site. Region for 'urban centre' withheld to protect participant confidentiality.

Key: Establishment status

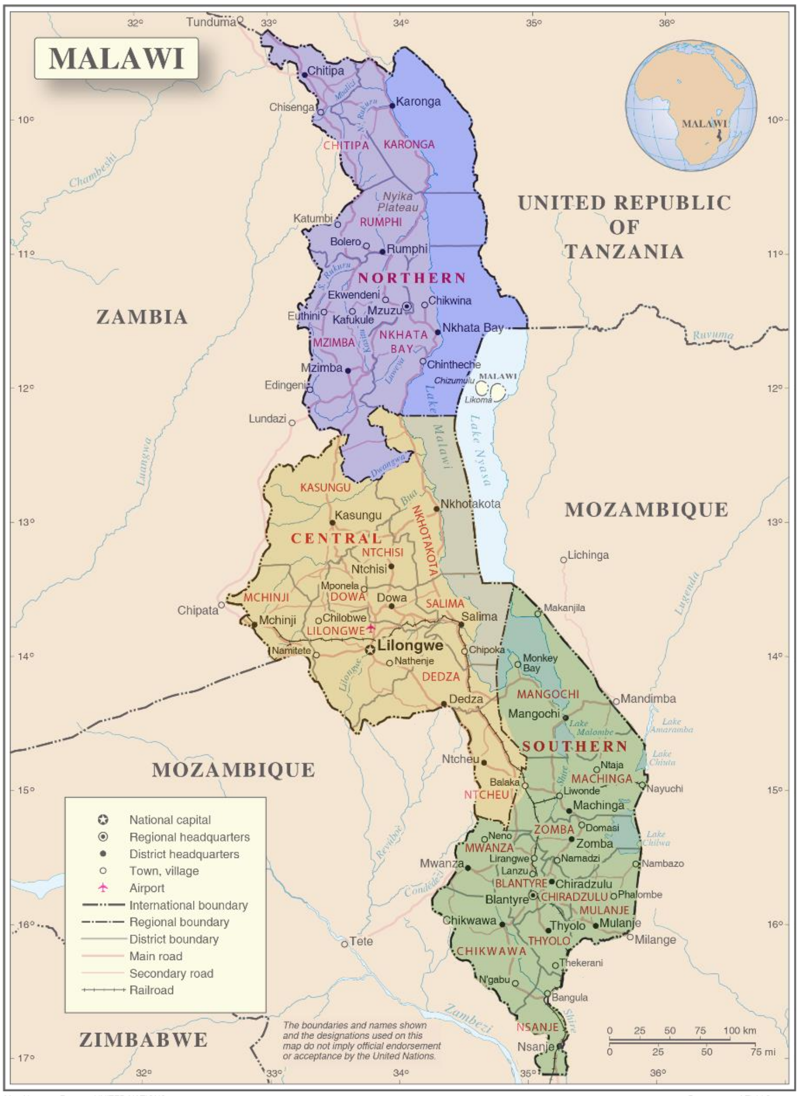
New = less than 2 years old

Established = 2+ years old

	District 1 (D1)	**District 2 (D2)**	**District 3 (D3)**	**District 4 (D4)**	**FEDOMA Headquarters (HQ)**
Location	**Southern Region**	**Northern Region**	**Central Region**	**Urban Centre**	**Southern Region**
Establishment status	**Established**	**Established**	**New**	**Established**	**N/A**
Financial support for DDF	**Yes (FEDOMA)**	**Yes (Private patron)**	**No**	**Yes (FEDOMA)**	**N/A**
Number of interviews conducted	**6**	**7**	**6**	**3**	**3 (managers)** **5 (staff)**

I also interviewed FEDOMA staff at HQ in Blantyre (Table 2) and engaged in further participant observation at FEDOMA headquarter.

Figure 2 below shows Malawi's three regions: Northern, Central, and Southern. The Northern region is the most sparsely populated and many areas are particularly deprived. The Central district is home to the country's capital, Lilongwe. The Southern district has Blantyre, Malawi's other large city; FEDOMA HQ is in Blantyre, so during my fieldwork Blantyre served as my home-city and base of operations. During my first visit, I stayed in Blantyre and travelled to surrounding districts in the Southern region with FEDOMA staff for project events. I did not visit the Central or Northern regions during that trip.



Map No. 3858 Rev. 4 UNITED NATIONS
April 2012

Department of Field Support
Cartographic Section

Figure 2. Map of Malawi showing its three regions. Based on UN Map no. 3858 Rev. 4, April 2012.

Key: Green = Southern Region; Yellow = Central Region; Blue = Northern Region.

During Stage 2 fieldwork, I again used Blantyre as a base of operations during my time at FEDOMA's HQ and for Southern district interviews and participant observation. I then went on an extended 'road trip' with a translator/research assistant/guide, James Elijah, to the other study sites, travelling to the Northern region and working my way back down the country to Blantyre.

3.2.2 Participant recruitment

I recruited participants from the membership of the DDF in each study site, through the internal DDF leadership. I conducted interviews with DDF leadership in all four districts, as well as with non-leadership members of the DDFs in D2 and D3. In D1, I engaged in a group discussion with several non-leadership DDF members after the formal interviews; data from this discussion was included in my participant observation field notes. (The conversation was not recorded.) I recruited FEDOMA staff and management interviewees at the end of the data collection from FEDOMA HQ in Blantyre, including one interview with a visiting staff member based in Lilongwe. I conducted staff interviews by myself, in English.

Initial contact with the DDFs was facilitated by the FEDOMA secretary, and an arrival date in each district and meeting with a contact person was arranged. In most of the districts, interviews were pre-scheduled for a number of participants via the contact person. However, in practice, communication and coordination difficulties meant that updated interview arrangements were made upon arrival in each district. Most of the interviews in each district were conducted in a central location suggested by the DDF members. Due to the difficulties of travel around Malawi, however, in some cases we travelled to a secondary location suggested by a particular interviewee. Having James as a guide was critical to my ability to find these locations, as they were often in remote villages without formal signposting or access, as seen in the photographs labelled Image 2.

Image 2. Photographs of a remote interview location in D3. The top and middle photographs show the area surrounding the location and the lack of access roads and signposting. The bottom photograph shows the interview location.

Arranging the interviews proved to have different challenges in each district, particularly when working through an intermediary. For D1, we attempted to set an interview schedule in advance, aided by the FEDOMA secretary. The interviews took place in a meeting room in D1's central hospital, where the DDF sometimes met. On the day of the interviews, the entire group of participants arrived at once, leading to a group decision that individuals would wait there for their turn. However, this proved to be uncomfortable as time passed, and we determined to encourage groups not to arrive all at once for future interviews. In D2, the DDF was planning a meeting, and given the difficulties of travelling across the district for members, the interviews were set for the day of the meeting. Again, the group decided to gather at once, though in this case the DDF had a meeting space of their own. The comfort of their own space combined with the planned meeting activities and cooler weather meant participants in D2 who were waiting were more comfortable. Upon arrival in D3, we discovered that we had been given contact information for one of the DPOs and not for the DDF. However, these groups are well-connected in this district, and we were able to obtain the correct contact information from the DPO's representative on the DDF. As a result of this setback, we determined that it was more time-efficient to travel to meet the DDF members individually, as they had not scheduled time in advance to meet with us. We did interviews at members' places of work, family homes, and in the common area of the lodge in which James and I were staying. In D4, we interviewed DDF members at a FEDOMA-provided office, and participants arrived one at a time during their scheduled interview time. Ultimately, there were logistical challenges in every district, but this proved to be an experiential learning process of the realities of scheduling and travel across Malawi. By the end of data collection, I noticed my initially rigid mindset regarding scheduling had shifted, reflecting some of what I had seen from FEDOMA and DDF members, enhancing my ability to problem-solve in-situ and understanding that those around me were well-aware of the potential issues and willing to adapt as needed.

I conducted a total of 30 interviews with DDF members and FEDOMA staff and management. Informed consent was sought from all interviewees, as well as district officials spoken with and participants in participant observation activities, as outlined in the (English and Chichewa) consent forms and procedures in

Appendix C. In keeping with the participants' roles as activists who may want their ideas and stories to be connected to them, participants were given the option of their real names or a pseudonym being used in this thesis. About half chose a pseudonym, while the other half chose to be identified by their own names. Tables 3 and 4 below provide demographic information about interviewees.

Table 3. Demographic information on DDF interviewees.

Interview No.	Name (* denotes pseudonym)	District No./HQ	DDF Position	Gender	Impairment/ Carer	Interview Language (Primary)
1	Mallory*	1	Chair	Female	Albinism	English
2	Saba*	1	Vice Chair	Female	Blind	Chichewa
3	Innocent	1	Member/ ADF Chair	Male	Deaf	Sign Language/ Chichewa
4	Kingsley	1	Secretary	Male	Physical	Chichewa
5	Leo*	1	Treasurer	Male	Physical (wheelchair user)	Chichewa
6	Duncan	1	Vice Secretary	Male	Physical (wheelchair user)	Chichewa
7	Ireen	2	Vice Chair	Female	Physical (wheelchair user)	Chichewa
8	Milo*	2	Member	Male	Blind	English
9	Emma*	2	Member	Female	Epilepsy	Chichewa
10	McDwellings	2	Chair	Male	Physical	English

Interview No.	Name (* denotes pseudonym)	District No./HQ	DDF Position	Gender	Impairment/ Carer	Interview Language (Primary)
11	Elena*	2	Member/ Area Development Committee Rep.	Female	Physical	Chichewa
12	Arnold	2	Secretary	Male	Visual/ Partial blindness	English
13	Lyness	2	Treasurer	Female	Physical	Chichewa
14	Felida	3	Member	Female	Carer	Chichewa
15	Ishmael	3	Vice Secretary	Male	Visual/ Deaf	English
16	Doreen	3	Treasurer	Female	Deaf	Sign Language/ English
17	Taonga	3	Vice Chair	Male	Albinism	Chichewa
18	Ester	3	Chair	Female	Blind	Chichewa
19	Rhodah	3	Secretary	Female	Physical (wheelchair user)	English
20	Charles	4	Treasurer	Male	Physical (wheelchair user)	English
21	Lonely	4	Secretary	Female	Carer	English
22	Grace	4	Chair	Female	Physical	Chichewa

Table 4. Demographic information on FEDOMA HQ interviewees.

Interview No.	Name (* denotes pseudonym)	Staff/ Management	Gender	Impairment	Interview Language
23	Eva*	Staff	Female	Physical	English
24	Martin	Staff	Male	N/A	English
25	Simon	Management	Male	Visual/ Partial blindness	English
26	Nora*	Management	Female	N/A	English
27	Cecilia	Staff	Female	N/A	English
28	Action	Management	Male	Epilepsy	English
29	Phyllomina	Staff	Female	N/A	English
30	George	Staff	Male	N/A	English

3.2.3 In-depth interviews

In-depth interviews enabled me to speak to DDF members about their experiences and opinions. The interviews were conducted in a semi-structured fashion, to let DDF stories drive the focus of the interviews – maintaining the participatory ethos of the project, while still engaging with the important themes developed in the design phase, ensuring comparability of the interviews. The interview guide was based on the work I undertook in Stage 1, through coding of my notes and autoethnography, discussions with Action Amos at FEDOMA about what I had experienced, and Action's experiences and knowledge. FEDOMA staff assisted in preparation of the data collection materials by translating the participant information sheets and consent forms.

At the start of each interview, there was a process of establishing rapport and informed consent. This pre-interview consisted of a greeting, introductions of the researcher and translator/research assistant, an offer of refreshment, briefing about the project, and a formal ethical consent procedure. Participants were encouraged to ask questions about the consent forms and project, and the consent forms were explained and re-read by myself and James (the translator/research assistant) as many times as necessary for the participant's understanding and comfort. The interview consisted of 6 sections: (i) introduction (participants were asked to introduce themselves however they saw fit); (ii) advocacy (questions about participants' work with their DPO, DDF, and FEDOMA and their feelings about the same); (iii) voice (questions about participants' definitions and experiences of voice within the DDF and FEDOMA); (iv) reporting pilot (questions about whether using mobile phones could help communication between FEDOMA and the DDFs); (v) additional background (specific questions about participants' background and socio-demographics); (vi) the rest (open-ended questions asking if there are other things participants want me, FEDOMA, or broader audiences to know). The questions within each section were kept purposely broad and open-ended, enabling the interview to achieve a more conversational flow and the participants to lead the discussion, speaking as much or as little as they desired. Socio-demographic questions were asked at the end (where necessary) to allow participants' descriptions of themselves and their lives to develop as organically as possible throughout the interview. The interviews were followed by a participant debrief (including review of rights and consent procedures), and a farewell and thanks. A slightly altered version of the interview guide was used during interviews with FEDOMA staff and management, to engage them in conversations about their own activities as well as those of the DDFs with which they work.

3.2.3.1 Translation

I travelled to each district with a translator/research assistant, James, who had done contract work for FEDOMA previously, though not in a research capacity. James translated during interviews where participants did not speak English or preferred to speak Chichewa. Two of the interview participants spoke using sign language and brought an interpreter that they were comfortable with to their interviews. In one of these interviews, the preferred interpreter was a professional, whom I paid for their work; in the other, the preferred interpreter was a personal acquaintance of the participant. The professional interpreter spoke

English. The personal acquaintance interpreter spoke Chichewa and James translated her interpretations. James also acted as a chaperone[24] and guide throughout data collection.

During early interviews, a rapport and style had to be built between myself and James. James asked questions about meaning and helped develop clarifications for participants – actively altering instances of overly neo-colonial, 'researcher' language in the interview guide. We also worked through issues around direct translation, use of first vs. second-person language, and shortening of responses. I listened closely to the participant's responses in Chichewa, comparing lengths and asking questions if I felt there may have been truncation of the response in James' translation. I was assisted in this by the fact that most Malawians have at least some understanding of English. Participant body language, nodding along with translations, and interjections all assisted in assessing the translations. As all of the Chichewa-language interviews were video recorded, I was also able to return to the recordings for signposting. This type of engagement is part of the process of knowledge creation within an interview setting – highlighting translators as non-neutral and vital to that process (Temple and Edwards, 2002; Berman and Tyyskä, 2011). Throughout fieldwork, James interacted with, responded to, and empathised with participants as much as I did. He also gained an understanding and appreciation for the movement for disability rights in Malawi (FNs, 2018/19). James' "insider knowledge" (Berman and Tyyskä , 2011) helped us to find study locations, engage with participants, and explain the project and consent procedures in accessible ways.

Engaging a translator enabled some participants who spoke English to choose to speak in their native tongue – emphasising their resistance to engaging in a language of oppressors. Grace (D4) said as much before her interview, expressing pride in speaking her own language; she offered this as a challenge to me, the researcher, as someone who might attempt to pressure her into speaking in English. I did not, and Grace enthusiastically carried on with the interview (FNs, 2018/19). On the other hand, some participants, such as

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[24] The original plan involved my employing a woman student from the university as a research assistant. However, it was decided that it would not be safe for two women to travel alone together, especially with one a foreigner. The research budget could not accommodate hiring more than one research assistant, so James, a man, was hired.

Charles (D4) were eager to converse in English, demonstrating their education and status. In this way, the complexities of navigating research power dynamics through modes of discourse were highlighted during data collection. I provide a broader consideration of power dynamics within the research setting in Section 3.2.5, on fieldwork ethics.

Interpretation and translation are critically important aspects of research, particularly when the researcher does not speak participants' primary language. The act of translation is always an act of interpretation, impacting the data collected – particularly in a project centred on voice. This introduces an additional order of distance between what the speaker says and what the researcher works with as data. Keeping this in mind is important for considering the biases and alterations that may have been introduced into data during the translation process. It also highlights Spivak's (1988) point about the language of oppressors used in research and the impossibility of representing 'authentic' voices.

While true authenticity may be an impossibility in a research setting (particularly one involving translation), I attempted to represent the 'voices' of participants as accurately as possible. One of the ways in which I did this was by not 'cleaning up' the language used in quotes. Malawians' vernacular English is as valid a version of English as any other. By not changing their language for one which would be considered more grammatically correct in my home context, I attempted to engage with participants' evolution of English into a language of their own. This is particularly important for work with persons with disabilities in the majority-world, whose voices are often excluded from the mainstream (Mji et al., 2014). I used the video recordings of interviews to match the rhythm of the original speech to the translations where possible. I was aided in this by the similarities in speech patterns between Chichewa and Malawian English. For example, a call-and-response rhythm is used in both, as seen in some of the quotes included in this thesis. Maintaining this cadence was an example of presenting quotations in a way that is "guided by the *principle* of authenticity" (Lingard, 2019, p. 360) (emphasis added), while understanding true authenticity as unachievable, and pushing back against the idea that 'imperfect' vernaculars of the English-language are less believable, intellectual, or worthy of print.

3.2.4 Participant observation

I engaged in participant observation in each district and at FEDOMA HQ. Engaging in participant observation and interviews allowed me to draw on both what I was told and what I *observed* in the analysis. Denzin and Lincoln (2000) discuss the use of multiple qualitative methods as "an alternative to validation. The combination of multiple methodological practices, empirical materials, perspectives… in a single study is best understood… as a strategy that adds rigour, breadth, complexity, richness and depth to any inquiry" (p. 5). I used Spradley's (1980) "Descriptive Question Matrix" to guide my participant observation activities (Appendix B), due to its inclusion of less physical aspects of observation, such as "goals" and "feelings". I also drew on the observational categories outlined in Family Health International's field guide to qualitative research methods, which include appearance, verbal behaviour, physical behaviour and gestures, personal space, human traffic, and people who stand out (Mack et al., 2005).

When the DDFs had activities planned during my time in the district, I asked to observe and participate. If there were no activities already planned, we were able to agree on key areas and individuals to meet with the DDF members upon our arrival in the district. I joined grassroots advocates in some of their activities, allowing me to experience first-hand their work and contributing an outsider's perspective to the story. These activities included DDF meetings, visits to persons with disabilities in the community, informal group discussions, meetings with district officials (and visits to their respective offices, district hospitals, and schools), tours of the districts, and FEDOMA events [including the International Day of Persons with Disabilities (IDoPD) celebrations]. I took extensive notes during these activities and had a translator (James in the districts and a FEDOMA staff member at FEDOMA events) when necessary for events and activities undertaken in Chichewa.

At least one meeting and/or conversation was conducted with officials (of varying levels of authority) in each district, as FEDOMA personnel (and often, DDF members) felt it was also important for me to become acquainted with authoritative stakeholders in the districts and the central government. Upon our arrival in each district, we sought contact information for district officials from the DDF membership. In some cases, where the DDF members did not have this contact information, we visited officials' offices in-person to arrange meetings. In cases where we were unable to speak with particular officials, the reason was usually that the official was out of town; only one official refused to speak to us despite being present in the district.[25]

This gave me context for what the activists do in their communities and the forces with which they must engage to advance their cause. It also provided insight into the marginalisation of people with disabilities, in that some spaces were in fact easier for them to occupy with the presence of an outside researcher. For example, in one district, the DDF members had never met the District Health Officer (DHO) or District Education Manager (DEM) before we went to meet with them. They used my presence as an 'higher-status' (or at least, foreign, Western) guest to get a foot in the door. Previously, they had planned to hold those meetings but had either been unable or unsure of themselves in actually setting them. In this way, engaging in the research project also seemed to open certain doors for participants.

3.2.5 Data recording and storage

I recorded each interview on multiple devices and made copies of recordings at the end of each day of interviews. During the consent procedure, participants were asked for permission to record. 29 interviewees agreed to video recording, while 1 agreed to audio-only recording. A phone on a tabletop tripod was used for most recordings, with a tablet as back-up. I also took notes by hand during all interviews. Field notes were recorded on a phone or in a notebook during visits to the districts, with additional field notes made using a

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[25] This official believed we should have contacted their office before ever setting foot in the district, despite the volatility of our travel timeline – an example of the importance of formal (neopatrimonial) practices in some Malawian contexts.

computer, after the cessation of the day's activity. For participant observation at FEDOMA HQ, field notes were recorded on the computer, supplemented by handwritten and phone-based field notes when the computer was not accessible. I transcribed interviews by hand, beginning during fieldwork and completing the transcriptions upon my return to Scotland. Consent forms and all data materials were stored according to the procedures outlined in the documents in Appendix C.

3.2.6 Ethics 2: Ethics in fieldwork

Throughout Stage 2, I continued to engage in reflexive practice and autoethnography – both during data collection and analysis. During data collection, I used autoethnography to respond to challenges in the field – for example, to consider how the ways in which we set up interviews impacted participants and what changes needed to be made to ensure as smooth and comfortable a process as possible. It also helped me to work through personal challenges during fieldwork – such as participants saying things which I found insulting or which challenged my identity. As a result, when coming to the analysis, I was able to reflect on whether I could be 'fair' and 'objective' in presenting results. For example, highlighting stories from participants who had insulted me – recognising that my own positionality gave me power over the representation of their words and approaching this in as professional a manner as possible. This approach helped me in reflecting on the ethical issues involved in the research process as well.

Beyond the institutional ethics discussed previously, there were a number of important ethical considerations to work through in conducting fieldwork. Research with human participants necessitates a duty of confidentiality and care for participants. In research with persons with disabilities, this must be tempered with respect for individuals and reasonable accommodation without essentialising or infantilising participants. Murray (2019) highlights this as a tension between the well-being of participants with disabilities and their exclusion from research due to "protectionism". Additionally, research in low-resource settings adds to and complicates in-situ ethical considerations. For example, research with persons with disabilities required ensuring that research activities were undertaken in sites that were as accessible as possible – for a variety of impairments – a particular challenge considering Malawi's infrastructural issues. In most cases, research participants suggested the location for the interviews and participant observation activities. This also required flexibility with timing and interview settings; we attempted to place the onus of travel on myself and James as much as possible, as we had access to a car. In some cases, we travelled to participants' homes and workplaces, used our car as transportation for participants, or provided funds for transportation. We provided drinks and snacks to participants – both to make the experience more comfortable and to adhere to expectations and procedures of Malawian and FEDOMA gatherings. We were not always successful in providing a comfortable environment – for example, as discussed above, the challenges in D1 around the wait-times for interviews. In these cases, I apologised for inconveniences and discomfort, attempted to correct the situation, both within that setting and in the future within others, and used these experiences to develop my 'toolkit' for practicalities of ethical research in the Malawian setting. Other ethical considerations included simple adjustments, such as using the preferred, identity-first language of Malawian disability advocates – I am accustomed to using the term 'disabled persons/people' in minority-world DRM parlance, but in Malawi, the preferred terminology is 'persons with disabilities'. Morris (2001) highlighted the importance of language in disability studies in a piece highlighting the social model's emphasis on "impairment" as separate from "disability": "To pay attention to the words we use is… to struggle for a language which describes the denial of our human rights, locates our experience of inequality as a civil rights issue, and, at the same time, creates a space to articulate our experience of our bodies" (p. 2). Malawian disability advocates choose to use person-first language as a way to emphasise their personhood, something which is at times denied within their communities (FNs, 2018/19).

This research also required a consideration of culture and the impacts of colonialism and neo-colonialism in the research setting (Grech, 2012). In the case of my research, this involved challenges to my identity which created an association between my embodied presentation and white European colonisers that was especially difficult for me to contend with. At the same time, I had to develop an awareness of my positionality and what I represented as a minority-world, English-speaking figure in the Malawian setting. To some extent, this ethical consideration is more about dampening personal reactions, hearing and listening to participants' concerns, and attempting to demonstrate respect. For example, I learned basic Chichewa phrases, adhered to Malawian customs for greeting members of a group, and wore chitenje, skirts instead of trousers, and shirts which covered my tattoos during fieldwork. Through this, I demonstrated respect for Malawian customs – participants picked up on and commented positively on these adjustments. It also helped me demonstrate my interest in learning about their lives, experiences, and culture – which grassroots advocates enthusiastically shared with me during participant observation activities. At the same time, my role was questioned and challenged within the research setting: participants asked what the research would do for them, discussed past troubles with researchers, and asked questions about my own personal life. Berghs (2010), discusses similar experiences conducting disability research in Sierra Leone, highlighting how the research encounter is coloured by previous experience, particularly negative experiences with exploitation by minority-world researchers. I attempted to answer questions as honestly as possible; in the case of previous negative experiences, I listened to their stories and validated their concerns, attempting to ensure that the research setting I created with participants mitigated their concerns as much as was physically possible.

Both research with persons with disabilities and research in majority-world countries requires a consideration of power differentials within research settings (Proctor, 2001). As a minority-world researcher, I was afforded a level of respect that I had not earned through a practical demonstration of skills. I was also considered white and assumed to be wealthy, which would traditionally afford me authority and power 'over' participants. I attempted to counter this narrative by ensuring participants were aware of their rights and knew they had the power to end the proceedings at any time. Furthermore, I tried to make it clear that I was there to learn from the grassroots advocates as the experts. Particularly in research with individuals with intellectual disabilities, ethical issues arise around an "assumption of incompetence" (Mckenzie and Macleod, 2012, p. 17). Similarly, persons with a broad range of disabilities in countries like Malawi are considered 'incompetent' victims; they do not fit the mainstream, established image of disability activists. This perception contributes to the perpetuation of historical views of disability and persons with disabilities as less than, "as painful reminders of the 'frailty', vulnerability, mortality and arbitrariness of human experience, rendering responses of fear… defining people with disabilities as ‘different’ and other” (Mji et al., 2014, p. 715). In this project, I attempted to position participants as the experts and thought of and referred to them as such in the field. In most cases, confidence in their abilities as organisers seemed to help reinforce their expert position. My power (and perceptions of my power) was also dampened by my presenting as a younger woman, a traditionally less powerful position. The presence of James as a translator may also have contributed to an equalising of power, emphasising that I required an escort to travel through the districts and could not speak their language – requiring assistance to understand what they said. James, on the other hand, may have been perceived to have a level of power greater than some of the (especially) younger women participants as a man. His general demeanour of friendliness, and status as an ‘everyday’ Malawian, may have contributed to balancing this. For both James and I, our association with FEDOMA helped us to gain access and build trust with participants. At the same time, the fact that neither of us were directly employed by FEDOMA, and that we were able to provide anonymity for participants who desired it, enabled participants to raise their issues with the organisation to us, seemingly without fear of reprisal. When participants did raise issues with the research setting, asked not to answer questions, requested clarifications or other needs, we were able to address them in-situ. However, it is important to note that there may have been feelings of discomfort that the participants did not express to us at the time, and as a result there may have been missed impacts of the power dynamics within the research setting.

3.2.7 Data Analysis

I applied an inductive, grounded-theory approach to data coding (Basit, 2003). I chose this approach to draw key areas for analysis from participants’ stories, in an attempt to ensure the analysis was “grounded in the views of the participants” (Hartley and Muhit, 2003, p. 105). Part of my approach to mitigating against my researcher’s voice over-shadowing participants’ (to the extent that this is even possible within a research setting) was to engage with the data without a preconceived set of codes. This also enabled me to focus on what the DDF members said about their relationship with FEDOMA, their priorities for the future, and the challenges they face, without attempting to fit their experiences into predetermined categories.

All field notes, interview recordings, interview transcripts, and autoethnographic/reflexive accounts were loaded into two separate NVivo projects. The first NVivo project contained the field notes I used to develop the autoethnography during Stage 1. I kept field notes, transcripts, interview recordings, and Stage 2 autoethnographic/reflexive accounts separate, creating a second NVivo project. Using NVivo, I created 'cases' for each interview participant, each DDF as a collective, and FEDOMA HQ, enabling me to connect participant observation materials/field notes and interviews for each interviewee.

I conducted several 'rounds' of coding and analysis on the Stage 2 data. The first two rounds were conducted in NVivo, resulting in a set of 50 codes. The codes covered a range of thematic material discussed in interviews, including voice, awareness of rights, DDF challenges, DDF priorities, connection to local or remote areas, and personal stories. There were also codes that referred to the relationships between grassroots groups and the DDFs, including FEDOMA ideology and internal conflict. Discussions with my supervision team about findings led to the identification of structuration theory as a potentially useful starting point for developing the analysis and connecting it to the literature. Using structuration theory as a basic scaffolding for analysing the data, I drew out the key themes, examples, and analysis for the thesis using coding reports and NVivo query functions. I then created codes related to structuration theory, such as rules, resources, and structures, to further interrogate its applicability to the data. During data analysis, I read and drew on a wide range of academic literatures to help me to understand and engage with various findings from the analysis. I conducted an extensive final round of coding while writing initial drafts of each thesis chapter. This was done using large sheets of A1 paper, colour coding codes, and diagramming connections between themes and data sources. I continued refining the analysis and integrating literature throughout the process of drafting and revising the thesis.

Throughout the process of data analysis, I continued to engage with autoethnography and reflexive accounts, considering why I was making the analysis choices I did, how this changed the 'story' of the thesis, and what alternative approaches might be missed. This was particularly important during the selection of key analysis areas to include in the thesis. For example, I had not planned a full chapter on the experiences of women (Chapter 7). This focus developed out of its clear importance during data collection, coding, and analysis, based on the direction participants steered the conversation. At the same time, I acknowledge that writing a thesis is ultimately a solitary endeavour, and it is my voice – through my interpretations of others' voices, that is presented most strongly throughout this thesis, despite attempts to centre the voices of Malawi's disability rights activists.

3.3 MOBILE REPORTING PILOT AND REPORT FOR FEDOMA

As part of my interviews, I also conducted a 'pre-pilot' on a proposed formal mobile phone reporting system for FEDOMA. FEDOMA was considering implementing this system to facilitate communication between HQ and the districts. This reporting system was seen by FEDOMA management as a way for them to quickly receive updates from the grassroots, chase reports and paperwork, and generally check-in with the DDFs. They also saw it as a way for the DDFs to report time-sensitive matters and ask for and receive support more quickly. The need for a faster method of communication between the DDFs and FEDOMA was something that came up during my Stage 1 fieldwork, particularly during my visits with a DDF. Issues of communication are intrinsically tied to the broader research questions of voice within the organisation, which led to the decision to include this pre-pilot in the research project.

The pre-pilot was intended to engage grassroots advocates in the conversation around whether FEDOMA should consider implementing such a programme (which would likely go through another, practical pilot phase if implemented). During interviews, I explained what the FEDOMA staff and management envisioned for such a programme and asked for comment. I asked the DDF members for their thoughts on the utility of a mobile reporting system, what implementation would require, whether they thought their group would engage with it, and if they had any suggestions for developing the project, if FEDOMA decided to continue with it. I also asked these questions of all the FEDOMA staff and management personnel interviewed. I aggregated the responses into a report for FEDOMA, providing a baseline analysis of common opinions, suggestions, and proposed equipment requirements.

In addition to the results of the pre-pilot, I provided FEDOMA with a report[26] relaying some of the initial findings with regard to participants' feelings about their relationship(s) with FEDOMA and whether their voices were heard within the organisation. I also forwarded suggestions and priorities raised by the advocates for the future of the movement and any specific suggestions raised for the five-year plan. While FEDOMA management was aware of the districts I visited, I anonymised the identities (including name and DDF role) of participants in the report. This report was the first output completed from the PhD and was sent to FEDOMA before commencement of the writing of this thesis, due to the time constraint of FEDOMA's five-year plan development process.

3.4 CONCLUSION

The experience of designing and executing this research project helped me to investigate my first research question, exploring not just the use of participatory methods in conducting research with activists in majority-world contexts, but also the ways in which participatory action research, autoethnography, participant observation, and in-depth interviewing can work together. I sought genuine co-production of the project design to identify key issues for research which contribute to the movement for disability rights in Malawi. PAR and autoethnography helped to generate more relevant and participant focused research foci, and therefore data and findings. Autoethnography also enabled me to empathise with participants and consider ways to cross over differences in the field. As a result of offering my time and expertise to FEDOMA to pursue practical projects of interest to them, such as the mobile reporting pilot, I was able to build deep and reciprocal working relationships. These relationships in turn resulted in my gaining key access to

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[26] See Appendix C for a copy of the report.

FEDOMA spaces, meetings, and resources which improved the project. It also represented an ethics of care and collaboration that meant the research was not just exploitative, though in some ways all research arguably is, but also had positive benefits. These benefits were made clear in the process of doing the research and not just in the findings and outcomes. The report for FEDOMA, as well as the analysis in this thesis were developed as an extension of this participatory, activist-researcher ethos.

4 FINDINGS 1: STRUCTURATION THEORY, MALAWIAN SOCIO-POLITICAL AND ECONOMIC STRUCTURES, AND THE HISTORY OF FEDOMA

In this chapter, I discuss how disability advocates have contributed to altering Malawian legal structures (RQ3), touching on the historical [pre-fieldwork] circumstances in which FEDOMA activists used voice as a resource (RQ2b), as a starting point for this thesis' consideration of voice within and outwith FEDOMA (RQ2; RQ3a). An extended example - Simon's (FEDOMA HQ) story, contributes to the discussion of constraining and enabling schemas for advocacy; it also sets up a useful contrast between the approaches of (formerly-grassroots) advocates within FEDOMA management and those at the grassroots today, which I explore further in Chapter 6.

Structuration theory can be used to discuss FEDOMA's history and organisational structure and the role played by its members in shaping the organisation as it stands today. It can also be used to explore the reciprocal impacts of FEDOMA-as-actor on Malawian cultural and legal structures and vice-versa. The exploration undertaken in this chapter is situated within the historical development of Malawian socio-political and economic structures discussed in the introduction. These structures impact persons with disabilities and disability advocates today. In this chapter, accounts of disability rights legislation in Malawi and FEDOMA's organisational history contextualise the ways in which they mutually constitute one another over time. I also analyse an individual advocates' personal history within the DRM to explore the evolution of disability rights in Malawi from an agent's perspective. This chapter addresses the question of how grassroots advocates in Malawi reproduced and altered structures and developed FEDOMA and the disability rights context within which I conducted fieldwork. It provides a first glimpse into the internal dynamics of FEDOMA, especially those which help explain the development of FEDOMA's own systems over time. This provides the necessary background to discuss (in later chapters) the systemic structures which impact voice and communication within and outwith FEDOMA today.

4.1 DISABILITY LEGISLATION IN MALAWI

In this section, I discuss key legislative changes over time which impact disability rights in Malawi. Structuration theory highlights the piecemeal altering of societal structures. Governance structures, including politics and legislation, reflect and mutually constitute cultural ones. Impacts to one are intertwined with impacts to the others, which Malawian disability rights advocates use as a resource in their work. Similarly, the interaction of systems is critical to the development of any individual system. This can be seen in Malawi's complex modern system, emphasising the intermixing over time of pre-colonial cultural structures with those imposed by colonialism, the post-colonial rule of Dr Hastings Banda, and on-going neo-colonial capitalist development. The development of Malawi's hybridity over time is reflected in governance that attempts to reconcile ever-evolving cultural structures within Malawi with the broader inter-systemic structures which impact its development within the international community.

The overall trend in Malawi's disability rights legislation over the last several decades has been government consideration and passage of legislation, without much action on implementation. These legislative changes provide an example of inter-systemic structuration. The timeline in Figure 3 below details legislative milestones which impact Malawi's DRM.

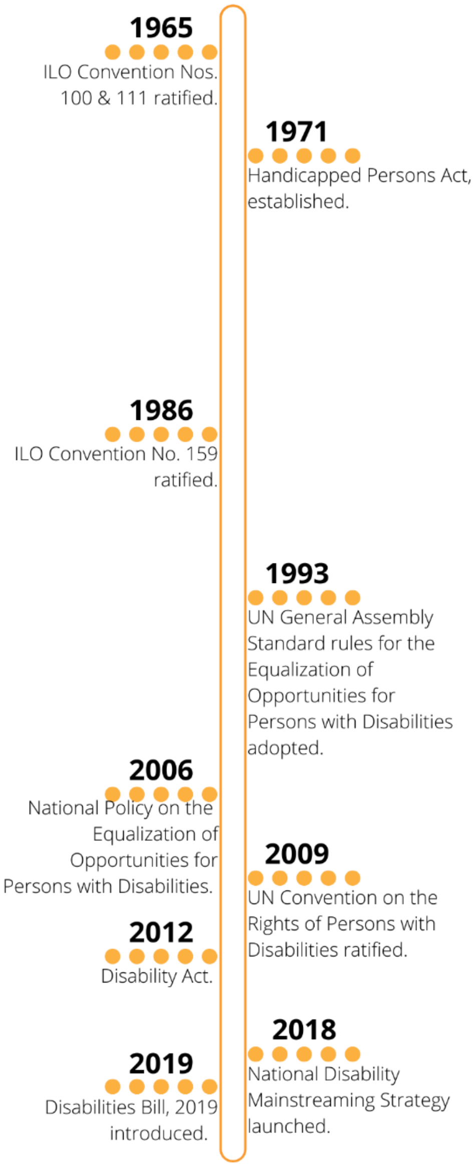

Figure 3. Timelines of legislation relevant to Malawi's disability rights movement. *Sources: Handicapped Persons Act 1971; International Labour Organization, 2007b; Act No. 8 of 2012; International Labour Organization, 2017; United Nations, 2019; National Policy on Equalisation of Opportunities for Persons with Disabilities; United Nations, n.d.b; Field Notes, 2017, 2018/19.*

As Malawi has sought membership in international systems, national leaders have passed human rights legislation to demonstrate their progress to the international community. The ratification of ILO and UNCRPD conventions proclaimed Malawi’s commitment to equal employment opportunity, reasonable accommodation, and disability human rights, though action on implementing these commitments has lagged. The Handicapped Persons Act formed the Malawi Council for the Handicapped (MACOHA), a quasi-governmental organisation that is tasked with implementation of (the limited available) government programming for persons with disabilities, e.g., vocational training. The 2012 Disability Act formalised Malawi's commitment to the human rights of persons with disabilities (as set out in the UNCRPD) and included provisions for the development of a Disability Trust Fund, requirements for new buildings to be accessible, and promoting the economic and social inclusion of persons with disabilities, for example. Widespread implementation of the Act's provisions is still lacking. As of the writing of this thesis, for example, implementation of the Disability Trust Fund has yet to be achieved. The 2018 National Disability Mainstreaming Strategy provided guidance on how institutions could incorporate codified disability rights into practice.

Haang'andu (2020) notes that the passage of this kind of legislation and policy may be a form of posturing toward dominant global powers. As a result, legislation exists but is not wholly enacted "on-the-ground". This view may see international forums as the primary circuit of meaning for this legislation. However, these legal resources do also exist within Malawi's national system and can be used by activists with a vested interest in circulating new schematic conceptualisations of disability rights and working toward implementation. These laws are necessary but insufficient - they can enable structural conditions in which it is possible for persons with disabilities to become citizens but on their own, they are not enough. The continued development, production, and circulation of legal resources into schematic norms by advocates is part of a relational process through which activism effects change. Focusing entirely on the role of international norms in inducing legal change in Malawi also obfuscates the work of in-country disability activists in pushing for the same changes from the "bottom-up", helping justify leaders' assimilation of international standards of disability rights to the local populace. In the next section, I explore FEDOMA as an organisation and apply structuration theory to their role in the development of national disability legislation as well as to the workings of the organisation itself.

4.2 FEDOMA'S HISTORY AND RELATIONSHIP TO LEGISLATIVE CHANGE AND IMPLEMENTATION

FEDOMA was founded in 1999 (Chauluka and Chiumya, n.d.), when Malawi's DRM was gaining momentum and an organisation to unite the various DPOs[27] was deemed necessary by activists. In this case, disability activists needed to gain access to decision-making spaces in order to influence national policy. FEDOMA united previously disparate DPOs to push for nationwide change together as a larger collective. One of FEDOMA's founders, Musse Chiwala, served as its Executive Director (ED) until 2014. Under Chiwala, FEDOMA focused on establishing the legal frameworks necessary for persons with disabilities to demand their rights, particularly in pushing for the passage of the National Policy on the Equalisation of Opportunities for Persons with Disabilities. The grassroots agents who founded FEDOMA established its priorities and contributed to the initial FEDOMA system, focusing resources on passing legislation. Simon (HQ), (whose individual story follows), a member of FEDOMA's management, noted their work:

> *FEDOMA managed to advocate for the adoption of the Policy on Equalisation of Opportunities for Persons with Disabilities… we also successfully advocated for… Malawi's signing and ratification of the UN Convention on the Rights of Persons with Disabilities [UNCRPD]. We also successfully advocated for the Disability Act to be in place… But, with all those kinds of achievements, what was noted, with the current… structure of governance, because we'd been influencing much at the national level. Going to the district level, where… much of the implementation is taking place, there was no real visibility of FEDOMA.*

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[27] Limited data is available on when DPOs first emerged in Malawi, but FEDOMA's 'oldest' member (according to available evidence) is Malawi National Association of the Deaf (MANAD), established in 1992 (MANAD, 2012).

FEDOMA as an organisation was partially credited with the passage of the Disability Act, signed into law in 2012, after its agent-constituents spent over a decade advocating for the legislation. Following the passage of the Act, as noted by Simon, the priorities of agents within FEDOMA shifted, resulting in a change in focus to its internal system, directing resources towards implementation of the Act's provisions. This example demonstrates the relationality inherent to structuration processes. Malawi's previous cultural, political, and economic structures constrained persons with disabilities to the point where agents decided to start a rights-movement. Inter-systemic resources such as the UNCRPD helped them to make changes to the national system. The creation of the legislation agents pushed for then became a resource to enable activists to work for the tangible implementation of rights, i.e., inclusive schooling, inclusion in subsidies. In this case, agents' expressions of agency contributed to the constitution of resources they could use.

FEDOMA's shift in focus, however, also required a change to its systemic structure. In the quote above, Simon notes the governance structure as a constraint to FEDOMA's influence on implementation. Up until the passage of the Disability Act, most of FEDOMA's work had been focused at a national scale. In monitoring implementation, however, district-level information was necessary, because Malawi's 1998 Local Government Act had dispersed responsibility for implementation of national-level policies to the district government scale. In 2014-2015, under ED Action Amos, FEDOMA's developed the District Disability Forums (DDFs) in response to this challenge (Int28). According to interviewees at FEDOMA HQ, DDFs became a critical structure in FEDOMA's activities, allowing the central office to gain access to information about what provisions of the Disability Act were being carried out by district governments (Int25, 28). The creation of the DDFs is thus an example of FEDOMA agents responding to an altering of schemas to which they contributed.

While FEDOMA had to change its organisational structure in response to the constraint of the Local Government Act, the new DDFs *also enable* FEDOMA's central office to much more closely monitor the implementation of national policy by various branches of local government. This is an example of schemas being both constraining *and* enabling; the latter being a critical aspect of structuration which Giddens (1984) suggests is at times overlooked. The enabling or constraining properties of a given schema will change based on the point in space and time in which it becomes relevant.

The restructuring of the organisation impacted the work of agents within FEDOMA's organisation and opened up space for new grassroots actors to join the movement. (Relationships between FEDOMA's "historical" and "newer" agents will inform parts of later discussions.) In the next section, I explore structuration using empirical data from my study, through the example of an individual agent and his experience within the DRM.

4.3 SIMON'S STORY: GRASSROOTS ADVOCATE TO FEDOMA MANAGEMENT

FEDOMA as an organisational actor is an amalgamation of individual agents, whose actions contribute the driving force behind organisational priorities. Over time, the organisational direction of FEDOMA has been driven by long-term members. These agents participated in FEDOMA's lobbying efforts in passing the Disability Act, and their roles in the organisation shifted with the success of their campaigns and the beginning of FEDOMA's current DDF-focused decentralisation process. One such agent, Simon, now holds a high-level position within FEDOMA. Simon's stories shed light on DRM operations, their significance in altering structures, and the role of individual agents within FEDOMA's development. Simon's shifting role also marks a transition from grassroots activism to a more bureaucratic organisation, which at times reflects the patronage and neopatrimonialism within broader society. Furthermore, his experiences as a grassroots advocate, based as they are in the past, colour his decision-making as a manager, setting up potential conflicts with today's grassroots membership.

Simon's account of his involvement in Malawi's DRM parallels the story of FEDOMA itself. The DDFs, while forming a part of FEDOMA's response to a structural constraint, are also themselves the brainchild of individuals engaged in processes of empowerment - both individual and collective - within the organisation. When we discuss things 'FEDOMA' did, what we are really capturing is collective agency. Individuals like Simon were part of the groundswell of individual disability activists who contributed to the power of FEDOMA through their exercise of agency.

In order to examine the complex interplay between individuals, collectives, and social movement organisations' structures, I present excerpts from Simon's interview that reflect how he impacts FEDOMA's agenda. I will first discuss the examples from the perspective of the individual, then complicate this perspective with discussions of broader structural factors. Simon currently holds a position within FEDOMA that allows him to set policies which directly impact the lives of grassroots members and the resources to which they have access. His past experiences, and the spaces he engaged with during his youth as a grassroots advocate, shape Simon's opinions on how disability advocacy should be undertaken. During his interview, Simon (HQ) revealed that FEDOMA sometimes sets up DDFs without providing any support or funding intentionally - as a tactical test of resilience and to see what they achieve on their own:

> *And some other times, deliberately you leave them. No giving them any money… so that you see how… passionate they are… Because you know… No one can cheat me because the time we were running the Student Union for the Blind, no one was giving us funding… No one was giving us funding! We had no funding.*

Simon continued with a personal story of his time as a youth activist, to underscore the point he was making about passion superseding the need for funding. In his own words:

> *It was our own pocket money. Taking the same money, we travelled, me and my friend [name redacted[28]] we go to Malawi National Examination Board… We meet the Executive Director there, and all the leaders there. The managers, and the directors. And I'm telling you, within a year or two, we had come out with very good results… We made an effort to meet the Minister of Education. We booked for an appointment. The Minister, he heard there are some other young men that are coming to meet you… And he arranged for all education stakeholders under the Ministry of Education to come to that meeting. That was the first time we had our transport paid for. Because the Minister said, "pay transport for these guys, book*

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[28] Now a high-ranking official in Malawi Union of the Blind (MUB).

> *accommodation for these guys" … When we were coming out of that, I will tell you: the Minister made a directive. That selection to secondary school for children - students with visual impairment, competition should be amongst themselves… At the same time, make sure you identify more secondary schools which should be open to children with visual impairment. Almost ten more schools were opened… As I am speaking now, we have at least a secondary school that is open to students with visual impairment… in each district… We didn't have funding. So… I say, no one can cheat me, that everything requires money…. You can still do something. Come up with results (Simon, HQ).*

Simon's personal experiences directly impact his contributions to organisational policy, in this case not automatically funding every DDF upon its founding, which in turn impacts the experiences of the current grassroots advocates within FEDOMA and the resources with which they work. As he has seen first-hand that change can be made even when resources are scarce, he does not necessarily believe that financial resource is something all of the groups should have immediately. This view is reinforced by the fact that FEDOMA does not have enough financial resource to go around. This dynamic reflects the broader neopatrimonialism of Malawi's governance system, in that a group of relatively powerful individuals make decisions about the allocation of funding. The test described by Simon above can be viewed as a form of patronage. In this way, the actions of FEDOMA agents can reproduce broader structures as well as alter them. This imbalance in funding is crucial for discussions in later chapters about how current grassroots advocates view the organisation and their role in it. These perceptions affect their opinions on whether their voice is heard within the organisation.

In an organisation like FEDOMA, small enough that individuals have a lot of power to set agendas, it is critical to remember that actors are impacted by other structural, spatial, and temporal factors, and by other agents expressing their own agency. From this perspective, Simon's explanation during the interview may be overly simplified, as he does not discuss the broader circumstances surrounding his experiences. In his story, he and his colleagues were among the fortunate few youths with disabilities who were able to attain an education at the time. They were well-off enough to have some pocket money to spend getting to where they needed to go, or well-placed enough to raise some funds - directly relating their empowerment and agency to socioeconomic status. They had the backing of the increasingly powerful Malawi Union of the Blind (MUB), itself backed by the (UK) Royal Society for the Blind.[29] Furthermore, Simon's account of his experiences provides examples of how he was impacted by the government and its agents. His own choices and opportunities were constrained because the government had yet to widely invest in resources for children and youth with disabilities. Conversely, his current status as one of the country's top disability advocates is partially due to the willingness of the government to give him an audience and of agents within that structure to perform hearing and *listening* to Simon and his peers' case. In this example, they were able to generate a positive audience response. The young advocates were able to gain access to spaces of decision-making and empowered agents within them, because at the time these powerful individuals viewed their movement positively. At the time when they were conducting their activism, there was political will for disability inclusion, with a lot of legislation being passed and a need for demonstrable gains to prove to the public that the government was willing to implement. Free primary education was among the early initiatives undertaken by Malawi's first democratically elected government (Kadzamira and Rose, 2001), so expanding access to schooling fit in with the political strategy of the day. While Simon is to a certain extent a proponent of a 'bootstraps' philosophy of advocacy [i.e., being able to support oneself with no external assistance], as evidenced by his policies for new DDFs, this approach is constrained by whether an actor is trying to influence a structure whose agents are willing to be acted upon - or who believe demonstrating such a willingness could bring an advantage. It also helps to start from a position of some advantage, such as being educated. (At least insofar as we are talking about the impact of individual or small groups of actors working within the system, as opposed to full-scale revolts in the Marxist proletariat-uprising vein.) This concept of 'willingness' demonstrates the relationality of agency, as discussed in the literature review. The interaction between expresser/performer and audience is critical.

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[29] I do not have additional details on Simon's socioeconomic status, etc. as a youth. This information could further discussion of the impact of privilege (or lack thereof) on decision-making and participation in neopatrimonial social norms.

Simon’s story highlights many of the major themes of this thesis. His experiences impact the ways in which he expresses his agency today, as a leader within Malawi’s DRM. The structures, developed through Malawi’s cultural, political, and economic history, which enabled and constrained Simon’s advocacy work (and contributed to his life history) have continued to evolve; today’s iterations of those structures impact agents within the movement. In telling Simon’s story, I have discussed a potential source of conflict around the question of whose voices are heard within Malawi’s DRM. Later, I discuss how FEDOMA HQ’s test is received by grassroots advocates, and how it impacts what they do. Simon’s history provides a helpful example of the temporal evolution of the DRM and a link between the past and present of the movement. The history of Malawi, the DRM, and FEDOMA contribute to the intersecting structures within which grassroots advocates work today.

5 FINDINGS 2: EXPRESSIONS OF VOICE - RESOURCES FOR DISABILITY ADVOCACY IN MALAWI

In this chapter, I explore the research questions as they pertain to advocates' work outwith FEDOMA, in broader Malawian society (RQ2, 3, 3a, 3b), including how grassroots advocates define voice (RQ2a). Advocates perform voice differently in different spaces (RQ2b, 2c). This work takes place across all of the intersecting scales of social life, including changing individual community members' perceptions, running programmes in villages, and national legislative advising. This multi-scalar organising is one of the ways FEDOMA reflects the national system in which it operates. It also highlights FEDOMA's attempts at systemic hybridity; altering constraining schemas for persons with disabilities and developing legislative (and other) resources results in a broader network of spaces which may be accessed and must be considered in organising.

Voice is a key resource in FEDOMA's approach to advocacy. The majority of its grassroots volunteers work with very limited financial resource, making interactions in everyday social spaces important opportunities for activism. The ways in which disability advocates conceptualise and express their voices are thus critical to the work of the movement. Other relational resources, such as emotion and trust, are strongly associated with agents' expressions of voice, emphasising the importance of understanding these factors within social movements as well.

As discussed in the literature review, voice is a relational, evolving resource. Scholars such as Swerts (2015) highlight the importance of considering the context, audience, and motivation behind expressions of voice by activists. Telling their own stories, and connecting those stories to policy, is a significant part of how Malawian disability advocates engage with their communities. These engagements exemplify the interplay of structure and agency in the strategic use of voice in social movements, as discussed by Bosco (2007). Voice encompasses storytelling but also includes activists' roles in disseminating facts and policy, (as noted by Krumer-Nevo, 2009), as well as other strategies of communication, performance, and expression in addition to relaying individual (or collective) stories. Performances of voice can be individualised or collective depending on context, drawing on personal experiences and group repertoires. Voice may initially be seen as privileging the vocal, which is not an avenue of expression available to all persons with disabilities. However, the term is used within the literature and by the disability rights activists I engaged with and has complicated, highly-context specific meanings. We can expand our thinking around voice by incorporating the physical occupation of space and other forms of expression into our conceptualisation of voice – whether in the telling of stories, or in other forms of expression. As Ladson-Billings (1998) put it, voice is "naming your reality" (p.13). Individuals can express this concept - their lived reality - in a multitude of ways which evolve with an individual's changing reality. In this chapter, I explore Malawian disability advocates' use of voice in their advocacy activities. In the next sections, I present the meaning of 'voice' as expressed by participants themselves. The DDF members provided their own 'definitions' of voice, allowing us to gain insight into what voice means to them specifically within the context of their advocacy work. Later in the chapter, I explore the various scales and spaces in which Malawian disability rights advocates express their voice(s), and what structural and contextual factors impact their decision-making around voice. This provides us with a lens through which to evaluate the utility of voice as a change-making resource. I will explore how grassroots advocates reproduce and alter the structures which affect their lives. I also discuss what grassroots advocates want to use their embodied resources, especially voice, to do in the future. This discussion contributes insights into the role of outward-facing advocate voices in Malawi's DRM.

5.1 VOICE AS DEFINED BY DDF MEMBERS

This section is an exploration of what voice means to the individuals who participated in the project, using the DDF members' own words to develop a contextual understanding of voice within this movement. In an attempt to mitigate a focus on my voice as the researcher or the voices found within academic literature, which Ashby (2011) points out as a problematic aspect of disability studies, this section highlights how participants conceptualise voice themselves. It is unhelpful to formulate a singular definition of voice; voice is multi-faceted, changing, individual, collective, situational, and relational. However, it is helpful to consider voice within the context of Malawi's DRM, as conceptualised by its members, in order to prevent an overly vague and undefined approach; this also enables us to focus on the 'activists' voice(s)', while acknowledging that this is just one part of a person's voice. For the DDF members, their activists' voices are closely tied to processes of empowerment, through their work. Differential definitions can thus also signpost individuals' engagement with empowerment processes. This can also help us to understand the multiplicity of voices within the DRM, and the critical thinking (and consideration of relationality) advocates use when performing voice to achieve their goals.

All interviewees were asked how they define voice (within the context of an interview about their advocacy work). Some put forth different positions as they considered the question throughout the interviews. Many of the advocates discussed voice in terms of the collective - the 'voice' of the DDF as a change-making group and the stories that constitute a collective repertoire. They recognised that individual voices make up the collective voice but generally expressed a cohesion between the two; the collective voice was seen as made up of individual expressions of voice in order to achieve the group's common aims. In the following sections, I explore the commonalities and differences between the definitions participants provided, in order to draw focus to expressions of voice that are key to Malawian disability rights advocacy.

5.1.1 Voice: public visibility and resource for empowerment processes

Advocates fundamentally defined voice as power. Voice was described by one participant as the power to be known and hold a position within your society (Int17). This is critical to the transformation of persons with disabilities into advocates through processes of individual and collective empowerment. Some interviewees described feeling powerless before 'being empowered' by FEDOMA to 'speak out', with voice as something they were given in the process (Int1, 6, 9, 20). For them, being provided with information about their rights and encouraged to work toward securing those rights in practice 'gave' them a voice. As such, advocates note the connection between voice and empowerment. An advocate being 'given' a voice can be seen as a manifestation of collective empowerment - an individual gaining support and access to resources (i.e., information about rights), enabling them to continue to engage in empowering processes. All individuals have ways of expressing themselves which constitute their 'voice' (verbal or otherwise), but there are societal structures that constrain the use of that voice and the interpretation of one's voice by others[30]. Empowerment can develop the sense of self-confidence and access to resources which enable expressions of voice as an exercise of agency. Part of accessing and developing their voices involved realising that their own embodied experiences could be a source of knowledge and that speaking about them 'gave voice' (and legitimacy) to those experiences, as highlighted in the literature (Pilisuk et al., 1996; Krumer-Nevo, 2009; McKay, 2010).

Empowerment through finding and expressing a voice meant that DDF members no longer felt invisible in their communities, in itself a more empowered view of their own position than they previously held. Processes of storytelling and knowledge dissemination within the movement enable this evolution; the DDF members' experiences of growing power through within-group solidarity echoes that of Swerts' (2015) immigrant youth and Caldwell's (2011) DRM open-mics. Developing an advocacy-voice helps grassroots

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[30] This may impact those with mental, cognitive, learning, and/or psycho-social disabilities in particular.

activists gain the confidence to reach out to others in their communities, forming relationships and winning over supporters to their cause. One interviewee described using his voice to define himself beyond disability, by discussing his taste in music and entertainment with others in his hometown (Int8). This in turn humanises him in his peers' eyes, making him a more effective advocate, emphasising empowerment as an 'effect'; community members see beyond his disability when he speaks. In these examples, voice is a resource for, and product of, empowerment processes which allow agents to express themselves, interacting with structures with an aim to altering them. However, these definitions stop short of including an audience's reaction to expressions of voice, which was something other participants addressed.

5.1.2 Voice: change-making expressions 'taken into consideration' by audiences

As the speech acts of persons with disabilities are often dismissed as irrelevant to broader society, rendering them 'inaudible', some interviewees incorporated the relational requirement that voice must be heard and *listened* to in order to be effective into their definitions of voice. Several interviewees used the phrase "*taken into consideration*" when asked to define voice (Int2, 7, 13, 19). For these advocates, voice (often phrased as 'having a voice') meant that when you stand up and speak out for your needs, wants, rights, etc., other agents listen to what you have to say and consider altering their behaviour: *"Our voice is heard. Previously, our voice was shattered. But nowadays, our voice is heard, people have begun to accept us as people who can make it in life. Even the Chiefs and the leaders of the community… they now accept us in different areas"* (Elena, D2; see also Int2, 7, 13, 19, 20, 27, 29). In this way, voice has power to create an effect in the audience's future actions. Additionally, Elena's statement points to the 'becoming' of voice through on-going processes of communication and hearing. Often, this is a long-term process and although persons with disabilities have a voice even in situations where they are silenced, an empowered voice is found through relationality, which depends as much on the listener as the speaker. Once expressions of voice gain an audience who *listens* to the message, they can be amplified to larger audiences through the media. This enables advocates' voices to be 'taken into consideration' by a broader audience. The media's presence is also an example of an audience considering advocates' voices, because their voices are seen as important enough to acquire media attention: *"Most of the time, if we have meetings, we also bring the media, so they record and do whatsoever they can do so our voice should be heard out there"* (Ireen, D2).

Beyond the attention of the media, actions taken to *implement* the content of their expressions of voice are important evidence of hearing and listening to DDF members. Some of the DDF members pointed out a distrust in the value of officials listening to them without seeing implementation of their suggestions (Int20). This is because of a historical lack of "mutual trust and respect" (Sprague and Hayes, 2000, p. 684), demonstrated by the exclusion of persons with disabilities – the base of experience from which Malawians with disabilities draw. It also relates to Haang'andu's (2020) critique of taking government officials' engagement with international legal structures at face-value. Implementation is seen as the outcome of a true change enacted by empowered agents.

5.1.3 Voice as process

One interviewee took the idea of voice as a resource used over time further and described voice as a part of the process of accessing services and justice (Int9). This definition acknowledges voice as one part of a broader interaction of schemas and resources over time that help the advocates to make changes to structures (and to the system(s) of Malawian society). In this case, voice is part of focused, intentional processes of structuration and empowerment. Voice is advocates' main resource for building relationships and engaging in processes of change-making to obtain the rights and services that persons with disabilities need.

For the advocates who defined voice in processual and relational ways, the interactions between agents and structures, and the temporal nature of these interactions, was key to how they conceptualise the use of voice as a resource. These advocates emphasised the incremental nature of change to broader social systems and how relationships between agents are critical to directing the flow of that change. Grounding our theorisation of voice in this empirical evidence, we can think of expressions of voice as performances that require reproduction to produce effects. Through these repeated performances and effects, the resource of voice continues to develop and change. Voice is continually evolving, expressed in multi-tonal ways to achieve different goals in different settings and incorporating feedback from the outcomes of different expressions. Virtual schemas constitute actual resources and vice versa; as the resource of voice is engaged, schemas are altered which reciprocally impact voice. This process of development is in itself a resource for broader processes of social change-making, ensuring the continual development of the DRM as contexts and structures change. This approach to voice encompasses the variety of definitions given by advocates and connects them to still broader processes of structure and agency within Malawian society.

5.2 FEDOMA HQ AND ADVOCACY AT THE CENTRE: EXPRESSIONS OF VOICE AT INTERNATIONAL AND NATIONAL SCALES

Just as disability advocates' definitions of voice vary, so do the ways in which they express or perform different voices depending on movement goals, the spaces within which they are trying to work, and the scale at which the work is taking place. Often, the scales at which FEDOMA and the DDFs undertake their advocacy work correspond with their physical position within the organisation; these scales also necessarily interact and shift. FEDOMA HQ, working at the 'centre' within spaces of economic and legislative power, handles much of the work done at the national and international scales; in cases where the DDF members are included in this work, it is still coordinated through the umbrella organisation. The DDFs focus on the district scale, working within a variety of spaces in a given district. Examining individual scales of advocacy work is useful, though at times too blunt an instrument. The interconnectedness of structure and agency suggest that most structures within a system are multi-scalar by their very nature: the actions of individuals have effects across scales to construct and alter social schemas. However, looking at the differences in approach to advocacy at specific scales is useful in understanding the work of social movements and the organisational hierarchies implicit in that work. This approach also allows us to engage with challenges in the development of an Afro- and Malawi-centric disability movement, such as those raised by Haang'andu (2020). In turn, this can help us navigate the creation of a hybrid disability studies that privileges both specific attention to local structures and scales as well as inter-system DRM solidarity. Later in the chapter, I will return to the discussion of multi-scalar effects and blur the proverbial boundaries between them.

FEDOMA HQ is the perceived centre of the organisation's power, given its location in one of Malawi's major cities and its connections to spaces of national governance and international organisations. When communicating with stakeholders at national and international scales, FEDOMA staff and management draw on and perform collective voices from the repertoire of Malawi's DRM. Communication is a useful proxy for expressions of voice in advocacy because of the inherent implication of a relationship between parties who communicate. This captures the importance of 'being heard', of audience receptivity, as highlighted by the DDF members' definitions of voice. In addition, the term 'communication' is inherently relational, suggesting a relay of information between parties, which is important to processes of advocacy work.

Starting from the 'international scale', Malawi's role as a signatory to international legislation such as the UNCRPD, as previously discussed, is a schema which enables disability rights advocates. The UNCRPD is considered the 'gold standard' of disability legislation by FEDOMA staff and volunteers; as a resource it provides (international) legitimacy and guidance on the rights to which persons with disabilities are entitled. Despite the problems raised by academics about applying a Western-centric disability paradigm to African countries, FEDOMA advocates find this internationally-legitimate grounding useful. FEDOMA staff often mentioned this and other international and national legislation in the field. FEDOMA's international contacts also help ensure that they are kept abreast of emerging research, laws, and the movements of other disability rights groups (FNs, 2018/19). FEDOMA also contributes to international conversations about disability rights in Africa and across the world, as a member of groups such as Southern Africa Federation of the Disabled (SAFOD) and participant in international forums. In this way, an Afro-centric disability studies must be careful to consider the interaction between systems, creating hybrid effects in societies. Local advocates work with and develop these structural hybridities, taking inter-systemic resources and engaging with them in a locally-relevant and movement-specific manner.

Similarly to international legislation, national legislation provides a key resource which enables persons with disabilities' expressions of voice as embodied knowledge. This is in part through the participation of DPOs in the development of legislation. As previously discussed, disability advocates have the most complete knowledge of relevant international law and so are critical to the development of national legislation that reflects these international obligations. FEDOMA is an oft relied-upon expert for the Malawian government in a variety of national-scale undertakings. This means FEDOMA representatives help draft legislation, testify in front of Parliament, write Cabinet papers, and organise national events. I took part in discussions about one such Cabinet paper, containing recommendations for the inclusion of persons with disabilities as Members of Parliament (FNs, 2018/19). During the lead up to Malawi's 2019 presidential election, FEDOMA leveraged some of its power to engage political parties with calls for disability inclusion within their platforms (FNs, 2018/19). FEDOMA uses its national platform to advance movement goals while also distributing information about disability in general (nationally and internationally), other nations' approaches to inclusion, outcomes of those approaches and lived experiences of persons with disabilities in Malawi. In these cases, FEDOMA is constituting and producing as representative the collective 'voice' of Malawi's DRM; as such, whose voices are heard within FEDOMA is critical, speaking directly to the messages that get magnified across scales. The constitution of voice within the organisation is explored in-depth throughout Chapter 6, particularly in Section 6.1.

Returning to the international scale, FEDOMA is funded mainly by international donors, in particular the Norwegian Association of the Disabled (FEDOMA, 2008). One of the main activities undertaken at the central headquarters is securing sustainable funding. Other international funders include DFID and USAID (Chauluka and Chiumya, n.d.; ForeignAssistance.gov, 2020). FEDOMA runs projects funded by international NGOs and conducts contracted activities for some NGOs, such as access audits for Save the Children-funded schools (FNs, 2018/19). Within the broad scale defined here as 'international', there are divisions, especially as the actors at this scale themselves belong to a variety of different systems. However, large systems not bound by nationhood, such as the UN, serve as points of connection for inter-systemic work. It is here that structuration theory's tendency to focus on a given system makes it difficult to consider the ways in which systems themselves interact. While processes of structuration occur within all of these systems, they also occur between systems. Inter-systemic interaction has impacts across scales and within the schemas and resources of various systems. For example, the role played by FEDOMA's international funders has a direct impact on what resources are available and how HQ agents decide to use them. Priorities set by international funders can determine what programmes FEDOMA can establish. This in turn impacts the resource available to grassroots groups. In this sense, different systems effect the schemas and resources of Malawi's DRM on a fundamental level. I explore multi-scalar impacts later in this chapter.

FEDOMA's development of relationships between actors across systems aids in the creation of 'horizontal networks'. Disability as an embodied characteristic impacts all aspects of an individual's life, making it necessary for advocates to work beyond 'disability-specific' spaces; since disability is tied to both physical and social schemas, arguably every space is 'disability-specific' (and/or 'disability-(*exclusion*)-specific'). In fact, FEDOMA's existence as a federation of national-scale DPOs is in itself an exercise in horizontal networking. FEDOMA also establishes partnerships with other organisations who can act in solidarity with disability advocates, whether or not disability is a focal point of their current work. To this end, FEDOMA is currently engaging in a campaign to encourage 'disability mainstreaming' - incorporating a disability rights lens into the work of all social organisations, reminding agents to consider the impact of their work on a population that may not be foregrounded in their minds (FNs, 2018/19). FEDOMA's approach to expressing a collective voice through events is one of the methods they use to achieve these goals.

FEDOMA holds panel discussions and formal public events, with a diverse audience of constituents, policymakers, and other guests. The media are also invited - local and national television stations, radio stations and newspapers. While I was conducting fieldwork, I attended one of these panel discussions, held in the ballroom of an upscale hotel in the city of Blantyre. The panel was designed to push the idea of disability mainstreaming and consisted of representatives from FEDOMA and NGOs who had committed to mainstreaming disability within their work (FNs, 2018/19). In attendance were disability advocates, local leaders, business people, and members of the community. High-profile agents with control over a variety of resources and spaces outside the DRM thus entered into a space governed by FEDOMA's internal schemas.

At the same time, persons with disabilities occupied a space usually associated with normative societal power-brokerage, i.e., a high-spec conference space used for high-level events. These schemas enable the participation of persons with disabilities in social life to a greater extent than the broader schemas of Malawian society. Public and high-profile individuals' participation in these spaces normalise these more enabling schemas, encouraging agents to amplify and echo-out the voices of persons with disabilities and alter schemas beyond FEDOMA-governed spaces. In these spaces, an authoritative collective voice is constituted and transmitted out to the public beyond the DRM.

Image 3. The disability mainstreaming round table event. Note: this image has not been altered to obscure panel members' faces because this was a public event covered by the media.

Image 3 shows the set-up for the discussion. Representatives from the DRM are physically 'placed' on a level playing field with NGO and funder leadership, for example, a representative from Brot für die Welt (an international charity). In addition to their physical placement, disability representatives on the panel perform empowered identities through their demeanour. In this space, FEDOMA representatives perform disabled identities that exude empowerment and competence. As a result, individuals with disabilities gain status in this space; their expressions of voice are legitimated as knowledge and presented 'professionally', reflecting

Krumer-Nevo's (2009) narrativization of voice through 'analytical' language. During events like this, participants personify confidence, knowledge, and moral surety. Their embodied experience of disability is placed on par with or even above the knowledge of non-disabled participants. As a result, non-disabled delegates may leave with an altered conceptualisation of disability and schemas from which to act in future. Kesby (2007) raises a concern that participatory spaces can become limited to a particular time-space arena, which fails to ultimately change other spaces. However, engagement in spaces such as those described in this example enables advocates to alter broader structures through changing the schemas which govern how different publics think of persons with disabilities. The event itself also becomes a 'reference point' – a 'place-transcending' resource on which activists draw to reconstitute and legitimate their voices in other spaces. Additionally, the use of different media to disseminate the message beyond the immediate physical space can help enable time-space convergence and access to a larger audience; just outside the main hall was a press room full to bursting with reporters, camera operators and equipment, relaying the video feed to their individual home stations (FNs, 2018/19). In this scene, not only was person-to-person communication used to relay information from experts to the people in the room, but media communication was also engaged to spread the performances of humanised, vocal disability beyond the confines of the ballroom. These expanded methods of communication allow expressions of voice to be amplified and transported into diverse moments and spaces. The way this information was communicated was also carefully chosen based on FEDOMA's perceptions of the intended audience. For example, dissemination via internet was not a priority, since many Malawians do not have regular access to the internet; in Malawi, the radio is the key virtual space for widespread communication. Just as international legislation provides legitimacy for the work of FEDOMA nationally, high-profile, public expressions of voice from FEDOMA's centre provide a grounding for the work of grassroots advocates in the districts. Using available communication methods helps to ensure this groundwork reaches more peripheral spaces, such as those the DDFs operate within, laying a foundation for local advocates to build upon. In these instances, the use of the organisational repertoire and repeated performances of similar messages is of critical importance. High profile events are a resource to be cited which can be seen by outsiders as legitimate, enabling further work at the grassroots.

5.3 THE DDFS AND ADVOCACY IN THE DISTRICTS: EXPRESSIONS OF VOICE IN LOCAL-SCALE SPACES

DDF members, as members of FEDOMA, are at times engaged in the national and international scale work of FEDOMA as described above. However, the DDFs as their own groups utilise communication in different ways, usually working within different spaces from the national organisation. The DDFs focus on change-making at local scales, from the district to individual villages and community social spaces. The link between FEDOMA and the DDFs in sharing information across scales is a critical function of FEDOMA's organisational structure. These processes of knowledge-sharing will be discussed in the next chapter, which focuses on voice and communication within the organisation, and how that in turn effects outward-facing expressions of voice by both FEDOMA staff and grassroots advocates.

5.3.1 Situating the DDFs in place: Landscapes of disability experience

Malawi has wide landscape variation across its districts, ranging from mountainous areas to beachy stretches along Lake Malawi (Autoethnography FNs, 2017; FNs, 2018/19), and has a tropical climate, with a rainy season from November to April (CountryReports.org, 2021). The impacts of climate and weather also vary across the districts, with changes in climate across Malawi's regions, and some districts suffering from seasonal flooding or drought (though there are districts which contend with both at various times of year) (FNs, 2018/19). Each district covers thousands of kilometres (in this study ranging from just over 2,000 square km to nearly 8,000 square km[31]) and has a main town or city, usually named after the district – for example, Blantyre City in Blantyre district. The rest of each district is often broadly rural, with smaller towns spread

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[31] Exact areas of each district in the study are omitted to protect confidentiality/avoid easy identification of specific districts included in the study.

throughout (FNs, 2018/19). The central towns range from the urban areas of Blantyre, Lilongwe to smaller towns in less populous districts (FNs, 2018/19).

The Southern region, where D1 is located, is hilly, with deep valleys as well as mountains, and a hot tropical climate (MalawiTourism.com, 2021c; FNs, 2018/19). According to fact sheets developed in 2013, D1's population density increased by 1/4 in the two decades preceding 2014 (PRB, 2014). In D1, 1 in 20 households has access to electricity, 1/30 women and 1/13 men complete secondary education, and 1/5 women and 1/11 men are unemployed (Ibid.). Distance to the nearest healthcare facility is a problem for 2/5 of women (Ibid.). Tea production is the main industry in D1 (FNs, 2018/19).

D2 is in the Northern region, which consists mainly of highlands, and has a temperate tropical climate (MalawiTourism.com, 2021b). D2's central town is a tourist town located on Lake Malawi (accessed by navigating steep, hilly approaches), around which much of life and industry in the district is centred (FNs, 2018/19. Much of the rest of the Northern region is sparsely inhabited wilderness (FNs, 2018/19). This district has a lot of agriculture, tourism, and fishing businesses, with very few people in 'waged' work (REFERENCE). The population of D2 increased by 3/5 in the two decades preceding 2014 (PRB, 2014). In D2, 1/18 households have access to electricity, 1/20 women and 1/8 men complete secondary education, and 1/9 women and 1/14 men are unemployed (Ibid.). Distance to the nearest health facility is an issue for 3/4 women (Ibid.).

The Central region contains Malawi's capital, Lilongwe. The presence of the capital plus a large area of national park may some sections of Central Malawi popular tourist destinations (FNs, 2018/19). However, D3 itself is not a tourist destination. D3's landscape is relatively flat (though high above sea level) and agricultural, with an economy based around tobacco production (FNs, 2018/19). Despite this agricultural industry, the district has poor water resources and soil nutrients; D3 is often among the hardest hit by famines (FNs, 2018/19). The population density of D3 doubled in the 2 decades preceding 2014 (PRB, 2014). In D3, 1/20 households have access to electricity, 3/100 women and 5/100 men complete secondary education, and

26/100 women and 6/100 men are unemployed (Ibid.). Distance to a health facility is an issue for 2/3 women (Ibid.).

D4 is an urban centre, with a climate which is good for agriculture (FNs, 2018/19). Many people migrate to Malawi's urban areas for employment, and the population density of D4 tripled in the two decades preceding 2014 (PRB, 2014). Employment remains challenging for persons with disabilities in D4 despite its urban nature, and major roadways in this city are often blocked by persons with disabilities begging and panhandling (FNs, 2018/19). 1/10 households in D4 have access to electricity, 4/100 women and 9/100 men complete secondary education, and 25/100 women and 3/100 men are unemployed (PRB, 2014). The distance to a health facility is an issue for 2/5 women (Ibid.).

The social, physical, and material contexts of the DDFs impact the activities in which they engage. Some of the challenges are common across the districts and reflect the broader challenges facing Malawi as a low-income country, for example issues of access to education, electricity, and employment, as highlighted above. Kingsley (D1) highlighted the intersection of disability, employment, and place in his own experience:

> *Being a man with a disability, life has been so tough. Because to earn a living, it was so tough. You know, in remote areas, we depend on family… Garden [subsistence farming] work – it was so tough. I shifted from [my] home village to come to a town and start doing a business. And now… business is doing well… I supported some of the people at the [home] village.*

Challenges associated with landscape may be common across districts despite differences in geography and climate between districts. For example, DDF members from every district highlighted that transport and travel around their district was challenging. This is due to lack of transportation options and infrastructure, but also to the size of the districts as administrative units. For example, Felida highlighted this challenge in D3: "*it is hard, because this district is a little bit huge. It is difficult because... some of the members, they do live in far distance… To come and attend meetings, it might be difficult. So, we [the DDF] do not come together as required".* Kingsley (D1) highlighted further consequences of distance for advocacy activities, in discussing the remote areas which the DDF struggles to reach: "*there are a lot of problems out there… in remote areas,* *people they don't know their rights. They [persons with albinism] don't know where they can get… the oil [sunscreen] for the skin"*. To the members of each district's DDF their district is large, despite the thousands of kilometres difference in area between districts. Relative to the DDFs' abilities to travel, all the districts *are* large, and challenging to traverse, particularly given issues of transportation infrastructure. This is exacerbated by the make-up of districts as consisting of a central town and broadly rural areas beyond it.

On the other hand, unique aspects of the landscape and climate of the districts also impact each DDF's activities and are important to consider. In D4, for example, several years of destruction caused by seasonal flooding led the DDF to focus on Disability Inclusive Disaster Risk Reduction (DIDRR) in the affected areas:

> *The other issue is the one which I was just mentioning... disasters. Which just came in around the year 2015, 2016, which took us by surprise. The people in [local areas 1 and 2], they have built strong walls. So, the water there… will hit the wall. But people in [local area 3]... it's a… let me call it a lower-class level. So those ones, they cannot afford to put high walls. So, the water will come from up land with heavy speed, and when they come down there, they will just [gestures destruction]. People in [local area 3], are the worst hit in [D4]… As I earlier said on… the evacuation centres were not accessible [for persons with disabilities]. We had to negotiate to make them accessible. And issues of relief, we had also to negotiate… So that our people [persons with disabilities] are also included in the relief (Charles, D4).*

Charles' story highlights the intersection of climate, infrastructure, and poverty and their impact on the work of D4's DDF. In contrast, the land in D3 is flat and agricultural. Here, DDF focal points were drought and seasonal famine (FNs, 2018/19), highlighting the impact of contextual factors such as the poor soil and high poverty levels on D3's DDF priorities.

D2's main town and centre of commerce are in a difficult-to-access section of the district on Lake Malawi, as mentioned above. Opportunities for employment as fishermen were denied to many persons with disabilities due to an inability to physically access the shoreline (FNs, 2018/19). In this example, disability constrains some individuals from engaging fully with their own place and landscape, reflecting new materialism's emphasis on the lived reality of bodies. While the (strong) social model of disability might claim that access could be designed into the area, it is also necessary to acknowledge that the existing material constraint cannot simply be dismissed. While technically this physical limitation is surmountable (though this is unlikely within the resource constraints of Malawi), it was not seen as such by DDF members. In fact, it is unlikely that DDF members could conceive of the geography of the area as surmountable given their acknowledgements of said resource constraints (as well as their own). Instead of focusing on engaging persons with disabilities in this aspect of the local economy, the DDF works to bring about alternative, accessible economic opportunities in the district - such as carpentry or sewing (FNs, 2018/19). This DDF also expanded their place-based resources, using a neighbouring district's central town for activities such as posting reports, because it was more easily accessible than their own (Int7, 8). Milo (D2) stated that this action "*takes a lot of money and sometimes a lot of walks… Because… we have a couple of kilometres from here to town to email*". These examples of DDF foci represent local collectives adapting over time to the changing everyday social, material, and physical/geographical circumstances of their constituents. The continuous processes of developing these collectives are explored further in Chapter 6, particularly in Section 6.2.

Through various forms of communication, the DDFs make changes to the structures which affect the lives of persons with disabilities in local communities, adapting to circumstances and challenges such as those presented above. Broadly speaking, the DDFs' main communications can be explored through members' performances of voice within spaces where different (but intersecting) groups exercise structural authority: community members, Traditional Authorities (TAs), and district officials. In their advocacy work, DDF members seek to insert themselves into these spaces in meaningful ways. Within the spaces in which each of these groups conducts its activities, there are different enabling and constraining schemas which influence advocates' performance(s) of voice. When DDF agents engage in these spaces, they seek to alter structures, gain further access to structures of authority, and broaden schematic conceptualisations of who should be included within a community. Engaging and making change within local spaces is the DDFs' purpose, and so is important to discuss in this thesis. However, advocacy within any specific space also requires an understanding of resources and schemas which can be drawn on from other spaces, reflecting Sewell Jr.'s

(1992) and Giddens' (1984) emphasis on the generalisability and transferability of virtual schemas, and adding a focus on the movement of 'actual' resources as well. While the examples in this section are discussed within the context of local advocacy, they actually reflect the DDF members' links to FEDOMA as an umbrella organisation with international legitimacy and a broad base of support. In expressing agency within a given local-scale space, DDF members are dependent on citation of resources performed, instigated, or authorised in other spaces. This highlights the importance of the collective in processes of empowerment, contributions to individual agency, and enabling greater access to resources.

5.3.2 DDF communication with community members

One of the DDFs' focal points for action is 'raising awareness' within their own communities. Building relationships wherever possible in the broader community can encourage the inclusion of persons with disabilities in community spaces. Some of the enabling schemas that aid this work stem from persons with disabilities' participation in spaces of established social communities, such as churches, schools, and college clubs. They are able to demonstrate to their neighbours that they have things in common, which in turn humanises them to their neighbours. DDF members in these cases perform the right to express their voices as equals in these spaces. When persons with disabilities are absent or excluded, these normative community spaces can reproduce schemas which further constrain persons with disabilities' participation. Engagement in these spaces requires local understanding, highlighting how Haang'andu's (2020) calls for an Afro-centric disability studies can help address Kesby's (2007) concerns with empowerment beyond the enabling confines of 'empowering spaces'.

The government of Malawi created legal protections for persons with disabilities, providing critical new resources and developing schema that have the legitimacy of state legislation for activists to draw on. However, the government has been slow to provide effective communication about disability rights across the districts. This both creates challenges for the DRM and opportunities for advocates to disseminate information and ‘control the narrative’. Advocates’ performances of voice act as conduits through which the virtual structures represented in legislation impact the material and social experiences of persons with disabilities ‘on the ground’. Just as FEDOMA ‘empowers’ grassroots members by providing them with information about disability, rights (both national and international), and services, the DDFs continue to spread this information to other persons with disabilities and the general public. During interviews, all of the DDFs reported that they had registered a level of success in this area. Many talked about discussions held with parents of children with disabilities, encouraging them to send their children to school by explaining the rights of children to an education, the illegality of preventing a child from attending school, and the power of an education to make a difference in the life of a child with a disability (Int1, 4, 6, 7, 13, 14, 15, 18, 19, 21, 23).

DDF members combine the use of state resources with personal stories of how education changed their own lives, demonstrating that this focus for advocacy is for many driven by experience. Many of them told these stories to me during interviews, performing them with conviction and emotive power. As the audience, I was convinced of the transformative power of school in their lives and found myself responding to, and moved by, the hope and surety with which they expressed themselves. For example, Charles (D4) regaled us with tales of himself as a schoolboy with a disability whose self-confidence and humour often saw him labelled a ‘troublemaker’. However, the ‘troublemaking’ Charles described were in actuality his youthful attempts to access the best education he could. Charles has a physical impairment and now uses a wheelchair. In his youth, he used crutches and sometimes did not want to go to school because of the difficulty in walking there. His father used to drive him to school when he did not want to go, then refuse to pick him up, telling him to walk home. On one of these walks, Charles met a man he eventually discovered was the then-ED of FEDOMA. Charles (D4) told the following story of his first interaction with the man:

> *Me, I didn’t know anything, okay? Just a small boy. So, he says, “Okay, how do you go in class?” We are talking of this; this guy is a human rights guy in disability. So, I was telling him. [He] Says, “What disturbs you there?” … I was telling him, “That small hill” ... The school where I was going it was like boys, girls - girls, boys… I was coming through the girls… The*

> *shortcut to my class was blocked… they had flower there*[32]*. So, I would go there with my crutch [mimes crutch ruining flowers] … smash them in passing… So, I told him, "You know there was a headmistress there, who has blocked my shortcut… I will come sometimes, weekends, when there is nobody. I would bring my friends - this is my shortcut. Monday morning, they will see me passing through… what I do, I go there on the weekend and destroy everything!" … He said "Good… Nobody should actually bar you from going to class… Tell that headmistress: 'This is my shortcut!'"*

Charles (D4) continued the story, telling us that the next time he went to school this way, the angry girls' school headmistress reported him to his own headmaster: *'Fortunately, the headmaster had a son with a disability… So he started talking to this headmistress, saying "No, no, no, no. Let him use the shortcut." And I was surprised. How come this guy is now defending me? I thought I was a bad boy!'* Not only did this experience jump-start Charles' career as a self-described human rights campaigner, but it also instilled in him an understanding that advocates can directly impact a child's - and future advocate's - life. Charles' experiences reflect those of Simon, where other agents and their willingness to make changes in spaces over which they have authority make a difference - the relationality of expressions of agency.

Charles began meeting with the FEDOMA director regularly and became friends with the headmaster's son. Eventually, a better pavement was put in place for Charles to more easily get to school. When Charles (D4) went to secondary school, he continued to fight for his right to an education, insisting on being able to take science classes that were initially thought 'too dangerous' for someone with a disability:

> *So, when I went to secondary school, my, my, my, my... So, I went to… a lab… This teacher says: "You know, this is a dangerous place… You know when these things happen, can you run? … Can you run away? If a fire starts here?" [I replied] "Madame, if I jump on your back,*

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[32] The boys' and girls' sides of the school were separated. Flowers were planted along a narrow passage that created a shortcut through the two sides. Charles used this shortcut to avoid a hill on the standard route to the boys' school.

> *I will grab you, will you know that I'm on your back. You'll run away with me!" … So [the teacher] reported me to the head teacher[33] (HT)… [who] comes in and says, "You! You want to do biology?" I said, "Yes, I will do biology." "No, you shouldn't. This is dangerous for you…" [the HT replied]. "So, you are saying education is dangerous to me?" [I said]. And then… he couldn't argue any more.*

Charles' sense of individual empowerment to speak this way and demand access to education were part of the processes begun during his primary school education. His individual development was supported by the advocates with whom he interacted, and the processes continued as he grew up and continued to engage with FEDOMA's adult activists. Charles' inclusion in primary school also meant that in secondary school, he had friends on whom to rely. The alterations to the schemas within the primary school changed the actions of other agents. Those friend-agents assisted Charles (D4) in his secondary school classes: "*Fortunately, from that primary school, there were ten guys in the same class, which were with me in the same class in secondary school… So, these guys, they knew how to handle me. They would pick me on the back [and put me on the stool]."* Even with assistance from his friends, Charles (D4) had continuous battles with his teachers in secondary schools:

> *This biology teacher didn't want me to do biology… So, when [s]he is doing experiment… she could hide it from me… I'd put off the Bunsen burner… I would tell the teacher, "This class is not going on if you don't allow me." They got used to me. The same thing happened when I went into a physical science class. This teacher said, "No you are not." I said, "Me, I am. I want to learn. You will see. I will learn."*

Charles' early self-advocacy continued processes of empowerment which had begun during his primary school days, impacted the behaviours of other advocates, and helped to alter structural constraints which could have prevented Charles from receiving an education. At the same time, his repeated clashes with

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[33] A new head teacher.

teachers throughout his education demonstrated the slow pace of structural change. Additionally, changes to structures can be extremely localised, again reflecting Kesby's (2007) concerns about empowering spaces. In some cases, only through repeated small actions by agents does structural change enter into new spaces. However, the empowerment effects gained from each small 'victory' can help continue to motivate agents to engage in the work. Charles' expressive, comedic, and insistent strategies did not always work - he was successfully barred from woodworking and metalworking classes. However, he did learn, as he promised his teachers. As a result, Charles became one of the small number of Malawians with disabilities to attend university. Here, he engaged in a fraught battle with the administration to construct ramps on campus, using his experiences and the knowledge of his legal rights gained from engaging with FEDOMA throughout his childhood:

> *I come to the university; they ask me… "You. You are coming here. Who allowed you? Who allowed you here?" "Government!" … I was telling him, "Government allowed me here!" … They almost withdraw me in college… I continued… I went to the students' president. So, I asked him "Do you… have a budget for disability?" "I don't know, let me check," [he replied]. When he check, he discovered that there was a budget for disability… but it was redirected. So, he said, "My friend, it is being diverted. Make noise now!" … So, I wrote a letter… to the principal. That I want this campus accessible to me… It was never responded… so I took it to the ombudsman. The ombudsman said, "My friend, you have to do… two reminders" … I showed her. Three months. Three reminders… So, she wrote… To my surprise, they put ramps… Very happy, I was spinning… my wheelchair… So, if you go to Chancellor College now, you see there are ramps (Charles, D4).*

Charles' interactions with university officials over disability funds reflect the broader neopatrimonialism of governance systems in Malawi. The fund was being redirected based on university decision-makers' priorities - until Charles made noise about it, performing his outrage, and using the available structural resources to engage authoritative agents. Charles in some ways can be seen as a pioneer within the DRM, and his personality is in itself a resource. Charles resisted constraining schema, ultimately obtaining an education which enables him to work in the civil service today. He also formed relationships which helped make broader and more lasting structural alterations. Charles communicated with his community members, discovered support in unexpected places, and developed new support, even if he was not always successful in maintaining access in the spaces he interrupted (such as the woodworking and metalworking classes). While Charles expressed agency and voice before he became politically-involved, engaging in everyday resistance, his voice and resistance were less effective – his audience did not always listen and respond to him in the way he had hoped. Later, greater access to enabling schema, resources, and peer support through the DRM enabled him to engage in more effective forms of advocacy and altered the impact of Charles' expressions of agency. Now, Charles is a member of a DDF, helping to expand the likelihood that a young person with a disability will encounter supportive forces in their district. In Chapter 6, Section 6.1, I explore leaders within the DRM and the role of individuals in contributing to collective practices and narratives.

In some instances, new spaces are created in order to facilitate participation and communication between disability advocates and communities. I encountered present-day examples during my fieldwork, such as reporting on a community sports day arranged for children with disabilities to play with their non-disabled peers. The event was intended to demonstrate the 'capabilities' of children perceived as different (FEDOMA internal documents; FNs 2018/19). All local children were invited; though the activity was run by disability advocates, it was open to everyone and sought the integration of children with disabilities with their peers. This approach enabled disability advocates to demonstrate that they did not want to disrupt or overturn the local way of life but become part of it. Engaging in sporting activities also allowed children with disabilities to display their strengths. Lawy (2017) described a similarly performative expression of voice: "By using his body... [his] voice was loud and clear" (p. 202). Disability advocates performed voice in a variety of ways during this activity - through speeches made to the assembled and relayed in the press, signs supporting equality for persons with disabilities, and the physical statement made by the participants that they are 'able' to play and enjoy sports, as their non-disabled peers do. In demonstrating their sporting abilities, children with disabilities "[change] the terms of the argument or discussion" (Lawy, 2017, p. 202). Smith et al. (2016) point out in their study of disabled athlete-activist identities that "talk is action-oriented" (p. 140). That conceptualisation can be reversed, and actions, in particular the deliberate actions of social justice advocates, can be viewed as "talk" - or expressions of voice.

Giddens (1984) also notes the importance of temporality in processes of production and reproduction. The DDF's advocacy activities are impacted by temporal factors. Some cases, such as the sporting example above, rely on temporarily created spaces. At the points in time where a temporary social space exists, miniscule shifts in schemas still would have been made, perhaps weakening the structures that constrain the participation of persons with disabilities in social life. However, this temporariness does not lead to the repetitive change required to fundamentally alter schemas, as noted in the concerns of Kesby (2007), discussed previously. Without spaces where persons with disabilities can continually engage with non-disabled peers, there may not be lasting change made. That is not to say that temporary spaces do not make any change at all. They retain a virtual existence as a citable resource and in the alterations to schema to which they contribute. Smith et al. (2016) argue that identifying as a disabled athlete is a counter-narrative which "hold[s] great potential for evoking social change and generating positive ways of being as a disabled person" (p. 146). Photographing temporary events, describing them in reports (as was done in this case), recording them in the newspaper, etc. can help activities in empowering spaces to gain permanence outside of them, lending a material dimension to their enduring virtual existence. Additionally, these are opportunities to continue developing group repertoires, practice skills, and demonstrate new opportunities for persons with disabilities to consider for their individual futures. Individual empowerment contributes to this idea of 'possibility', as exemplified by children with disabilities seeing themselves as athletes, though it is enacted through the work of the collective. Social change is the main purpose of advocacy, and activities such as the sporting programme can help to develop the agency and positive self-image of persons with disabilities, ultimately strengthening the movement overall. The critical importance of this within FEDOMA is explored further in Chapter 6, particularly in Section 6.1, regarding the role of emotion in motivating activism. These temporary spaces are also potentially the beginning of more permanent spaces of inclusion, especially if friendships and networks can be developed from relationships established in these spaces.

The acceptance of persons with disability into mainstream community spaces, either temporarily or long-term, can in itself be thought of as a disruption of societal norms, making changes to the schemas that constrain their participation. This can also be interpreted as an expression of persons with disabilities' voice – the statement they make is embodied in their physical presence in public spaces. Some of the disability advocates described this process of participating in daily life as 'humanising' people with disabilities, broadening the construction of humanity within those spaces and altering the norm. Superstitions and views of persons with disabilities as 'magic', 'cursed', etc. are challenged by DDF members' insistence on their own 'normality'. In these cases, their actions can be interpreted as performances of voice because for the advocates, their 'normality' is deliberate. Interviewees described points in their life where they were *"just staying at home"* (Int7). For these individuals, participation in society was a radical act, which they grew in confidence enough to perform only after 'being empowered' and becoming advocates. From within these community spaces, in which they participate using a physical expression of voice, advocates can impart their knowledge about disability issues and rights to the broader public, develop legitimising resources to be cited by other advocates, and spread the message of inclusion beyond just members of the disability rights movement.

5.3.3 DDF communication with Traditional Authorities[34] (TAs) and village leaders

If the new schema, resources, and forms of agency that DDFs operationalise are to survive and produce effects in everyday Malawian society, they must navigate the tension of working with, alongside, and yet also changing, the schema, resources, and forms of agency that constitute life in Traditional Authorities* (TA*s). Lawy (2017) highlights the impact of political schemas on marginalised people's expressions of voice and emphasises the dominance of performativity in "acceptable" forms in both expressing one's voice and

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[34] 'Traditional Authority/ies' can refer to both a person and/or a place. For this thesis: 'TA/Tas' = person and 'TA*/TAs*' = place.

impacting an audience. When the DDFs communicate with Traditional Authorities (TAs) and village heads, they draw on some of the same legal structures that enable them in communicating with local community members, by emphasising that they are members of the communities that TAs lead. The DDFs make these appeals through the use of resources such as government legislation about disability rights. With the TAs, there are rules about participation in the spaces they govern, both in specific meetings and the broader community, and additional schemas which both constrain and enable communication.

Respect for (or at least participation with) authority is fundamental in Malawian society and ingrained in the current neopatrimonial governance structures, so DDF members are in some ways constrained by the official way of conducting business - gaining access to the spaces governed by TAs is up to the discretion of the leader. DDF members seek formal audiences with the TA or village head, inclusion in community development projects, and invitations to speak at village meetings (Int1-22). Access to these formal spaces and activities is determined by the TA's judgment of the merits of providing access. It may be difficult for an individual advocate to make the initial contacts necessary to communicate with busy local leadership, particularly if that TA does not respect the rights of persons with disabilities to participate. In these cases, the hierarchical system makes it difficult for an advocate to make inroads without seeming disrespectful. However, formal procedures also act as protection for the DDF members. Following established practice lends legitimacy to advocates and reinforces their desire to work within existing structures. Haang'andu (2020) highlights the importance of engagement with local leaders for DRMs. Enabling legislation and temporary spaces of engagement are not enough - the legislative and network resources generated in these spaces must be citable in other spaces and times. When the DDFs do engage within the TAs' spaces of authority, participation is enabled through their ability (both in access to knowledge resources and agency in speaking up) to cite legislation. However, given the disconnect between national enforcement and local realities, the DDFs must work between and across scales, combining resources, challenging, and/or accepting, particular structural constraints and enablements. This allows them to constitute new spaces - both physical and metaphorical - and transform existing spaces in ways that provide benefits to the local disability community.

The TAs are legal entities within Malawi's governance structure and so are answerable to the national government on certain matters. This includes national programmes implemented at a local level. One example is the distribution of fertiliser subsidy coupons to local communities. This is a national programme, implemented through the districts and the TAs/TAs* (FNs, 2018/19). In these cases, TAs are required to follow the laws of Malawi, which means that if persons with disabilities are excluded, the DDFs have some legal recourse to push the TAs to include them. The legal resources created at a national level enable DDFs to argue for their rights as citizens of Malawi, though the pathways to said legal recourse are often unclear and challenging. The TA's legal duty of care to all of their constituents enables the DDF members to insist on their inclusion, within the bounds of expected respect for authority. In these circumstances, the DDFs' formal knowledge about rights and laws, as a consequence of their training within the organisational space of FEDOMA, includes knowledge about the TA's duty of care. Reports on how the TAs understand this duty, and whether they violate national disability rights law, can be passed from the local level to the national organisation.

The usefulness of this knowledge is, however, dependent on the TAs' understanding that the DDF members possess that knowledge. Again, the impact of expressions of voice by advocates is determined at least in part by the audience, and what the audience believes about the expresser. Lawy (2017) highlights the difficulty for advocates of working within formal systems and through established forms of "acceptable" communication, which can constrain efforts to change the schemas which determine "acceptability" itself. The DDF members contend with this not just in spaces governed by TAs but also those of district officials.

5.3.4 DDF communication with district officials

In DDF communications with district officials, respect for authority, insider networks, and the law are the primary structural factors which enable the DDFs to do their work. For monitoring districts' implementation of disability rights and programming, a more 'professional' performance of voice is used. The DDF members are often in ‘lower’ status positions than the officials with whom they deal. This schematic reflection of neopatrimonialism can be both enabling and constraining, depending on whether local advocates can engage in an almost patronage-like relationship with local officials. The DDFs can aid government officials in responding to national legislative priorities and deliver a politically supportive interest group if officials are willing to work with them. FEDOMA’s reputation as an organisation, coupled with advocates’ extensive knowledge, aids them in representing their voice in these more formal spaces. However, these are also the hierarchical schemas that the advocates are trying to alter – so their approach is not to adhere to schemas around social position quite as strictly. Their stories in this case are meant to be equalisers. There is a subtle difference here that underscores Seale’s (2017) concept of the “multi-tonality” of a single expression of voice. This was made clear across all of the meetings between DDF members and district officials which I observed. In formal settings, the DDFs present themselves as the experts – arguably more knowledgeable than the individuals with whom they are speaking. Their voices are expressed in a way that underscores this expertise (FNs, 2018/19). At the same time, adherence to social mores such as using an official’s title, deferring to them as a leader, etc., reinforces the socioeconomic hierarchy and removes any threat the DDF members might seem to pose to that official’s position (FNs, 2018/19). This engenders a more receptive space, which ultimately impacts whether the DDF will be able to build a functioning, continuous relationship. This notion of status is especially complicated in cases where the DDF advocate has a well-respected job, for example as a teacher. In these cases, the hierarchical structures become blurred, and the consideration of those hierarchies depends largely upon the space, point in time, and audience.

One of the best examples of this blurring of hierarchy and use of insider networks is in the DDFs’ work toward securing accessible education for children with disabilities. All of the DDFs I spoke with had at least one member who was a teacher. Teachers are ‘insiders’ within district education spaces, more easily able to navigate the internal workings of education departments. They are considered well-educated and respectable (FNs, 2018/19). Englehart and Miller (2019) hold that this type of “multipositionality” is what constitutes successful “critical actors” (or agents), individuals who are well-positioned to alter specific structures. Many of the gains in inclusive education DDF members discussed specifically involved these well-placed critical agents:

> *We are also able to fight for the rights of children with disabilities, more especially… education-wise. Previously, it was very tough for a person with a disability to be selected to go to a national or district secondary school. But… since the DDF was established, we are able to fight - going to the DEM [District Education Manager], and we are also linking with the desk officer for special needs here in [D1], saying "This learner have been in Standard 8 for maybe 2 years, 3 years." Because previously people were able to have passed, but it was tough for them to be selected… I am a teacher, that's why I can be able to go in. So, we are able to discuss, and they say "Yes" ... For this time, for a learner of disability, any type of disability, gets a pass… they are able to be considered to a boarding school for security… and for a good environment for them to learn (Mallory, D1).*

The DDFs use their existing access to governance spaces to open the door to communications about disability rights. These communications are reinforced by framing against national laws. The difference between working with district officials and TAs is that officials are generally more familiar with national disability legislation and its impact on their sector. In these cases, the DDF members can be confident that their audience knows the law. Their ability to make progress is still to some extent affected by their audience, however, as district officials may or may not believe in the DDFs' ability to garner support for actual enforcement from the national government.

Another way in which the DDFs have leveraged their success with critical agents in official spaces is by securing the placement of persons with disabilities (often DDF members themselves) within other local governing bodies, thereby accessing additional community spaces and building networks. For example, D2's DDF Chair is a member of the District Peace Committee, while others in that DDF are members of various area and village committees (Int10, 11, 12). Establishing these roles is important in building the status of individual advocates as perceived by district officials. The shifting bounds of an individual's identity in this case encourages officials to think beyond their ‘status’ as a person with a disability, demonstrating the ways in which disability activism can utilise intersectionality.

Along with utilising insider networks to navigate dealing with district officials, the DDFs conform to social norms such as being punctual, respectful, and knowledgeable of the ‘proper channels’, to help them push their agenda forward (FNs, 2018/19). This includes knowing how to shift the system instead of trying to topple it. Once again, they use the tactic of pushing to increase the inclusivity of existing services and programmes, instead of pushing for additional, special provisions for disability. Through presenting as a group who know their rights and are willing to push for them (within reason, as perceived by their audience), the DDF members have altered schemas which constrain their access to services and the implementation of laws protecting their rights. Charles (D4) put it this way: *“We have tried to actually… avoid budgetary issues. Extra budget issues just for disability. We are saying the same budget should be inclusive… But if you look at all these ministries, we have not campaigned for any other budget. But we are saying - that’s a budget. Let us make it inclusive.”* In Charles’ example, he established his expertise by communicating that he has knowledge of the budgets allocated to various programmes. However, he also refrained from framing persons with disabilities as necessarily deserving of special consideration. Instead, he presented the officials’ duty of care to include marginalised people in community programming. At the same time, he demonstrated awareness that officials are themselves constrained, in this case by lack of financial resources. Reflections of the DDFs’ approach to community communication, which strives for inclusion of persons with disabilities in the ‘normal’, are found in this formal argument for economic inclusion. In this case, context is an important consideration for setting an agenda, reflecting Haang’andu’s (2020) emphasis on place-specificity in building disability rights movements. In Malawi, there is little resource to go around. Disability advocates realise they may not be successful in convincing non-disabled community members to support their efforts if they were asking for something ‘special’ in a space where no one has enough.

All of the examples above involve the use of resources across spaces and scales, in relation to schematic constraints and enablements which change depending on the space and point in time. The performance of voice by a marginalised individual in a given space alters that space in that moment; simultaneously, that specific moment can have a ripple-effect of impacts on the schemas and resources governing unrelated future events in an unknown quantity of spaces. Changes made to virtual structures affect their use both in that moment and in other contexts. In the next section, I delve further into cross-scalar impacts.

5.4 DEVELOPING UNDERSTANDINGS OF MULTI-SCALAR STRUCTURATION WITHIN MALAWI'S DRM

Understanding the impacts of multi-scalar interactions, even those which play out in the background of day-to-day advocacy activities, can help lend some insight into what makes advocacy work possible and what impact that same work can have across scales. The examples in the previous section discussed ways DDF members draw on cross-scalar resources in local activities. However, this is a reciprocal process, and the experiences and advocacy activities engaged in at the grassroots level are forms of knowledge used to inform priorities and actions across the whole organisation, from local to national scale. Several examples of the movement of knowledge between the scales within which FEDOMA works came up throughout my fieldwork. At the same time, participants acknowledged and largely embraced the influence of global and national factors on local organising.

5.4.1 Impacts of the international scale on the national and local

Some of the ways in which international scale schema and resources impact the work of disability rights advocates across all scales were discussed previously. International legislation such as the UNCRPD provides a framework from which advocates can draw when engaging at any scale. This connection to an international covenant is precious to Malawi's disability activists as something which justifies their very existence as a lobbying group at the national level (FNs, 2018/19). FEDOMA also uses examples from other global actors to make recommendations to the Malawi government. For example, I participated in a FEDOMA session to draft a position paper on disability representation in Parliament. In developing the report, FEDOMA staff drew on examples from Uganda, Kenya, Zimbabwe, Rwanda, and Egypt (FNs, 2018/19). Using other countries' examples is in itself an exercise in cross-scalar, inter-systemic, and Afro-centric interaction: the legislation they refer to 'exists' at a national level, but its existence and content are communicated to FEDOMA via international connections. Individual systems interact at any and all scales, as well as between them. These interactions are often made possible by changes to communication technology and the increasingly connected, globalising world. This example also provides insight into the international spaces Malawian advocates consider most relevant to their own national system. All of the exemplar countries had some physical or virtual similarities to Malawi in place or social/governance system. Since disability legislation is often the product of popular organising, if taken far enough one can see the impact of local organising in a completely different system (for example Kenya's DRM) across the scales of Malawi's national system. This process is part of the scalar politics of disability, which emphasises individual impairment and responsibility, and foregrounds disability as a community, national, and international phenomenon. Additionally, the interaction of resources, schema, and agents within and between 'scales' highlights the social production of scales as useful for organising social life but ultimately ever-evolving and non-linear.

A similar complexity can be seen in the interactions between FEDOMA and international funders. As discussed, funders may be both governmental and private, operating at different scales within their primary system (i.e., home country), as well as in their work in Malawi. Since Malawi's financial situation is precarious, with a government whose budget is reliant on external aid (Strasser, 2016-2017), some of these funders provide financial assistance to Malawi's government, as well as to its civil society organisations. This complicates the internal hierarchies of Malawi and FEDOMA. The rest of this section, however, will focus specifically on FEDOMA's relationship with its funders.

Funders enable the work of disability activism through provision of material resources. Through this funding, spaces where advocates can make their voices heard are developed. Arguably, without external funding, FEDOMA would not exist as a space for advocacy work around disability rights[35], at least not in its current iteration. Similarly, funding from international donors goes to programming at a district level. Some of these programmes, such as the sports day previously discussed, facilitate temporary spaces for engagement in advocacy. Other programmes are on-going. For example, the Village Savings and Loan (VSL) programmes administered through the DDFs in some districts. These are intended first and foremost to support persons with disabilities in villages. However, the VSLs also include non-disabled community members. This creates a space of integration, and since the VSLs will eventually be run entirely by the district's DDF, the persons with disabilities become community leaders (Int29). Phyllomina (HQ), FEDOMA's VSL project coordinator, discussed how through these programmes, persons with disabilities have acted as community leaders and spread their knowledge to others:

> *I was with the district coordinator. And he was telling me that this other group... [laughs]. They have very similar books like ours. They have only removed the logo for FEDOMA, but everything is the same. And they even approach some of our members... To come and teach them how they fill in. And also to teach them how we share out.*

The VSLs are part of a focus on the 'economic empowerment' of persons with disabilities. Set against the larger backdrop of globalisation and Malawi's ongoing development toward a more capitalist system, the influence of the international on the local can also be seen in grassroots advocates' priorities. All of the persons with disabilities I met want to work, and most want to start their own businesses. The influence of global capitalism can be seen in a shifting emphasis toward 'entrepreneurial spirit' as a positive aim. News articles lauding this entrepreneurial spirit are printed in Malawian newspapers. Examples[36] include an article titled "Using alms to take children to school" which outlines the story of a woman who uses proceeds from begging to fund her small business, and in turn pay her children's school fees (Wasili, 2017). This

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[35] See Post-Script

[36] Articles were part of the review done of the Malawi News Agency's (MANA) online archives. See also Huque et al., forthcoming.

resourcefulness is presented as both surprising and righteous. Another story of 'astounding' economic success is presented with the headline "Charles George: Bicycle taxi operator with magical leg" (Nayeja, 2017). Some theorists and activists have criticised this "supercrip" approach to promoting inclusion as one which continues to other persons with disabilities, presenting success stories as outliers and reinforcing an individualist narrative of disability (Clare, 1999). On the other hand, articles like these also evidence the development of new schemas within a system, based on the schemas of other systems, over time and through the influence of national history: colonialism, independence, globalisation, democracy, "partnerships" with international organisations, etc.

These multi-scalar influences can also be constraining for disability advocates. Most funding comes with rules about use and reporting requirements. Funding is usually applied for, which can result in FEDOMA needing to work within another organisation's agenda and at their pace. At the same time, funders often do not appropriately consider local context, leading to a lack of budgetary support for meeting funding requirements:

> *Other activities are not budgeted for… They even require to send activity reports, which no money [is allocated for]. It's online. Using the internet. This makes them [DDF members] use their own funds to queue in the [cyber] cafes, so really, this is a challenge as well. Because the project has no issues of providing them with computers, or laptops, at least one in the districts (Cecilia, HQ).*

In addition to constraints on the use of funding, reliance on donors for funding is often unsustainable, constraining how long certain programmes can run and introducing a level of uncertainty to operations that can be damaging for movement cohesion.

The impact of the global on the local is not only in legislation or material resource. There is also the virtual schema of international solidarity that has been built up between disability rights movements across the world. For example, the International Day of Persons with Disabilities (IDoPD) is a day of action which is celebrated every year in Malawi and across the world. As an international event, the celebrations garner attention well beyond the disability advocacy community; media and national dignitaries attend, from famous traditional dance troupes to government Ministers, as depicted in Image 4 (FNs, 2018/19). Disability is 'scaled' beyond the individual and outside of strictly-DRM spaces.

Image 4. A Nyau dancer performs at the 2019 IDoPD celebrations in Salima, Malawi.

Demonstrations, including protests which close streets are also planned for these days, as seen in Image 5 below.

Image 5. Participants protest in Salima town as part of Malawi's 2019 IDoPD celebrations.

This annual day makes the international influence of the movement particularly visible, while the national celebrations maintain a specificity of focus on disability rights in Malawi.

5.4.2 Impacts of the local scale on the national and global

FEDOMA as an organisation tries to ensure impact from the grassroots at a national level by using the information provided by the DDFs in its national scale undertakings. This clearest example of local impact on national and global priorities is explored further in the next chapter, as it is impacted by which voices from the grassroots are actually heard within FEDOMA and relayed ‘up’ to the national scale. The relationality of agents, actors, and structures demonstrates that at some level, all interaction has impacts across spaces and scales, even if it is solely in the reproduction of existing structures. In this section, I explore more direct examples of the cross-scalar impacts of local organising in broader communities and systems outwith

FEDOMA, to emphasise the broader transformative potential of local organising. FEDOMA is actively altering the conceptualisation of disability at the level of the individual and ‘scaling’ it into a broader issue. At the same time, I discuss how marginalised peoples’ voices being heard at these scales may not achieve a tangible change in schemas or access to resources back at a local level. These processes of broadening the scope of disability face challenges of engrained social schema which consider disability an individual issue.

One example of the impact of the local on the global in the case of Malawi, and the complexity within this seemingly simple sense of movement across scales, is in the international recognition of violence against persons with albinism. This recognition was the work of civil society organisations and NGOs, and eventually national governments, working together. Through long-term efforts of organising (from within several sub-Saharan countries - demonstrating inter-systemic locality which belies simple scalar classification), this problem has in recent years received a large amount of media attention, spurring international recognition of the violence. Working with the media is a key aspect of organising in this case, and media involvement enabled the stories of violence to transcend borders and enter spaces of international concern and governance. In 2014, the UN launched the first “International Albinism Awareness Day” (United Nations, n.d.a) and in 2017, the European Parliament passed a resolution condemning the violence, in which the Association of Persons with Albinism in Malawi (APAM) is specifically mentioned (European Parliament, 2017). Malawi was one of the countries visited by the UN’s first Independent Expert on the Enjoyment of Human Rights by Persons with Albinism (United Nations General Assembly, 2017). Amnesty International has run campaigns to address the violence against persons with albinism in Malawi (Amnesty International, 2016; 2018). The extent to which this global impact in turn has a reciprocal impact on the lived experiences of persons with albinism is yet to be determined. Amnesty International (2018) reported a decrease in instances of violence after the release of its first report on this issue, but a “resurgence in attacks the following year” (p. 2). Malawian activists continue to engage in cross-scalar work to keep this issue in the news and on international agendas, through engagement with local and international media, participation in international for a, and engaging the support of individuals with wider platforms. For example, Lazarus[37], a Malawian musician with albinism, has become a worldwide sensation in the last several years, and uses this platform to continue to bring attention to the experiences of people with albinism (*Lazarus*, 2019). APAM works with the media to communicate their message and de-escalate the graphic descriptions of violence by reporters (Massah et al., 2016). At the same time, there are challenges to this engagement – for example, APAM has struggled to convince media outlets to use person-first language in their descriptions of persons with disabilities (Ibid.).

Advocates often undertake awareness-raising campaigns to combat violence in dangerous spaces. During our time visiting local community members in D1, Mallory told me about her plans to attend an event the next day. She expressed confidence in her group's ability to change some minds but also spoke of the potential dangers, which she also discussed during her interview:

> *…During the rallies, we are able to go there and speak more special things like understanding albinism… the people are being killed… Different things… happening to people with disabilities, for example albinism, as I've already said, and we're able to talk through those rallies. Through those meetings in the villages and in different places that we are supposed to be… cared for, or security has to be there (Mallory, D1).*

The members of APAM travel to these events in groups, hoping to discourage attacks through strength in numbers. Mallory (D1) linked feelings of security to the relationships her DDF had developed with the police: *"There is also a good relationship with the DDF and the police. Because sometimes, they do visit our homes for security, just come and chat with us, ask us maybe things which are hard to ask. This time, to say for sure, things are getting better."* Mallory expressed a great deal of belief in herself and walked confidently around the community in which she lives and works as a teacher. Despite the danger, Mallory performed belonging in these spaces, and over time this formed part of a resistance to violence which has increased other

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[37] I met Lazarus during a Scotland-Malawi Partnership event in 2019.

community members' acceptance of people with albinism in those same spaces. Mallory's movements are part of her performance of voice. Persons with albinism's physical presence in public spaces, demanding their rights, is a powerful statement against elements that might harm them. Compelling expressions such as these are part of the reason this issue captured international attention. However, without narratives, schemas, and resources of disability rights, Mallory is an individual whose albinism is perceived by most others to be entirely located in her own 'deviant' body. As schemas have been altered over time – through the reciprocal work of local advocates and international organisations, she now has a different set of resources with which to alter her position. Albinism, including Mallory's embodiment of it, is rescaled into a national issue, and the violence against persons with albinism is now where deviancy lies (to an extent). Similarly to Pain's (2014) conceptualisation of domestic violence as "everyday terrorism", the albinism-related violence and terror imposed upon Mallory is a political issue, not simply an individual one. Mallory and others' determination to participate in community life form part of the on-going performances required to alter schemas, even though the pace of change is frustratingly slow for those living in fear for their lives. Despite the political change of recent years across a variety of scales, the on-the-ground work of advocacy continues, especially in the translation of political declarations into practically safer communities. In fact, before the 2019 elections in Malawi, international news reported a surge in violence against persons with albinism in rituals meant to bring luck to candidates (Economist, 2019). This demonstrates the continuous, negotiable processes of structuration and the need for on-going action to sustain tenuous change. A recent study highlighted broader challenges to sustainable change around the exclusion of persons with albinism in Malawi, including widespread lack of knowledge about albinism within communities, combined with the entrenched superstitions discussed in the introduction (Section 1.1.2.2.2) (Tambala-Kaliati, Adomako and Frimpong-Manso, 2021). These associations highlight the challenges to changing social schema in post-colonial countries such as Malawi, in which long-held superstitions conflict with evolving information around the 'science' of disabilities such as albinism (which emphasises persons with albinisms' normative humanity) and human rights combine with the difficulties in dispersal of information about albinism in a believable way, to a large enough sector of the population to significantly alter violence against persons with albinism. The study also notes that the murders of people with albinism in 2015 contributed to further isolation of persons with albinism from their communities, as friends of persons with albinism fear becoming suspects in police investigations of violence (Tambala-Kaliati, Adomako and Frimpong-Manso, 2021). This isolation highlights an unintended consequence of increased awareness of and enforcement of rights, presenting a new challenge to DRMs. This development may contribute to continued stigmatisation, constrain advocates' efforts to alter relevant schemas, and enable future violence, such as that seen in 2019.

5.5 DORMANT AND UNINTENDED OUTCOMES OF THE DDFS' AGENCY

Examples in the preceding sections largely come from disability advocates' discussion of what Giddens (1984) would classify as, the "intended outcomes" of their work. Voice and communication can only go so far, and any exercise of agency can go differently than planned. If we utilise Giddens' (1984) notion of intended outcomes to describe situations where the outcomes of an action successfully match the agent's original plan, then logically we might extend it to say that unsuccessful outcomes, or outcomes that are successful but in ways that differ from the agent's original plan, can be thought of as unintended[38]. Unintended outcomes can be both negative and positive, though most of those relayed by interviewees could be categorised as unsuccessful. However, these unsuccessful outcomes largely come in the form of *dormant* outcomes; advocates report activities which do not make an *observable* change at that moment in time, as opposed to a conceptualisation of unsuccessful outcomes as those which make situations worse for persons with disabilities. For example, a first interaction with a government official may not lead to an immediate change in behaviour but may prime said official to be more receptive to future outreach. These two categories of outcomes are both 'unintended' but do not belong in a category together. For example, some

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[38] I acknowledge here that any exercise of agency could have unintended results in addition to the intended ones, but without hearing from an individual affected by those unintended results, it is difficult to measure or discuss them.

of the DDF members interviewed said that while officials and TAs say they are willing to engage with the DDFs, they do not always see that willingness translate into action, particularly when it comes to service and resource provision. For example, Charles (D4) told the following story:

> *You know these people are… I can call them politicians. Another ministry we targeted was Agriculture… They told us they were going to implement our recommendations… They have what they call… lead farmer. So, it's an area where they share in the ideas on farming. So, we said, "All these farmers, you see there is no one with a disability." You see… They promised… Later on, we discover that they didn't. We had to go back to them… They say, "How can we make someone with a disability lead farmer?" And yet, when we were talking to them, we're like on the same… line… So, we say, "Is there any farmer with a disability who is successful?"*
>
> *"Yes, in fact there are a few of them..."*
>
> *"One of them, you can make lead farmer."*
>
> *So, you can actually see that it's... a bit political. You are not really sure… whether they are getting our message or not. 'Til when they start implementing.*

Giddens (1984) does not provide for a differentiation between unsuccessful and dormant outcomes in his use of intended and unintended outcomes, despite the contribution of the dormant outcome in reproducing and altering structures. I argue that dormant outcomes warrant further consideration as contributing to the gradual changing of schemas over time. A dormant outcome provides a space to consider outcomes whose impact on structures is unknown. A dormant outcome may still result in changes to individual agents' thoughts on an issue, despite no *observable* change at that moment in time. This may result in the reproduction or alteration of structures, depending on actors' future exercises of agency. In Charles' example, the first instance of communication led to a dormant outcome, masquerading as an unsuccessful outcome - no observable change in schemas. However, the next expression of voice around the same issue did lead to a change. This 'successful' outcome may or may not have been influenced by the agent's experience in the previous dormant outcome moment. This consideration of dormant effects has been explored in other fields.

For example, Butler (1993) emphasises that the reclamation and transformation of the term “queer” by the queer community does not entirely dispel the potential for negative meanings to re-emerge. The lack of impact from an expression of voice does not mean that it cannot contribute to an individual’s cognitive processes and future actions. In Butler’s (1993) example, the reclamation of a negative term retains the possibility that it may be redeployed, and its older, derogatory meaning could re-emerge. Turning this logic on its head, even when new resources appear to lie dormant and are producing no effects, they retain a potential energy. They can be animated at some future point if the conditions are right or if other resources somehow link to them or energise them. Dormant outcomes can contribute to a ‘chipping-away’ of entrenched norms, contributing unobservable changes to schema which may ultimately result in an observable change. I propose adding the dormant outcome to represent this ‘lack’ of change as an unknown impact within structuration analyses.

The continued violence against persons with albinism in Malawi provides an illuminating example of the complexity of outcomes. While the DDFs and FEDOMA have run multiple campaigns to address the issue of violence against persons with albinism, from local trainings to funded projects to protests, this kind of violence is still a major issue in Malawi. Here the issue of scale is important - DDF members reported changes in the beliefs of their friends and neighbours, but the overall problem has not been stopped. In this, defining the measure of the intended outcome is important, and depends on the intended scale of change. For example, if the outcome measure for the DDFs’ organising around attitudes towards those with albinism were increased acceptance in their home communities, then perhaps we could say that they had achieved the desired outcome, at least in part, when talking about efforts within particular communities. But if the overall outcome measure were the total end of violence against persons with albinism in Malawi, we *could* report a dormant outcome. The DDFs’ work did not make the violence worse, but they did not stop it, either. They may have, however contributed to ‘chipping away’ at schemas that encourage violence in a way that will not be clear until farther into the future, if at all. In this example, we see the impossibility of eradicating oppression, stemming from the same processes of individual empowerment that enable social movements to start. As society changes around them, some individuals’ sense of their own agency and steadfast belief in the positivity of past social structures enable them to resist change, even as the rest of society changes around them.

Other examples of unsuccessful use of a resource raise questions about whether the resource was utilised to the fullest extent possible. 'Possibility' in these cases is dependent on the cultural schemas that constrain agents' performances of voice. Change in the way advocates use communication is more likely to change the outcome in these cases, because the lack of a successful outcome is less dependent upon external agents choosing not to alter their behaviour based on the communication received. For example, I attended a monitoring and evaluation (M&E) meeting for a DDF in one of Malawi's more 'modest' districts. Malawian schemas of 'modesty' are especially strong in remote communities. This 'modesty' generally entails respect for authority, 'extreme' courteousness, formal rules for social interactions, and not speaking out or drawing attention to oneself (Scotland Malawi Partnership, 2015). Malawian modesty is hierarchical, class-stratified, and gendered, rooted in consideration and care for community members and adherence to established social schemas. For example, the wearing of the chitenje cloth over clothes is part of women's performance of modesty[39] (McBride, 2006). Concerns for modesty can prevent individuals, especially women from seeking medical care for 'private' issues (Kohler et al., 2017; Moucheraud et al., 2020). Modesty can manifest as a lack of belief in one's right to stand up for oneself and difficulty in pressing authority figures on an issue. In this case, the DDF had reached out to the District Health Officer (DHO), to ask for a meeting on disability issues. The desired outcome in this case was scheduling a meeting with the DHO. The DHO brushed the DDF off, and the DDF members did not press the issue, so they did not receive a meeting (FNs, 2018/19). The cultural schemas of modesty were stronger than the DDF members' sense of empowered self-belief and agency and access to knowledge-resources about organising. When this was discussed with FEDOMA's monitoring and evaluation (M&E) officer, she gave the group an impromptu class on performing advocacy – how to be polite but firm and persistent when requesting meetings with officials, how to tap into other

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[39] I wore a chitenje during fieldwork as a demonstration of respect for local schemas. As an outsider, this was commented on and ingratiated me to the community members with whom I interacted.

networks to gain additional support and backing to put pressure on officials. The group agreed to go back and try again with the DHO (FNs, 2018/19). While this may not result in a change in behaviour immediately, the group was energised and expressed feeling more empowered than at the beginning of the session. This sense of greater empowerment within a safe space may be difficult to re-perform in external spaces, as Kesby (2007) points out. However, it may also have provided a usable enough resource to the group that they are able to engage more confidently, for example by returning to the DHO. Over time, small adjustments like this can help to alter the strength of constraining schemas, contributing to an individual's evolving sense of empowerment, and changing the extent to which it is possible for a given individual to utilise resources and express agency. Ultimately, shifts in belief in personal agency can lead to changes in the outcomes of advocacy activities.

5.6 CONCLUSION

Resources are critical to performances of empowered agency. Voice is both a resource for and an outcome of processes of individual and collective empowerment. An individual's feelings of agency may impact how voice is performed at a given point in space-time. At the same time, performing voice can reinforce feelings of empowerment. In Charles' tale of his school years, he engaged in on-going processes of empowerment and performances of voice. By achieving some of his goals with each expression of voice, he was encouraged to continue when he reached the next obstacle.

FEDOMA advocates use expressions of voice as deliberate actions of social justice. At the same time, their voice (or an alternate but connected voice) is expressed as much through 'doing' and 'being' (occupying space) as through speaking. The (strategic *and* unconscious) everyday resistance of persons with disabilities is entangled with purposeful, movement-based resistance. These actions involve challenging and working within the 'accepted' and 'appropriate' in a given space, as evidenced through the engagements with TAs, district officials, and community members discussed in this chapter. Over time, persons with disabilities' acceptance into the community 'mainstream' demonstrates a disruption of established norms and the creation of new ones - an alteration of the structures of a given space.

Entangled with the immediate space-time of a given action are the multi-scalar interactions of structures and agents. These interactions highlight the relationality of structuration processes. Schemas and resources within a particular structure impact other structures, multiple structures form a system, and systems interact with one another and with each other's structures. The continuing violence against persons with disabilities (especially albinism) in Malawi provides an example of the complexity of outcomes and multi-scalar interaction. Performances of voice by many local advocacy groups across several national systems successfully drew the attention of an international audience to the issue of violence against persons with albinism.

Despite the potential multi-scalar impacts of expressions of agency, those impacts are not always equally reciprocal or clearly discernible. In the albinism example, there was little impact seen in the everyday lives of persons with albinism in places such as Malawi that could be attributed to international, inter-systemic campaigns. Despite grassroots voices being heard in spaces with much larger platforms, reaching a greater number of individuals, the violence persists, and in the case of Malawi, rose prior to the 2019 election. On the other end of the spectrum, the actions of individuals with albinism, such as Mallory, within their local communities did have a discernible impact on specific community spaces, in addition to inter-systemic impacts at the UN. While the problem has not been and may never be eradicated, the cultural and legal structures which enable violence against persons with albinism have been altered at local, national, and international scales. This may in turn provide supporting evidence for the necessity of locally focused disability movements. Local engagement in areas where this issue is culturally relevant has generated greater impact than a broader, internationally focused campaign. At the same time, this distant support has been useful in redefining deviance and re-imagining albinism beyond individual bodies. International support may also prove to be useful resources for albinism advocates in the future, as other UN declarations and campaigns have for the broader disability community, used in the spaces in which violence occurs. Rituals using persons with albinism's bodies are intrinsically tied to the hybrid cultural structures within Malawi.

Those running for office may turn to sacrifices and magic in order to achieve success in an election – demonstrating the collision of modern Malawian political and cultural structures with those which are longstanding and more difficult to alter to the point of eradication. The potential for changing those structures lies with those who understand them and those who believe in them - advocates like Mallory who express confidence and empowerment in the face of danger.

In this chapter, I explored the ways in which voice is a vital resource for FEDOMA's disability advocates in engaging with their communities. These expressions of voice are grounded in the embodied experiences of marginalised peoples as knowledge. In addition to the multiple voices of a given individual, a collective voice can arise from shared experiences of marginalisation. Advocates use the collective voice to present a united front to a broad audience, such as during FEDOMA's national-level public events. However, voice as a resource is also accessed, performed, and heard and *listened* to within FEDOMA as an organisation. In the next chapter, I explore the ways in which voice is performed and heard internally across FEDOMA spaces, focusing in particular on the personal-political, relational resources which drive voice - emotion and trust - and which can contribute to the development of leadership, engagement, and disillusionment of individuals and collectives within the movement.

6 FINDINGS 3: THE IMPORTANCE OF PERFORMING HEARING AND *LISTENING* - EXPRESSIONS OF VOICE WITHIN FEDOMA

In this chapter, I focus on the internal dynamics of FEDOMA as an organisation. In particular, I explore those factors crucial to the link between the organisation and its grassroots participants (human resources), which FEDOMA relies on to effect change (RQ2). I consider the role played by grassroots voices within the organisation, how grassroots members perceive organisational representation, and whether grassroots experiences are understood by those at FEDOMA HQ and reflected in the broader objectives of the organisation and its national-scale undertakings (RQ2c).

Voice can have just as much of an impact *within* a given social movement as it does in wider society - perhaps more impact, given the predisposition of social movement actors to the ideas espoused by its members. Swerts (2015) highlighted that changes to a group's approach to and strategy of activism happen as a result of amplifying different voices within activist circles. However, ensuring that grassroots members 'have a voice' within a movement can be challenging, especially when (i) grassroots membership is rapidly growing and (ii) grassroots outposts are physically distant from organisational HQ. Developing the local and experiential, embodied knowledges of grassroots members can be critical sources of information for social movement organisations, providing opportunities for internal growth and evolution. It can also be difficult to ensure that all members can participate to the extent that they wish. Dowse (2001) emphasises that social movements are internally heterogeneous and that "collective identities… are not fixed but rather express a relatively fragile social composition" (p. 132). This internal heterogeneity informs on-going processes of organisational development. The internal and external contexts within which FEDOMA's DDFs operate impact members' perceptions of their relationship with HQ. At the same time, as an umbrella organisation focused on collective action, FEDOMA seeks to present a unified front for the movement. Dowse (2001) goes on to note that "the disability movement, like many social movements before it, faces this task of maintaining coherence" (p. 132). Meyers (2014) also points out that participation and centralisation are both necessary for a social movement to be effective, but there is difficulty in maintaining the balance between them. How social movements navigate the creation of a cohesive organisation with the inclusion of diverse viewpoints is one of the challenges in popular organising today, as emphasised by feminist strategic essentialism (Spivak, 1988; see also Kelly, 2010; Sharp, 2011a, 2011b). Kelly (2010) highlights the use of "strategic essentialism" to unify disparate disability groups in the USA's independent living movement. This approach moves away from a fundamentalist approach to marginalised identity and emphasises that individuals within a movement *perform* group characteristics and solidarity: "Rather than asserting that individuals in a group have something fundamentally in common and thus they can act as a movement, strategic essentialism suggests that individuals can collectively perform a set of characteristics in order to further the goals of a social movement" (Ibid., p. 4). At the same time, this approach is only effective with membership buy-in and participation in the performance. FEDOMA leadership's approach to strategic essentialism attempts to integrate grassroots priorities into the national organisation's focus; in this chapter I explore the extent to which they are successful in creating an inclusive collective voice, from the perspective of the grassroots. I use interview and participant observation data to explore the extent to which the grassroots membership of FEDOMA feel they are represented by the national collective and the extent to which they perform solidarity with the organisation as a result. I consider the role of empowerment, emotions and trust, leadership, socio-spatial context, and individual and collective identities in producing, reproducing, and altering relationships between FEDOMA and its grassroots outposts.

6.1 INDIVIDUAL IDENTITIES: EMPOWERMENT, LEADERSHIP, AND THE IMPACT ON COLLECTIVES

The development of lay community members into grassroots advocates is important for FEDOMA in combatting constraining societal schemas, especially in its continued devolution of operations to more local spaces and development of voice as a collective resource. In many of these spaces, people with disabilities have not yet developed the sense of self-belief that Sadan (1997) highlights as critical to processes of individual empowerment. They do not yet *feel* empowered enough to exercise their agency (express their voice) or feel that if they do, they will not be heard. This disempowered feeling results from negative emotional experiences and lack of access to resources and spaces that support, rationalise, and legitimate their experiences and encourage engagement with empowerment processes. For example, in many TAs*[40], persons with disabilities are not encouraged to participate in community forums. In addition to this exclusion, drawing attention to themselves may invite physical or emotional abuse. However, if Malawians with disabilities do not feel safe speaking out in their communities, others in the community may take this in itself as evidence that they are not 'capable' of contributing to the community narrative. This conceptualisation on the part of community members may contribute to the reproduction of constraining schemas, enabling oppressors to further marginalise people with disabilities. In such a scenario, the interconnectedness of individuals' feelings of power and a social movement's actual power are highlighted. Developing individuals' feelings of power and agency can grant the organisation and the movement access to more spaces and

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[40] 'Traditional Authority/ies' can refer to both a person and/or a place. For this thesis: 'TA/Tas' = person and 'TA*/TAs*' = place.

resources, which in turn constitute and develop agency, concurrently developing collective and individual empowerment.

6.1.1 Engaging individuals in processes of empowerment: developing a grassroots base

In order to understand the impact of voice within FEDOMA, it is first necessary to discuss the ways in which the organisation has provided resources and spaces for the development of its grassroots base. In addition to generating support and human resources, this approach ensures the organisation's ability to work and evolve within Malawi's legal structures, especially those which devolve implementation of national policy to individual districts. One of FEDOMA's priorities in setting up the DDFs was to train individual persons with disabilities to be local advocates. For many of the advocates, this was a key point in the processes of individual empowerment which helped them to constitute their voice(s) as a resource and develop an advocacy identity. Through recognising the embodied knowledge of persons with disabilities, educating individuals on their rights, and emphasising their humanity, FEDOMA recruited its grassroots base. In doing so, FEDOMA evoked individuals' emotions to motivate them to join the movement, drawing on negative past experiences and presenting a positive vision for the future. This approach demonstrated that these experiences, while individual, are also shared, combatting feelings and experiences of isolation. These processes rescale what it means to have a disability, continuously shifting between the individual and the collective in different spaces and at different times. During recruitment, persons with disabilities are presented with the possibility of change through their own development into empowered change agents. This is achieved through advocacy work and the resources collective advocacy can provide, including safe spaces to develop their voice(s): in the physical spaces of the DDF meetings, the intellectual space to be able to think differently, and the emotional space to reveal vulnerability and find support. While undertaking fieldwork, I participated in Area Disability Forum (ADF) formations. These bodies echo the DDFs but cover smaller areas. The ADFs are set up in the same manner as the DDFs. These events offered a model similar to the original, though at a different scale and time. One difference of particular note is that DDF members participated in the ADF formations in a leadership and 'bridging' role. ADFs and DDFs are meant to work closely together, and development of ADFs is primarily being undertaken in areas with well-established, 'successful' DDFs. During the ADF formations, the DDF Chair, an individual well-acquainted with both the local community and FEDOMA staff, encouraged local DPO members to engage in the process and introduced FEDOMA agents to the community. At these empowerment-focused events, performances of voice and hearing and *listening* were used to evoke emotion within the participants and encourage them to engage in this new forum, dispelling feelings of isolation and generating collective solidarity, which I recalled in my autoethnographic accounts of these events:

> *George [FEDOMA staff] and Lyric[41] [Parents of Disabled Children Association of Malawi (PODCAM) representative] gave rousing speeches to the crowd, talking about their rights as persons with disabilities and the fundamental tenants of activism within FEDOMA. Lyric, a powerful representative of PODCAM who also has a physical disability, told the assembled crowd stories of injustices committed against their community and the work done by FEDOMA to rectify those injustices. She discussed an 'Access to Justice' project case, responding to a question about a similar situation in this area[42]. Just that morning, Lyric had told me about the case during our travels to the event. It involved the rape of a young, non-verbal child with impaired mobility. She was assaulted and impregnated by a family member. The FEDOMA groups involved in Access to Justice worked with police and the Malawi Human Rights Commission (HRC) to ensure the perpetrator was imprisoned. She said they hope to work with police to develop the programme further, and that hopefully it will help to discourage violence and combat corruption within public services. The rollercoaster of*

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[41] Pseudonym

[42] For further information see: Huque and Amos, 2017.

> *emotions I experienced was reflected back to me from the audience, in the crowd's expressions and reactions – anger and frustration giving space to hope and determination.*

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> *Towards the end of the meeting, George addressed the crowd again. He encouraged the newly formed ADF to work together. He reminded them about the commitments made by the local representatives who participated in the event (whose enthusiasm and participation I found pleasantly surprising) - among them the police, TA, village heads, and head teacher - to aid the disability community, and encouraged them to go to these officials with their problems and concerns. He reminded them of their specific rights, including that of children with disabilities to attend school. George told the new committee to "be empowered" and start working from today, telling them that it is their right to fight for their rights. As he spoke, I could feel the energy in the room lift (Autoethnography FNs, 2017).*

Stories of the dehumanising injustices experienced by persons with disabilities brought to the surface negative emotions associated with the assembled participants' current situation. Messages of hope and declarations of possibilities for change in the future validate these negative "bodily memories" (Routledge, 2005), while encouraging emotions such as joy and hope in considering a better future. George and his counterparts are not only empathising and professing hope: they are developing a new collective, motivating the group toward unity by providing knowledge. This is part of the process of 'collectivising' experiences of disability, scaling disability, and re-locating the 'problem' which creates negative experiences in the normative social imaginary and not the body. This knowledge focuses on a legal structure of rights as resource. The effect of this newly acquired knowledge is a heightened sense of injustice which supercharges the emotions in the space, based on an understanding that there are alternate schemas, which in turn imply knowledge within Malawian civil society that these injustices are wrong; the local schemas are not to be expected and endured, but can be altered and there are already resources in place to do so. The rallying cry of *"disability rights are human rights"* (Autoethnography FNs, 2017) was a particularly powerful message to spread in areas where persons with disabilities' humanity is questioned; these declarations were met with cheering, clapping, and singing by participants. This declaration again situates disability as a global issue, scaling the experiences of individuals into a condemnation of broader structural issues instead of deviant bodies. Rallying behind simple, strong messages from the FEDOMA repertoire enabled the FEDOMA representatives leading the sessions to encourage the group's buy-in of the collective and its goals. The circulation of empowerment discourses and emotions in a space where representatives of disability organisations hold authority alongside more traditional authorities (with the power to support the empowerment of the marginalised in their communities) reinforces the potential of advocacy to make change in individuals' lives. The events drew in public figures and forged connections with them, through officials' *public* performances of voice – commitments to disability rights that can later be held up as leverage; retelling stories of public officials' engagement and speeches can be a resource in advocates' repertoire.

Lyric and George's speeches demonstrated that voice can be used to engage other members of an oppressed group with a relevant social movement through the expresser's emotional labour, used to elicit an emotional response in audience members (Bosco, 2007). As an audience member, even I felt emotional responses akin to those the FEDOMA staff hoped to inspire in listeners, as mentioned in the autoethnography excerpt. I could see that my own emotional experience when listening was experienced (more so) by the target audience. Facial expressions, spontaneous exclamations and clapping, group singing, excited conversations, and other expressions evidenced the emotional reactions generated in the crowd by event leaders' expressions of voice, enabled by the very legal structures which they introduced to the audience (Autoethnography FNs, 2017). The intended audience of the FEDOMA representatives' performances of voice was potential advocates *and* allies; the emotional connection forged in these spaces is intended to entice the audience into acting for disability rights outside of the immediate space, when the crowd has dispersed, the energy died down, but the bodily memories remain. These performances emphasise persons with disabilities' humanity in the rallying cry, establishing a connection to non-disabled audience members, who can be moved by other humans' emotional experiences - as long as they think of the 'deviant other' as human. Bosco (2007) argues, "emotions are often strategic to activist mobilisation and to the sustainability of activism across space-time" (p. 549). During my fieldwork, this effect was visible among audiences listening to inspirational talks given by current activists, especially leaders.

Sometimes, however, schematic obstacles to the effectiveness of empowerment through storytelling became apparent. The Malawian 'modesty' discussed previously can constrain the development of an individual's confidence in their own agency. In the field, this sense of modesty conflicted with the desire of current and potential advocates to fight for their rights. During the ADF formations, this may have been reinforced by experiences of public meetings as spaces where 'common people', and especially persons with disabilities, do not get to speak. As much as the ADF spaces being created were empowering and supportive, they were also brand-new, unusual, and uncomfortable for some participants:

> *The process of this second ADF formation takes longer and is a bit more confused. Partway through the event, the DDF Chair tells me that people are failing to put themselves forward [to join the ADF] because these villages are typically very modest. Norms around modesty are less ingrained in the district's main town, where the previous group was based, so the ADF formation process was easier. However, in these remote areas, people often do not know their rights or have the confidence to put themselves forward to push for the realisation of those rights. Eventually though, we get to the point where registration of the new ADF members has taken place… Modesty slows the process down again when George asks the new ADF members to put themselves forward for committee positions; people seem to be particularly hesitant about the role of treasurer. We get through the nominations and move on to voting, with George, Lyric, and the DDF Chair shepherding the group through, like schoolteachers in a classroom of shy learners. I was surprised by the conflict and tension between shyness and modesty and passion and struck by the courageousness that seemed infused in just the act of stepping forward – because these actions were so much harder for this group. I join in with the crowd in celebrating their new ADF Chair. The young man elected chair buried his face in his hat when his name was called and the group clapped.*

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> *Despite the quiet and shy nature of the group, they elected a chair with albinism, in the face of a very recent local grave desecration in which the body of a person with albinism was dug up to be sold for use in spells and rituals. This seemed to me to indicate a certain level of defiance toward the oppressive elements of the community, or maybe simply a desire to uplift their most marginalized members (Autoethnography FNs, 2017).*

The modesty of this ADF group is reminiscent of Power et al.'s (2016) findings regarding shyness among some new disability self-advocates in the UK, who "did not self-identify as confident and/or vocal people… many in the groupthink session admitted being initially very shy and only built enough confidence to contribute to a group over time" (p. 187). Situations such as these, observable in the minority-world, are potentially critical for understanding disability in majority-world contexts such as Malawi. In Malawi, deeply ingrained hierarchies, systems of modesty, neopatrimonialism, and hostility toward persons with disabilities are prevalent and public. Broader understandings can contribute to an examination of the way in which common experiences among persons with disabilities worldwide are compounded and magnified within particular contexts. The new members of the ADF discussed above belonged to DPOs and seemed to have built enough confidence to join the new group, if with difficulty. Over time, participation in the ADFs may continue to grow this confidence. Upon my return to Malawi in 2018/19, I interviewed the ADF Chair from the first group. While the schematic modesty for that group had been less intense, there was still a noticeable increase in his confidence and willingness to speak out about the issues facing his constituency from the year before (Int3; FNs, 2018/19). In the case of the second ADF, the life-or-death struggle of persons with disabilities (of which they had a recent example) conflicted with the modesty of the citizens. These schemas are constraining and mutually reinforcing for persons with disabilities: their treatment in society and the expectation that they will not cause disruption in their communities. However, FEDOMA as an organisational system engages agents in structures which enable them to combat schematic constraints, beginning processes of individual and collective empowerment. FEDOMA structures and societal ones are in this case at odds, as is fundamental to social movements. The conflict between the two requires agents to make decisions about engagement based on their trust in FEDOMA. Their assessment of trust in FEDOMA is based in part on emotional responses to the legitimisation of their embodied experiences, including through the telling of stories and speeches during meetings and the evidence provided of a possible better life and the resources to achieve it. The speeches also emphasised the need to speak out, the power of voice, and the broader base of support FEDOMA could provide. These factors impact community members' assessments of FEDOMA's *morality* (making positive changes for persons with disabilities) and *capability* (the resources to make those changes happen) as discussed in the work of Purdue (2001), in deciding whether to join and/or deepen their advocacy work.

That these induction activities took place in person was crucial to developing newly inducted advocates' trust in the movement. Bosco (2007) found that personal visits from distant heroes/leaders/role-models "cemented their [activists'] emotional connections" (p. 553). Moore (2006) similarly discusses "facework" (derived by Giddens, 1990) as critical for building trust. The initial empowerment activities FEDOMA presents are done in-person, emphasising the importance of that proximal connection in setting off or pushing further processes of empowerment. At the same time, FEDOMA uses a strong identity-driven basis for unifying groups across the country. This may mitigate against the idea of trust networks as necessarily physically close in space. By developing a passionate and positive emotional connection to the broader organisation at these events, FEDOMA attempts to create "organisational geographies" that transcend physical and social distance and are strong enough to last over time (Bosco, 2007) and space. The distanciation (see Kesby, 2007) of FEDOMA raises questions about, and potential problems related to, the impact of spatiality on trust, which I discuss in more depth later in this chapter.

The in-person events also provide an example of leadership from the centre, "shaping expectations about the behaviours and intentions of the members of a collectivity" (McEvily, Perrone and Zaheer, 2003, p. 98). As part of developing the collective voice and discursive language of the movement, FEDOMA staff and national movement leaders engage in "facework" (Giddens, 1990; Moore, 2006) and encourage DDF members to emulate them. Facework is inherently spatial; by coming to meet and thus alter marginalised communities where they live, representatives demonstrate an alternative way of being to the community, build new spaces of support for persons with disabilities and create change in everyday lives and spaces.[43] However, FEDOMA staff cannot always maintain a presence in these spaces, and the empowerment processes and advocacy work begun at these formation events has to continue through the agency of local collective members. Just as individuals from FEDOMA help the ADFs and DDFs to start, individuals within these new groups impact whether they carry on or dissolve. Returning to the DDFs as the main unit of focus, in the next section I discuss the role of individuals in the DDFs further, including formal and informal leaders.

6.1.2 Individual voices and local leadership: DDF internal politics

The small size of the DDFs means that their effectiveness is closely related to the personalities and actions of individuals. The influence of individual identities on the group was raised in interviews by both DDF members and FEDOMA staff. It was also visible in-situ during participant observation. When looking at individual influences on the group, in addition to the feelings of empowerment discussed already, it is important to consider critical agents' actions, norms surrounding the official leadership roles within the DDFs, and the way these bring conflict and/or cohesion to the local group setting.

Agents' actions, particularly those that forge connections between individuals, disseminate agents' knowledge (Bunnell and Coe, 2001) to advance their cause. The individual's knowledge informs their actions, and their actions help to spread their knowledge and influence others, reflecting the interplay between virtual schemas and 'actual' resources in constituting structures. In the global justice network literature, individuals with particular influence are called "imagineers," (Routledge, 2009) the descriptors of which are similar to Englehart and Miller's (2019) critical agents. Imagineers very specifically facilitate solidarity (Routledge, 2009) - so some, but not all, critical agents could be considered imagineers. The FEDOMA staff who led empowerment activities and inducted new advocates into the DDFs and ADFs could be considered

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[43] This is arguably decreasing in importance with continued development of video-calling technologies, however these are often unavailable in the physical and infrastructural contexts in which the DDFs work.

imagineers, as their role was specifically to encourage solidarity and participation. Routledge (2009) emphasises the cultural capital of imagineers. In FEDOMA's DDFs, imagineers and critical agents more broadly were often those in leadership positions; those who become leaders in movements are often those already in advantageous positions (Foster-Fishman, 2007; Kelly, 2010), reflecting broader normative social hierarchies, including those that constitute standards of 'modesty'.

6.1.2.1 Who becomes a DDF leader?

Each DDF is established with a governing board to guide its activities and delineate roles, as well as to meet FEDOMA and external funder requirements for any funded district activities. The core positions are Chair, Vice Chair, Secretary, Vice Secretary, and Treasurer. Some DDF boards also include representatives from other local organisations, such as Village Development Committees (VDCs). If there are ADFs within a given district, the ADF Chairs represent the ADFs to the DDF. Not all DDFs fill all board positions, based in part on the capacity of members to undertake the requirements of the roles.

Cultural (and social) capital is directly related to the material circumstances of individuals and the enabling and constraining schemas that effect that materiality. Of the four DDFs I conducted interviews with, two were chaired by teachers, one by a community health worker, and one by a retired secretary who now runs a small business (FNs, 2018/19). For a community which suffers from high levels of unemployment, having leadership all in the workforce, and most in jobs which require tertiary education, is significant. This is not to say that these individuals do not face significant struggles in their own lives, but that there are enabling schemas which produce resources within their lives, resulting in better material circumstances than many of their peers. This material advantage is likely taken into consideration by the DDF members when voting for leaders, considering that certain skills and access to particular resources are necessary to undertake each role. For example, one of the official duties of a DDF Chair is communicating with FEDOMA and sending reports to HQ. It would be difficult to undertake these duties without access to a phone and funds for minutes, among other costs. McDwellings, D2's DDF Chair, described the financial toll the role took on his life:

> *And in reporting, we face challenges… Sometimes we delay in reporting, because I can travel maybe from where I am… 25 kilometres to [neighbouring district]. To report, and with this electricity… On and out, it means sometimes you miss… the electricity. It means I can stay here; I go tomorrow… So, it is very hard. And there is no other way that FEDOMA can do at the moment… But it is through the funds. Communicating to us is about funds.*

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> *We cannot manage. So, myself, I have been sacrificing myself. Using my own what? Money. Pocket. Taking advantage of the work I am having. I take that advantage because what I want - I want to assist someone. From what I have.*

McDwellings was able to undertake the responsibilities of Chair - including travelling to the nearest post office, in the *neighbouring* district, to mail reports to FEDOMA - in part because he is a salaried teacher. Holding a good job is also an indicator of a 'better' position in the social hierarchy. As discussed in Chapter 5 (particularly Section 5.3), this higher socioeconomic position can come into conflict with the expected 'place' of persons with disabilities, in itself challenging established notions of societal hierarchy and the ability of persons with disabilities to contribute to society. At the same time, it demonstrates that disability activism is conducted within existing structural hierarchies and does not always challenge them, even internally, as those of lower (socioeconomic) status may be excluded. Many movement activities seek to enable more persons with disabilities to access the subjectivities to which other axes of their personhood would normally give them access. Those DRM agents who already have access to advantageous subjectivities may also have more success in establishing themselves as social movement leaders. A stronger socioeconomic position can increase confidence, advancing empowerment processes and counteracting constraining schemas with actual financial resource. McDwellings, for example, expressed confidence at all times during our interactions. He spoke to us about his participation in the District Peace Committee, his regular appearances on talk radio to discuss disability issues, and his promotion of accessible education from within the district education sector. He even sang a song he had written for us, explaining the lyrics after he had finished:

> *It means... persons with disabilities should at least advocate for our? Rights. Hmm? Because, this country, this world is for us all. So, we have to advocate for our? Rights. But advocating for our rights... We have to be? Courageous enough. Because it is not simple. There is fight… and we have to hold hands… FEDOMA, District Disability Forum, government, organisations, we have to hold what? Hands! Albinism, physical, or move, the epilepsy, we have to what, what? [Sarah and James:] "Hold hands"! [McDwellings:] And fight (McDwellings, D2).*

McDwellings revealed it was his dream to record the song and get it played on the radio. He brought all of this confidence into his role as DDF Chair. He described how his empowered performances of voice, including singing in his church choir, had gained him a following of people who now supported disability rights in the community (Int10). Participation in a variety of organisations, coupled with a socioeconomic or spatial-access advantage can increase an individual's self-confidence. Confidence might impact an individual's likelihood to put themselves forward as a candidate, both within the DDF and other community roles. The intersection of various community spaces demonstrates the complexity of structuration processes; the schemas and resources which impact an individual in one space contribute to expressions of agency both within and outwith that particular space. The interactions between schema and resources in various spaces are also social and relational; an individual's recognisability in a particular forum may influence others' willingness to listen to them in a different space, as McDwellings found in enmeshing his activist and church communities.

Confounding the levels of confidence an individual may have in their own leadership ability is a hierarchy of disability within the community itself (see for example Deal, 2003; Foster-Fishman, 2007; Kelly, 2010; Martin, 2012). DRMs around the world are grappling with 'disability hierarchies'. The term 'disability' broadly spans a varied and continually changing range of impairments. The constitution, experience, and definition of disability is influenced not just by physical impairment, but constantly changing subjective circumstances, depending on the interplay of time-space context, embodiment, interaction with the material environment, and governing structures (Hall and Wilton, 2017). These differences can manifest in unequal representation of particular types of disabilities within social movements. Hierarchies of disability can be both common to diverse contexts and context specific. For example, persons with albinism may be more prominent in Malawi's DRM and 'higher' in the hierarchy given the visibility of APAM and the urgency of the violent acts committed against persons with albinism in this context. In a minority-world context, albinism may have less prevalence. On the other hand, those with cognitive and psychosocial disabilities are often 'lower' in DRM hierarchies across the world, including in Malawi. Action (HQ) highlighted this issue when discussing plans to increase the inclusivity of DDF leadership in the future: '*Because some, by nature… of their disabilities, they are not… that much, you know, outgoing. So, think of someone with a psychosocial disability. To say - We want to select a Chairperson of DDF. They will not come forth and say, "We would want!"'* In addition to not being 'outgoing', individuals with psychosocial disabilities in Malawi are often those who have the most trouble accessing education and employment (Int28, FNs 2018/19). A lack of material resource to help build one's social position influences their chances of being elected to DDF leadership; this would have an impact even if those with more marginalised positions within the disability hierarchy *did* put themselves forward for leadership roles. The connections between obtaining a leadership position and material and social capital are mutually reinforcing, compounded by internal hierarchies and shutting some out from participation entirely. As a result, most of those who currently occupy DDF leadership positions have physical or sensory disabilities.

While all of the DDF Chairs I met were employed, not all board members were, so there is scope for those with more constraining material circumstances to move into leadership roles. These individuals often have other advantages, for example knowledge of rights, other/familial means of supporting themselves, access to transport, or residence in the district's central town. There are some basic geographic factors that can limit or enable access to leadership roles. Most of the DDF groups meet in the district's central town; members from outside these areas have to find ways both physical and financial to travel from their homes for meetings. As a result, most DDF leaders in less advantageous socioeconomic positions are those who live in or near the main district town (FNs, 2018/19). Their access to the group meeting place enables them to engage in leadership roles. Here we see the spaces that have been created for persons with disabilities to organise are still spaces at times restricted to the relatively privileged among them. “Time and income constraints” (Burgham and Downward, 2005, p. 82) such as these, layered with personal identity and internal hierarchies, can impact an individual’s calculations about whether they can participate in movement activities, and if so, to what extent. This is exacerbated by individuals’ historical access to spaces which can impact individual privilege, such as schooling. This internal conflict reflects the representational debates within the feminist movement discussed in the literature review; inequality within social movements is a major challenge and part of the motivation for this study of FEDOMA’s internal dynamics.

As highlighted by McDwellings, DDF leaders are also sometimes members of other village, area, and district committees. Purdue (2001) emphasises the importance of social capital in developing trust: a leader’s social capital encourages others to trust them, if they can demonstrate the development of their individual social capital into collaborative and communal social capital - that is, into relationships and outcomes that benefit the collective. One of the ways in which a leader can demonstrate their value to the collective is in developing local social capital into partnerships with other groups (Purdue, 2001). This can help an individual secure a leadership position by turning their individual advantage into a collective advantage. These connections enable the DDFs to work in a variety of spaces throughout the wider district community.

While FEDOMA does not officially restrict who can take on DDF leadership roles[44], the schemas and unequal resource distribution of systems constrains some individuals from participation. This results in a heterogeneous effect, where sometimes a higher socioeconomic status as a prerequisite for a leadership role is reinforced, but not always. The heterogeneity often relates to spatial positionality, enabling those living closer to the ‘centre’ of district life to counteract the constraints of limited material resource. This localised hierarchy in turn impacts whose voices are magnified within the local collective of the DDFs. However, the collective does not exist in a vacuum, and the contexts of life in a particular district are as important as

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[44] Beyond being at least 18 years old and a DPO member

individual identities in developing each DDF's *collective* identity and collective leadership as representatives of the broader district disability community.

6.1.3 Collective voice(s) of the DDFs

Interviewees often spoke of the DDFs as having a collective identity. The development of a collective identity for a social movement outpost is intrinsically tied to the development of collective empowerment. As discussed in the literature review, Sadan (1997) highlights the importance of a "common critical characteristic" (p. 85) (such as disability) and geography (such as the district in which one lives) in establishing a basis for formation of a community and engagement in community empowerment processes. Community empowerment processes and collective identity mutually constitute one another, generating solidarity and an on-going system of support which can strengthen bonds between members of a community. Additionally, rallying around a "common critical characteristic" (Sadan, 1997, p. 85) is a basis for the strategic essentialism required for social movement cohesion. In a group such as the DDF, place-based commonalities can help to shape the focus of this strategic essentialism, as the lived experience of life in a particular district helps the group to identify and rank priorities for action. Through these processes, the DDFs as collectives become representative leaders for local persons with disabilities, attempting to form a cohesive approach to solving local problems and empowering local people. Just as FEDOMA represents Malawi's national disability community, each DDF represents their district community; the contextual factors of life in a particular district impact the development of its DDF. Take for example, the previous discussion of education as contributing to DDF leaders' social capital. In some districts, education is harder for persons with disabilities to access than others. FEDOMA staff interviewees noted that DDFs with a larger number of illiterate members struggled more than others. This is particularly important given that many funders provide guidelines in English and require written English-language reports from the participants in their funded projects. For example, the Economic Empowerment Programme (EEP), a donor-funded VSL project:

> *You know most of our DDF is comprised of… They are illiterate… They can't write, you see, a report in English… We have the implementation guide, in English. They were like: "No, it's difficult to follow the project implementation guide. Can you please… translate it into Chichewa?" I feel like it's slowing down the… progress of the project (Phyllomina, HQ).*

The above highlights that while it is important to consider individuals when looking at the development of small-group collectives, it is equally important to consider the place(s) those individuals inhabit, the spaces and resources they do or do not have access to, and the broader context within which a collective is formed. If focusing on a given individual's literacy level or the particular role of the DDF Secretary, for example, we might miss that broader constraints on literacy impact the pace of this DDF's work. The DDF had a slower pace of work and struggled to meet the project goal of independently keeping the VSL running. The programme was in this case extended by FEDOMA and the funder for an additional year (Int29). While this can be seen as a positive outcome, it also introduces additional constraints on this DDF, limiting their ability to diversify their activities. For example, the DDF uses an external partner to help them in translating their reports; they rely on an external agent, and the time and funds to reach them, to produce the 'right' narrative for the funder's system (Int29). Another year of funding also means another year of the DDF engaging in these additional steps to acquiesce to funder requirements. This case demonstrates that empowerment processes centred on emotional resources and collective critical consciousness are not always sufficient to produce empowerment effects which enable social activism.

At the same time, a collective critical consciousness can help advocates develop awareness of injustices in their access to resources, such as education (through which they could have developed the English-language skills necessary for active participation in the powerful foreign-aid sector in Malawi). A "shared emotional template" and "common grounds for cohesion" (Bosco, 2007, p. 546) can be developed; this common ground helps the DDF to establish its collective identity and sub-repertoire for activism. In the next section, I discuss how the collective identity of the group also shapes the spatial aspect of the DDFs, including the community spaces DDFs work within and the spaces they create for themselves.

6.2 DDFs IN CONTEXT: IDENTITIES IN PLACE AND SPACE

DDFs are impacted by the particular structures of their district. Nelson (2003) emphasises “place… as a symbolic and material locus of identity and meaning” (p. 562). Adapting to the context in which advocates live is part of developing a collective that can address the specific needs of local constituents, as highlighted in Chapter 5, Section 5.3.1. In turn, local collectives can develop place-based identities. Nelson (2003) found that “political vocabularies and identities… became embedded and reworked over time within the nooks and crannies of daily social and political practice” (p. 562). The extended organisational structure of FEDOMA emphasises embodied, place-based experiences in developing grassroots representation. Each DDF member represents a different DPO, but they must also be a resident of the specific district which that DDF represents. Through my interactions with different district officials, activists, and community members during fieldwork, the importance of socio-physical-environmental geography, economy, and social programmes on DDF development became clear. When faced with exclusion from local spaces, advocates seek inclusion but also to develop alternative spaces (and other resources) specifically for their local community. These spaces are part of the work of advocacy and provide important forums for developing grassroots advocacy, constituted through the establishment of a local collective paradoxically tied to a larger organisation; this broader connection enables the critical consciousness needed to imagine alternative possibilities.

The presence of the DDFs creates a forum of support for persons with disabilities, constituting community spaces where they and their families can turn for help, guidance, and companionship. The establishment of these spaces is part of FEDOMA’s organisational plan and contributes to the development of empowerment processes, advocate identities, and voices at the grassroots level. As a result, the DDFs are a major part of the internal support system the DRM builds throughout Malawi. Mallory (D1) spoke of activities her DDF engaged in at meetings that went beyond the scope of planning advocacy work: *“Here we are able to meet. To chat. To sing. We have a choir here… The time we meet, we share experiences, maybe in* *marriages… Others who feel tough, we counsel each other. We share other experiences; other people are getting their families… We are able to do some plays, poems, as we chat."* Spaces internal to a social movement are places for advocates to grow in support and confidence (Swerts, 2015), which ultimately builds their capacity as organisers. The DDF members are part of the community whose rights they are working for, making the work of advocacy deeply personal and each DDF space reflective of the experiences and needs of persons with disabilities in that district. The DDFs can act as an "intimate" space, "where they could place privately suffered grief and collectively transform such emotions into a political project filled with hope and joy" (Bosco, 2007, p. 552). This approach also reflects the work of feminist scholars on the personal as political and political intimacy. bell hooks' (1990) work on the importance of a "homeplace" for resistance, for example, highlights the importance of complex, often bittersweet, intimate spaces of resistance which also serve as places of rest and transformation. Bosco (2007) found that activist groups were strengthened by creative, expressive internal activities, in addition to their externally facing activism. These activities strengthen the intra-network bonds between individual activists and enable the production of stronger collective action. The same was true of the DDFs I interviewed, with D1's choir and poetry serving as an example. The contexts in which the DDF members live impact the content of their meetings, the ways in which they express themselves, and the focus of the stories they tell. In turn, this helps to develop advocates as "critical citizens" who both "challenge... institutions" and "build spaces in which social (selective) trust is formed" (Della Porta, 2012, p. 36). Sharing and understanding one another's contextual experiences helps to form place-and-experience based bonds of trust between the advocates within a given district.

6.2.1 Local collectives: group conflict and cohesion

As a collective, the DDFs negotiate the tension between individualism and collective identity to develop a diverse, locally relevant advocacy body. Nakano (2013) maintains that diverse voices have to be "present" in collective spaces. Organisations like DDFs open up spaces for persons with disabilities "to elaborate ideas within discursive, open and public arenas, where citizens play an active role in identifying problems but also in elaborating possible solutions" (Della Porta, 2012, p. 38). However, the DDFs, while open to a broader section of FEDOMA membership, are themselves representative bodies, officially made up of at least one representative from each DPO in the district. This is an attempt to ensure representation across the variety of impairments found within the disability community. However, not all DPOs have a branch in every district, despite, as Action (HQ) suggested, the probability that there are persons with all types of disabilities in every district: *"We believe that in every district, we should have representation of every DPO. There is no area where we say we can't find persons with albinism, can't find people with psychosocial disabilities."* Action (HQ) went on to state that when the DDF places cannot be filled by a DPO representative, *"those that are dominating tend to bring in their other colleagues".* In these cases, a particular DPO's agenda can become the focus of the DDF. As Della Porta (2012) put it: "participation and deliberation are in fact democratic qualities in tension with those of representation and majority decision" which require a "precarious equilibrium" (p. 40). This equilibrium is at least in part contingent on the actions of individuals. The positions of individuals may be presented as relating to movement ideology, but "they may be rooted in an implacably material reality" (Dowse, 2001, p. 46). The shared material reality of a particular DPO's members may overpower their commitment to diversity within the DDF, especially if they hold leadership positions. This is one of the ways that individuals within a group, especially leaders, can have an out-size effect on the collective, limiting the voices that are heard even further than representative democracies already do. While the DDFs strive for an ideal of representative democracy, with two representatives from each local DPO, they face similar issues as those faced by all representative systems.

DDFs as small systems engage in internal structuration processes, through which they develop their own schemas. Control of the resources available to a particular DDF plays a role in how DDF structures are constituted. Communication with FEDOMA is one such resource. Purdue (2001) points out that leaders often place themselves at key points for communication within networks. Several DDF members mentioned that their Chair was the only member in regular contact with FEDOMA. The following is an example from my fieldwork of this constraint on communication.

After concluding that day's interviews, I sat outside of D2's DDF meeting house with the group, in the shade of a large tree. Rain clouds threatened on the horizon, while the DDF finalised a report in advance of a meeting with FEDOMA's Executive Director (ED), later that day. As the afternoon wore on, the group finished the report, but the ED was late. The group prepared to wait, but the rain clouds were growing dark and close. A few members decided to head home, disappointed that they would miss the meeting, but very tired from the day's events. The DDF Secretary, Arnold, explained to me that only the Chair, who had missed the meeting for a District Peace Committee event, had the phone number for the ED. He then asked me if I had it. I did and called the ED to ask when he would arrive. He was about half an hour away, and I passed on the message. None of the group members asked me for the number. Once the ED arrived, I left the group to their discussion and observed from afar. The ED sat outside under the tree with them (as seen in the accompanying Image 6). After a while, the rain began in earnest, breaking up the meeting (FNs, 2018/19).

Image 6. The DDF-ED meeting described in the preceding passage.

If I had not been with the group, they would have been unable to reach the ED, since the Chair was absent from the proceedings. It is possible that the members who had gone home may have stayed had they known the ED was only half an hour away. The dominance of the Chair in this group, within the DDF's internal schemas, meant that even after learning I had the number the group did not ask for it. Ultimately, power over communication with the central organisation is still in the hands of the Chair. The DDFs, as new, alternative, and radical social structures are also in many ways normative. The influence of broader Malawian social hierarchies and neopatrimonial legal structures is integrated into the DDF spaces. This is to an extent to be expected within an organisation that has hierarchical roles built into it. However, this allocation of roles within the DDFs also gives the groups structure and means that they are responsible to one another for specific tasks. If, for example, the Chair missing meetings were to continue to be an issue, the DDF would have a clear path to complaint. This reflects Della Porta's (2012) point about the tension between equality and participation versus centralisation and standardisation. This tension highlights the potential for a lack of diversity of voice in communications between the DDFs and FEDOMA. Kingsley, D1's DDF Secretary, explained the process: *"As of now the Chairperson is the one who is responsible for communication, between DDF and FEDOMA. So, she takes all the laws and report to the office of FEDOMA, then she will receive the… outcome there, then she tell the people."* The information received by the group is filtered through the Chairperson, instead of all members of the group hearing messages directly from the central organisation. Uneven processes of empowerment within representative groups, exacerbated by the use of positions with an implied hierarchy, can thus reproduce normative structures within Malawian society, many of which constrain persons with disabilities within the broader system. Similarly, since the Chairperson is the one reporting to FEDOMA, her voice serves as a representative for the whole group. This potentially takes away from FEDOMA's ability to gauge the diversity within the grassroots groups and hear a variety of perspectives. Some of the interviewees suggested changing this in the future, making communication with the central organisation more open. Image 6 above shows the ED during his visit to D2, engaging in facework with the local advocates in as egalitarian a way as possible in that circumstance. He demurred from the offer to move the gathering into the building, a more formal space but also a less comfortable one, given the heat and still air. As depicted above, everyone sat at the same 'level', with a chair for everyone, arranged in a circle. This contrasts with the common lecture-style set-up of meetings with 'big men' - in which some (high status) men have chairs, and most women sit on the ground. The ED listened to everything the group members had to say, including and beyond the report they were meant to give (FNs, 2018/19). In this way, he negated some of the normative expectations of the organisation's 'big(gest)' man. However, meetings such as this are uncommon. Establishing more channels of communication in general, through phones and in-person visits, was most often raised as a practical solution to internal power imbalances, but it could also be a way for more members of the DDF to have their voices heard beyond district spaces.

The fact that individual leaders of DDFs have a good deal of power to direct the group's activities is tempered by the fact that the Chair is elected by the DDF and responsible to its membership. This membership also belongs to various DPOs and to FEDOMA, so the group have means by which to seek support if issues arise with the individual Chairperson. During interviews with FEDOMA staff, it was revealed that there have been times when FEDOMA has had to step in to help resolve disputes between the DDF membership and the Chair. According to FEDOMA staff, this was most often because a DDF Chair had become self-absorbed: *"They have a 'big man syndrome'. Yeah? Such that they... They don't have an interest... Of the entire district disability movement at heart. Their interest is about making themselves as big as possible" (Simon, HQ).* Big man syndrome is not unique to the DDFs and is a fundamental aspect of many neopatrimonial political systems (see for example Booth et al., 2006; Tiessen, 2008; Shawa, 2012), demonstrating again that Malawians with disabilities engage with normative political structures despite their perceived deviance from society. Furthermore, despite their work in challenging normative structures and reducing the social production of disability as deviance, the DDFs also reproduce other normative political structures. In fact, FEDOMA's internal hierarchies and approach to advocacy may be as strong an argument as any that Malawians with disabilities are 'no different' from their peers. A central strategy of activism used by Malawi's DRM involves reproducing normative structures to appear less deviant. This hybridity of approach - undermining some normative structures while reproducing others - highlights the importance of a contextually nuanced approach to disability studies.

Big man syndrome can disrupt DDFs' cohesion to the point where they ask the central organisation to step in. In these cases, one voice dominates others within the collective, shutting out other voices. However, when the collective decides that this silencing of group members is unacceptable, they have the broader organisation to which they belong to turn for support. This process helps to temper the domination of individuals with a lot of social capital over the collective. It also represents a key mechanism that does *not* exist (or is not as successful) in other neopatrimonial structures within Malawi. However, this is another area where communication may be difficult if the means of communication is controlled by the problematic leader. In such cases, other group members may struggle to communicate with FEDOMA. Tensions between the intention and the execution of movement structures like this highlight the importance of evolving levels of connectivity across the scales of FEDOMA. In this way, the processes through which the DDFs challenge normative structures contain tenuous mechanisms that should be constantly reconceived and developed.

An important way in which DDFs constitute their collective identities is through how they present their advocacy activities. During interviews and participant observation, members of the group often told nearly identical stories; they shared experiences which defined their group. In doing so, the DDFs formed their own local advocacy repertoire, while simultaneously reflecting and using the framework of a wider advocacy repertoire promoted by FEDOMA HQ. These stories often start with a challenge and end in change made possible by the DDF. For example, multiple interviewees from D2 told me the story of Florence[45] as evidence of their success. Below is an excerpt from McDwellings' (D2) version of the story:

> *There are so many stories, but I think I can say one…a lady with albinism. She completed her Form 4. Secondary school education. She applied for teaching. And she was called there. When the interviewers saw her... They said "Okay, because you have this disability, you sit there. After we have done with your friends, we will come back to you." Unfortunately, at the end of the interviews, that one was not attended to. So, she came to District Disability Forum. She reported to me as the Chairperson… I am living very far, in the remote area… But I came*

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[45] Pseudonym

> *to meet the DEM, the District Education… Manager. I said, “This one, we have our friend who has not been attended to during interviews, what's the problem?” And... the District Education Manager, did not know that this has happened. So, we said that: “This is a human rights issue. Because a person with disability also wants to be employed.” Then we pressurized them. We pressurized; we could find the ones who were there at the interviews… Then later on, the DEM decided to... discuss with the principal at [Teacher's College], until this one was sent there, after one month... Her friends have already started. Now she has completed, and she has been employed.*

Arnold (D2) told a very similar story, with one key difference - where McDwellings specifically discussed his own role in the story, Arnold attributed the work to the collective:

> *And she reported… and the DDF went to the DEM's office and told them that… this happened on… this day. And that story was taken seriously, and... After they considered, they took him [sic] to attend college. To attend a course at the teacher's training college. At this time, she is a teacher.*

The basics of the story are the same - an injustice, followed by the DDF’s work to correct that injustice. As the person who conducted the meetings, McDwellings highlighted his own role in the narrative. Arnold used the story to represent what the DDF as a collective does, even if it involved direct action by only one member. It is possible that the group has a limited number of success stories they deem worth telling, and the group focuses on these to present the DDF in the most positive light. McDwellings using ‘we’ later in the story indicates his acknowledgment of the collective, either as a source of additional pressure after his initial overtures or as the supportive space through which he was able to demonstrate that the disability community was aware of the problem and would be paying attention. McDwellings, as an individual member empowered by the group, could appeal to the group structures and as an agent mobilise its resources (as well as the codified rights-based resources of Malawi’s legal structures).

These stories are meant to move audiences to their side, and the DDF repertoire echoes the discursive environment (see Finke, 1993) established by FEDOMA at empowerment activities. These are true stories retold through the discursive lens of the movement; FEDOMA trains advocates to create exemplar stories. Repertoires form a critical aspect of a group's strategic essentialism, by developing cohesion and creating movement role models that transcend the point in time of the original action: legends who fight against social constraints and to whom others look up. Repertoires provide all members with ready-made examples of the group's priorities; the stories can be adapted to the variety of spaces and scales in which the DDFs engage. The story in the above example begins by giving the audience a sense of the injustice committed against Florence, but by the end provokes positive associations with the DDF who helped her overcome that injustice. DDFs use stories to elicit emotional reactions from a broad variety of audiences, while maintaining the specificity of the story to their district and their group's work. The consistency and practice with which the same stories were told by multiple members of each DDF reveals how the advocates want the DDF as a collective to be seen by outsiders, and what they want outsiders to know about their work. To the audience, these stories present positive icons of normative life who also happen to have disabilities. For the expresser, performing stories can be a way to constitute, realise, and present the collective and/or the self as such a positive icon. This strategy works particularly well in Malawi's context, as storytelling is a normative mode of speech in Malawian (and much of African) society.

Understanding the specificities of individual DDFs is critical in investigating the relationships of the DDFs with FEDOMA. Central procedures may be more or less accessible to a particular group given the collective (and individual) identities and circumstances of the group. When discussing the difficulty of documenting activities in English, as described previously, Phyllomina (HQ) described the problems associated with official paper-trails and confidentiality, which reflect this complexity:

> *Sometimes they [particular DDF] call me... Then after calling, I tell them put it in writing. Of course, it's a lot of papers, eh? Since they don't have any access to the internet. And apart from having access to internet… Which I'm saying most of them are illiterate. So, because they don't have email addresses, they just write it down in vernacular writing. After writing,*

> *I see it. With [another DDF], it's different. The DDF… with a lot of teachers. They send me emails. But with [first DDF], phone calls. Followed by a written document, but in vernacular.*

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> *Maybe it's a burning issue. That we can't even talk on the phone. We need some proper documentation, not even in vernacular. I tell them to go to the district coordinator. They should trust the district coordinator to write everything for them. So, they write everything in English, they send the email, copy me, say, and [Head of Programmes]. So… it's like that. Though I know there's no confidentiality, since it's someone writing for them… But then, we have no option.*

The two DDFs Phyllomina discussed (neither of which were among those whose members I interviewed) are engaged in the same funded programme but have different experiences in communication with their coordinator. In the first group, each individual's illiteracy combines to impact the collective. In this case, the similarities in individual circumstances, due to the structural schemas of their district (lack of inclusive education for persons with disabilities), constrain the group. This makes engaging in the same process considerably more difficult for the group with lower literacy levels than the group comprised mainly of teachers. In the next section of this chapter, I develop the discussion around disparities in engagement between different DDFs through members' experiences of and emotional reactions to communication with FEDOMA.

6.3 VOICE ACROSS THE SCALES OF FEDOMA: COMMUNICATION BETWEEN THE DDFS AND HEADQUARTERS

The DDFs' schematic circumstances contribute to members' experiences of their relationship with HQ. Voice and communication within FEDOMA also contribute to grassroots advocates' perceptions of this relationship, through the experiential outcomes of their use of these resources within the organisation. The response of FEDOMA as an audience to different DDFs’ expressions of voice was highlighted in interviews as a crucial factor in developing those relationships. The DDF members interviewed presented a range of opinions on DDF-HQ relationships. For example, members of the D1 DDF represented their relationship with FEDOMA as positive, while many D3 DDF members expressed less-positive experiences. DDF members’ definitions of voice emphasised that in order to ‘have’ a voice one’s voice must be ‘taken into consideration’. The reception by and impact on the audience evidenced the *power* of voice. This applies to feelings of agency and representation within the movement, and the question of whether grassroots voices are taken into consideration within FEDOMA operations. The ways in which FEDOMA *performs hearing and listening* impact the DDF members’ perceptions of the relationship. In turn, DDF members’ use of their resources is affected; even a resource like voice can feel finite, as embodied resources are tied to one’s own sense of resilience and motivation. These perceptions are important to understand when considering movement cohesion, group activity, group morale, and effectiveness of grassroots advocacy. Through consideration of similarities and differences in the ways the DDF members perceived their relationship with FEDOMA, we can explore the importance of expressing and *listening* to voice(s) within social movements, the multiplicity of grassroots voices, the impact of socio-spatial factors on member experience, and the existential imperative for social movements to ensure grassroots groups feel heard and invested in.

6.3.1 Evidence of hearing and listening (or a lack thereof): grassroots advocates’ experiences of voice within FEDOMA

Most DDF members expressed positive emotional associations with joining FEDOMA, being elected to positions on the DDF board, and supporting their community members. These positive emotions were associated with trust in the organisation and passion for the movement. An initial sense of empowerment can be fed by positive emotions generated through continued engagement and action, feeling supported by a powerful organisation, participating in a bigger movement, and seeing tangible outcomes to your concerns - all reciprocal and relational parts of deliberate processes of structuration to create social change. At the same time, less positive experiences, feeling unsupported, and a shutdown of activities, can have a disempowering effect, ‘stalling’ the process. These associations, trust, and emotional responses impact perceptions of FEDOMA’s performances of hearing and *listening* to DDF voices. Trust and emotion are also key to the relationality of voice and the importance of audience reception and response in contributing to the impacts and effects of voice. Voice plays a role not just in helping FEDOMA stay engaged with and relevant to its constituents, but also in whether its grassroots volunteers continue working toward movement goals. This motivation to make social change supports the arguments advanced by Sewell Jr. (1992) and Whittington (2015), that purposive action on the part of agents is as important to understand as Giddens’ (1984) focus on habit and reproduction of structures.

The variety of emotional responses to experiences by individuals within the same DDF highlights the grey area in interpreting the relationships between ideology, solidarity, trust, actions, and experiences in impacting the actions of collectives. While some described negative experiences with FEDOMA as leading to a breakdown of trust, for others hope and a level of trust in FEDOMA remained. On the other hand, many interviewees were unerringly positive in their conceptualisation of voice within FEDOMA, despite not always receiving affirmative response to requests. In looking at the experiences which contributed to DDF members’ responses, we can gain a deeper understanding of the causes of people’s emotions and consider the complexity of their opinions and actions as a result. Highlighted in the experiences of the DDF members were the importance of physical engagement with FEDOMA staff, proximity to the centre of the organisation, and the provision of material support to the DDFs. Considering these experiences is important in interpreting the ways in which grassroots advocates’ perceptions of FEDOMA influence their current and future actions.

6.3.1.1 Resource provision as ‘evidence’ of hearing and listening?

Perceptions of whether individuals’ voices were heard at HQ were often related by participants to the provision (or lack thereof) of material support. Responding to DDFs’ requests and providing material support are ways FEDOMA can perform *listening*, another profoundly relational social phenomenon. In particular, funding for DDF activities was raised by every interviewee. Of the DDFs interviewed, D1, D2, and D4 had received some level of financial assistance facilitated by FEDOMA, in the form of funded projects or direct support. (Refer to Table 2 in Chapter 3, Section 3.2.2.) The members of these DDFs drew a direct connection between the provision of support and their voices being heard within FEDOMA. As Grace, D4's DDF Chair, put it: "*Yes, our voice is heard at the umbrella body. Because when we have any request or anything, so we have asked them to provide for something, so they do provide for us, so that we should go out with our programmes".* Similarly, in D1 receiving material support from FEDOMA on occasion reinforced their belief that the DDF's voice is heard within the central organisation. D1 DDF members spoke of receiving direct support from FEDOMA, as opposed to project funds (Int1-6). They had received enough on-going support through continued contact, positive reinforcement, and funding to reinforce their trust in FEDOMA's "morality" and "capability" as Purdue (2001) phrased it.

The importance of financial support reflects FEDOMA HQ's role as 'patron' of the DDFs and the influence of neopatrimonialism within the organisation. It is another example of how some normative social relations are reproduced within activist organisations *even as* they strive to challenge normative representations of disability. Despite not necessarily wanting to engage in 'patronage', systemic constraints mean FEDOMA takes on this role, reproducing the expectation (on the part of funders, government, and individual members) that they will play this role. For example, an independent NGO in Malawi must have a qualified bookkeeper by law (Int20, 21). Most DDFs would not be able to engage a bookkeeper and thus must work through FEDOMA to obtain funding, which they expect FEDOMA to find ways to provide. Several D1 DDF members told stories from their repertoire about specific instances of support provision. For example:

> *We see FEDOMA taking a good position. Because when the problem rises up, we inform them about that need. So, the FEDOMA took our position in financial assistance. By then, they gave us 60,000 Kwacha [about £60]... [Another time] we asked for a vehicle from the Council, here in [D1]. We then refilled that with… petrol, because FEDOMA has funded the money. So, we really appreciate it. And we know that FEDOMA is listening to our voice (Kingsley, D2).*

Kingsley associates FEDOMA listening to their voice with their response, an active performance of *listening* through provision of financial assistance. Saba, D1's Vice Chair, also discussed the 60,000 Kwacha in her interview. Saba (D1) added how the support and attention paid to the group by FEDOMA reinforced their feelings of empowerment and positive emotion toward the movement:

> *Then, we were feeling inferiority. Maybe our voices were not taken into consideration, but now, after we have spoken, we feel good, because... They put it into action... We are seeing thoughts from FEDOMA that we are doing a good job... If we have a need, we communicate it with FEDOMA, and they brought those needs. So, the relationship is really good. And we are living in unity with FEDOMA.*

FEDOMA demonstrating that they listen to the D1 DDF's voices through material and emotional support encouraged members' continued engagement in advocacy work, and over the years they have undertaken a variety of projects in their community (Int1-6). As described by Saba, the effort put into the *relationship* between FEDOMA and D1's DDF on both sides created mutually beneficial outcomes for the grassroots advocates and the broader organisation. The DDF members conducted themselves confidently when showing me around the district and are known within villages and small communities as well as in district officials' offices. When we visited persons with disabilities in the villages, the DDF members knew their names and stories; the people we spoke to talked about the impact of the DDF on their lives (FNs, 2018/19). In interviews, D1 DDF members did not hesitate to offer suggestions for FEDOMA and seemed confident in their ability to raise concerns to HQ and in their concerns being taken seriously. This also made the group more accepting of the times when FEDOMA could not help them financially or was slow to respond:

> *Most of the times when we ask for trainings - or support from FEDOMA, they take it and put into consideration... Sometimes it takes... It takes time to communicate with us, because… FEDOMA, as an umbrella… has a lot of things to do. So sometimes it takes time for us to be helped (Leo, D1).*

Leo's description of his DDF's interaction with FEDOMA included his assumption that FEDOMA *would* help them, even if it takes time. Over time, the positive relationship between the DDF and FEDOMA has helped grow the confidence, experience, and empowerment of the collective. This in turn develops advocates' confidence and skill in making their voices heard outwith the organisation, within district communities, working towards securing movement goals.

However, monetary support is a scarce resource in the disability rights sector in Malawi. While monetary support is not the only form of material support FEDOMA can provide, it is arguably the most critical. In as much as providing funding is a performance of *listening*, not providing support can be seen as an indication that FEDOMA does *not* hear the voice of a DDF; it is a performance of *not-listening* (ignoring), from the perspective of DDF members. Financial constraints may inadvertently lead to a lack of response from FEDOMA and thus, a perception by grassroots agents that the central organisation does not hear or *listen* to them.

At present, due to an organisation-wide scarcity of financial resources, DDFs are at times intentionally left without material support to see how they develop on their own, as discussed in Simon's story (Chapter 4, Section 4.3). This lack of material support contributed to some DDF members' negative opinions about the intentions of those who work at headquarters:

> *If they have agreed, helping us out, they really need to help us out. Not just saying to satisfy us… It's one way of hindering the rights of those who are disabled… Some people are greedy… They just don't want to see us succeed. They are greedy… There are those kinds of people there. They don't want to help - Maybe if, for example, the problem is of money. They don't want to help 'cause they want the money to be theirs (Doreen, D3).*

During the interview, Doreen expressed anger and frustration about her DDF's interactions with FEDOMA. In the quote above, she claims that FEDOMA staff are keeping project money for themselves. Part of her reasoning for this is her understanding that FEDOMA said they would send the group financial support, but that support has not materialised. This is set against the experience of life in the broader Malawian system, in which corruption is a habitual national (and regional) problem. Corruption, as a normalised schema, plays a role in setting individuals' expectations of authority figures. In this case, FEDOMA's performance of hearing, saying that they will provide what the group needs, is not supported by experiential evidence. To some of the D3 DDF members, this makes FEDOMA's performances of hearing akin to lying, breaking down the trust between the grassroots group and the central organisation. Put simply, FEDOMA may *hear* the DDFs, but they have not *listened* to them.

Financial support is not the only material resource DDF members discussed, and another support request made by D3's DDF contributed to negative emotional responses from some interviewees. Taonga (D3) discussed his newly formed DDF's first actions:

> *We do come up with a plan… For us to run our project very well, we do have a training from where they have introduced us… We were not empowered. From there, we do have connections with Mr. [Head of Programmes], and we called him that yet - "You have introduced us that we should start the DDF, but we might need your encouragement and your support". Just to teach us. So that we can go out with knowledge. So that we can go out with vigorous. But since then, they didn't provide training for us. But on our own, we started visiting one another, and doing some small things at the grassroots. But also, we came up with the suggestion that we should raise some money. We started with about 1,000 [Kwacha] [about £1] and went up to the amount of 8,000 [Kwacha] [about £8]. So that we can open an account. But 'til now, we have not opened the account.*
>
> ***
>
> *And we were choosing to open an account to National Bank. But also, they [National Bank] were interested to bring up a constitution from FEDOMA. Which they don't provide for us, for us from FEDOMA… We are hoping that they would provide for us. But we didn't receive from them.*

Almost all of the D3 DDF interviewees told a version of this story, focusing on the bank account. In order to open the account, Taonga (who represented the DDF at the bank) was told they needed a letter from FEDOMA, to prove their membership in the organisation. DDF members described how they contacted FEDOMA about the letter but months later had not received any response. Interviewees' emotions when telling this story included anger, resignation, and disappointment. All of these emotions seemed to translate for individuals into a sense of apathy, similar to that described by Meyers (2014), and as a result the collective had stalled in their activities. FEDOMA's mobilisation of this group was deterred by a range of negative emotions leading to a breakdown in trust and collective action, such as that described by Bosco (2007). These experiences contributed to the D3 DDF feeling as though their voices were not heard, constraining them from moving forward as a group. Doreen (D3) put it as follows, stating she does *not* feel that her DDF has a voice within FEDOMA:

> *The DDF… we don't know much. Compared to FEDOMA. But FEDOMA doesn't show any sign of trying to help us know what we don't know…*
>
> ***
>
> *We feel depressed. We feel like - like we have been left out.*
>
> ***
>
> *If our voice was heard, we would work hard, with the DDF. But now we don't give much effort to the DDF. Because our voice is not heard.*

The lack of response to their communications, coupled with a dearth of financial support from the organisation, was a negative experience for D3's DDF members. Over time, this counteracted the positive emotional responses generated by the initial 'empowerment' of the grassroots advocates when the DDF was established. Members expressed less positivity toward, and trust in, their relationship with FEDOMA than expressed by members of other DDFs. Initial actions need to be combined with on-going interaction and provision of resources that facilitate independent working to reduce the dependency and paternalism noted above. While some DDFs may thrive without financial or other material assistance, others will not, especially considering the extreme marginalisation and poverty experienced by most of Malawi's disability community. In this case, D3's DDF arguably rose to HQ's tactical test of resilience - they raised funds on their own and created an action plan. However, broader systemic constraints prevented them from taking the next step (opening a bank account), and FEDOMA's systemic structure did not enable them to move beyond this constraint, due to a lack of meaningful communication between HQ and the grassroots.

The differences in experience between the DDFs (as exemplified by D1 and D3) indicate that agents within FEDOMA HQ may not understand the metrics used by DDF members to judge their place within the organisation. All of the FEDOMA staff members interviewed spoke of the DDFs as the most important fora within the organisation. While many acknowledge that the lack of material support was an issue, the staff did not focus on how FEDOMA's responses to DDFs' requests for resources might impact grassroots advocates' perceptions of their relationship with FEDOMA. The staff under-emphasise the importance of their performances of *listening* in reinforcing or altering bonds of trust. This discrepancy of understanding in itself may indicate DDF voices are being lost across the organisation's scales. Based on the DDF members' own definitions of voice, *listening* is a metric for determining whose voices are heard. For *listening* to be effective, it must be relational and performative – there must be an observable response. In the time between a dormant and observable outcome, emotions and trust bonds fluctuate and change.

6.3.1.2 The importance of physical proximity

In addition to material support, physical proximity to FEDOMA was another important factor in DDF perceptions of their relationship to the broader organisation. The distrust some members of D3's DDF felt toward FEDOMA partially related to the physical distance between FEDOMA and D3. For example, Doreen's suggestion that funds were being kept by staff was based on her speculation of the goings-on in a space she could not easily access. She went on to further speculate that the staff might be spending the organisation's funds *"there in Blantyre. Or somewhere else, not here"* (Doreen, D3). Differentials in access to the physical space of FEDOMA HQ contribute to differences in the relationship between FEDOMA and individual DDFs. If FEDOMA's central leadership intend for the organisation to continue developing effective grassroots outposts, more work must be done on *listening*. Failure to do so could continue to be read as 'typical corruption' by some members, slowing movement action and demoralising the base. FEDOMA's observable response may be (i) providing resources, (ii) explaining clearly the reasons for a lack of resources, or (iii) demonstrating that they are *listening* in another way. Whatever the response, of greatest importance is its *interpretation* by the original 'speaker' (now the audience), mitigated by bonds of trust, in determining the effect of a particular performance of *listening* on the relationships between the grassroots and HQ.

It is useful to think about the geographical, relational dimensions of listening between DDF members and FEDOMA. Many interviewees felt that physical proximity to FEDOMA HQ and/or in-person communication with staff were important factors in successful advocacy at the district level. This was mainly due to a perceived advantage of physical proximity to the central organisation in receiving support. In Malawi, with its chronic difficulties in communication, being able to make in-person visits is an advantage, based on interviewees' reports. Doreen (D3) emphasised the feeling that they could be lied to via text and letter writing; she felt in-person communication was an important part of having a positive relationship with FEDOMA, which was missing for her DDF given the physical distance:

> *We can communicate using letters, or text messages, or phone calls… The communication, through text messages. People can lie. Rather than a member going straight to the office and report. And this one - using letter writing. It takes time. Yeah, you can write, we can write our problems now, we send the letter. But for them to reply back, it takes time. So, the best way is for us to go… to the office… It's a bit difficult since it's far.*

In this case, Doreen perceived the physical distance between her district and FEDOMA as a disadvantage to honest communication. This shows evidence of the erosion of Doreen's trust in the organisation, based on negative emotions associated with the DDF's experiences with FEDOMA in the first year after their formation.

Moore (2006) emphasises the importance of in-person contact in the development and maintenance of trust. Since the DDFs were set up at an event with face-to-face contact with FEDOMA staff, their subsequent interactions may be less powerful: “faceless relations are not rewarding when compared with facework relations, so the latter, deliberate, self-conscious re-embedding of trust in personal relationships is vital to the overall dynamic” (Moore, 2006, p. 419). In addition to faceless communication being less satisfying, in the case of D3, faceless communications (empty promises of support) or lack thereof (the missing bank letter), actually weakened the trust of individual DDF members in FEDOMA. Perhaps faceless communication could bolster trust if there were material support as evidence of *listening* as well. In the case of D3, this material support has not been provided. As the organisation develops, prioritising meaningful responses to faceless communications with physically distant groups may help to counteract burgeoning negativity, though this must be balanced against whether direct financial support might be more or less important. However, the D2 and D4 DDF members spoke more positively of their relationship with FEDOMA, despite also being physically far from the central headquarters. Both of these DDFs were established earlier than D3 and had confident leaders, previous experience of advocacy work among members, and financial support. In these differences, we see that structure and agency are not abstractions which are the same everywhere but are embedded in and affected by geographies (as well as individual personalities and place-based, embodied experiences). For some individuals, the habitual and place-specific experiences of marginalisation, corruption, and problems in communication will perhaps inevitably be read negatively, with negative outcomes for the organisation. At the same time, positive experiences with groups outside of FEDOMA may erode unsatisfying movement relationships further. For example, Doreen mentioned having positive experiences with D3 district officials prior to joining the DDF. Individual experiences of positivity outside the organisation thus also contributed to her disappointment in FEDOMA as an organisation and their lack of responsivity to her (and her community’s) needs. FEDOMA as an organisation must develop approaches to navigate this diversity of experience and need.

In the Southern region, D1 neighbours Blantyre, and so is much closer to FEDOMA headquarters than D2, D3, or D4. D1 DDF members characterised their ability to travel directly to FEDOMA as an integral part of healthy communication experiences between themselves and headquarters. D1 DDF members indicated that they took advantage of the ability to travel to FEDOMA in-person rather than mailing their reports whenever possible. The perceived advantage of this contact is emphasised by the costs involved in making the trip. While it is easier to travel from D1 to FEDOMA than from districts in the northern and central regions, there are still substantial financial burdens and potential dangers involved in making the journey.

Physical proximity may also provide greater opportunities for involvement of grassroots agents in cross-scalar work. Mallory (D1) spoke of the ED and other FEDOMA staff coming to the DDF in-person after they had reported difficulties (Int1). Additionally, the D1 DDF was approached when FEDOMA sought to gain grassroots perspectives for national advocacy, possibly because it was an easily accessible DDF:

> *For example, previously, FEDOMA wanted… [to] raise other issues that persons with disabilities are facing to the president. They came here, at local place. They meet each one of us... persons with disabilities here, and the committee, to ask things we are lacking and things we are doing better. They recorded, and they took us to the main events, to the president. There is a good link (Mallory, D1).*

FEDOMA's proximity to the D1 DDF may confer advantages on the variety of activities in which members of this group are involved. FEDOMA HQ is also constrained by resources for travel, so it follows that when seeking a grassroots opinion, they would venture to those closest first. However, this potentially amplifies the voices of the grassroots actors closest to the centre of the organisation over those in more geographically distant places. Emphasising the impact of physical positionality (as well as social and relational circumstances) on voice reflects "situated knowledges" (Haraway, 1988), in that where a voice comes from and is based matters. Haraway's (1988) focus is on authorial voice, but it can apply to any expression of voice. FEDOMA's privileging of proximal voices acts as a metaphor for the experiences of marginalisation within the organisation; these actions lend support to the perceptions of advocates, like Doreen, of FEDOMA's internal inequality. While a decreasing level of support based on distance from the centre is not intentional, as interviews with FEDOMA staff and management indicate, it may nonetheless be the outcome in practice. The perceived implications of this physical reality by different grassroots actors are dependent on all of the factors discussed in this chapter - individuals' emotional responses to communication with FEDOMA, the district context, collective identity, and local leadership. The majority of the DDF groups do not have easy access to FEDOMA headquarters, and not all of those who are far from the central organisation struggle to engage. In addition, while some DDFs are closer, financial and physical/impairment-based constraints on engaging transport may present an issue even over shorter distances. Social and material constraints reflect a 'friction of distance' making the experiential distance greater than just the number of miles. However, all DDF members interviewed highlighted contact with the centre as something they would like more of; so, regardless of confidence in their own ability as advocates, strengthening ties to HQ remains a priority.

6.3.1.3 Emotions as process: evolution in response to changing performances of listening

Emotions help to form DDF members' perceptions of both FEDOMA and themselves as advocates. Feeling as though their voices are heard, within the organisation and within the community, reinforces positive emotions required for building resilience in grassroots organisers and keeping the movement progressing, as demonstrated in D1. Without this resilience and positive reinforcement, the drive to action can be broken down, especially when dealing with injustices relating to your embodied existence, from which an individual cannot escape. Social movements rely on driving emotions to succeed. For FEDOMA, the loss of faith in their support stalled the D3 DDF, a new grassroots group, from moving forward. However, in an identity- and ideology-driven movement, the erosion of trust does not erase grassroots individuals' belief in movement ideals. The damage to the D3 members' trust in FEDOMA does not mean that they no longer wish to engage with the movement. During my time in D3, for example, the DDF members interacted with district officials and community members with confidence and enthusiasm (FNs, 2018/19). Some of the D3 members, for example Ishmael and Doreen, spoke to previous, personal, positive interactions with district structures; these experiences may have encouraged a belief that they would have similarly positive interactions in their role as advocates. This belief was bolstered, at least on a discursive level, during the discussions with district officials which I observed. My visit was taken as an opportunity to arrange these meetings with district officials; all of the meetings I was able to observe were the DDF's first official interactions in these spaces. DDF members had not felt confident introducing themselves in these spaces without additional support from FEDOMA. My presence, tangentially associated with the central organisation, and the (unearned) status conferred upon foreign researchers gave the group an excuse to enter into spaces of local decision-making. When enabled with an opportunity to engage, DDF members were well-prepared, enthusiastic, and confident in their discussions (FNs, 2018/19). They did not need outside support to give their knowledge legitimacy. However, they *felt* that they did, which was enough to constrain them from taking that step on their own. The DDF members perceived their own positions as advocates as 'less able' and dependent upon FEDOMA leaders for guidance. This point highlights the importance of a sense of self-belief for the development of agency in processes of individual and collective empowerment, especially given the general Malawian schema of hierarchy and systems of authority as broader context with which persons with disabilities contend. Understanding and responding to specific attributes of individual grassroots groups is necessary for the central organisation to continue to mobilise its membership.

Changing support provision can help to re-establish trust, affect individuals' emotions, and change their perceptions of the organisation. For example, during my time in D3, the DDF Chair and Secretary were invited to participate in a training event with FEDOMA's Head of Programmes. I interviewed the Chair and Secretary after they had returned from the training. Their opinions about FEDOMA were starkly in contrast to their peers, who had not gone to the training (and had not yet met with the Chair and Secretary post-training). Rhodah, the Secretary, expressed only positivity toward FEDOMA in her interview; she focused on the training as evidence of FEDOMA's support for the DDF. Contrasted with Rhodah was Doreen, whose anger over FEDOMA's lack of support made her want to break from the organisation. If FEDOMA were to engage more with D3 DDF members, whether via trainings, financial support, or the provision of a letter enabling them to open a bank account, that could combat individuals' negative emotions and help to re-build trust. Performing listening in this way could help to re-engage disaffected groups in advocacy work. This would be a boon to the movement overall, as these individuals could then engage in advocacy activities within their communities, FEDOMA's ultimate goal in setting up the DDFs.

6.4 DDF AND FEDOMA PRIORITIES FOR THE FUTURE

Social movement organisations like FEDOMA are continually engaged in organisational structuration through the production, reproduction, and alteration of the organisation's internal schemas and resources. The driving force behind FEDOMA's decision to participate in this research project was to gain insight into the DDFs' needs, wants, and perceptions of the movement. The reasoning at FEDOMA HQ was that this information could help in developing a new five-year plan, centred on the DDFs. The focus on grassroots organising over the last several years has shifted the priorities of the central organisation and in doing so shifted the balance of power slightly more toward the periphery. Most of the DDF members spoke confidently about the DDFs as an entity both connected to and independent of FEDOMA. They wanted to see the organisation focus on empowerment and development of the grassroots in increasingly remote spaces. Most interviewees, both at HQ and the grassroots, felt that this shift in focus and power was the best way for the organisation to move forward. This was mediated by an on-going respect for hierarchy within the organisation and the understanding that as the seat of funding, FEDOMA HQ would maintain a certain level of power over the DDFs. For example, Doreen (D3), during the interview, double-checked to ensure "*the director won't see me signing*,[46]" even as she opened up about the injustices she felt were carried out by FEDOMA. Doreen did not hold back from letting us know what she thought, and she was aware that her comments would be relayed in some format to the central organisation. She did not ask for a pseudonym. The chance that the director might actually see her performance of voice first-hand, however, was a step too far at the time. In her interview, the tension in navigating individual agency within an organisation containing

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[46] Sign language

at-times conflicting schemas and imbalances in resource distribution was clear. Members' suggestions for the future reflected this, specifically focusing on ways for the DDFs to become more (financially) independent from FEDOMA, prioritising increasing the power of local collectives. Participation in a large collective can sometimes have a dampening effect on individual and small-collective empowerment processes and exercises of agency. In order to discuss these ideas for the future, it is important to consider how the staff at the central organisation view the role of grassroots voices at present and in their potential future, as this is currently where power within the organisation is most concentrated and decisions about how to proceed are ultimately being made.

6.4.1 The view from the 'centre'

FEDOMA staff and management discussed their perceptions of communication with the DDFs and whether the DDFs' voices are heard at the central organisation. Action (HQ) described the process of gathering input from the DDFs:

> *Okay, so currently we get the… information… They send them through the project coordinators. Or if we don't have a project within that district, we get some kind of manual reports… but not as frequent as we would want them to. But when we get those reports, they are shared with the Head of Programmes. Then we use them for our programming. We use them for, you know, proposals writing. So, we take them as cases and… it's input too.*

The process of input Action described focuses on official reporting from the districts. During my time with D2, I watched the group compile one such report. They wrote it as a group, each contributing sentences, which the Secretary then recorded (FNs, 2018/19). The report would later be mailed to FEDOMA by the Chair. While the Chair is often the only member in direct contact with headquarters, reporting-writing's collaborative nature helps ensure that more of the group's individual voices contribute to the collective voice that ultimately makes its way to HQ. This approach reflects the intersection of a variety of structures which make collaboration natural: broader cultural structures which see families or groups as the base unit of society, educational structures characterised by a lack of resources and thus the necessity of sharing materials, persons with disabilities' material need to obtain support in navigating systemic constraints, and the democratic and cooperative goals of the DRM. The DDFs in this case are acting in what may be broadly considered a normative way to achieve non-normative outcomes, including increased diversity of input to movement HQ.

Most of the FEDOMA staff said they believed the DDFs' voices were heard at FEDOMA headquarters. FEDOMA staff may feel that the DDFs' voices are heard because the ones they work with most are those with a better connection to the central organisation. For example, project coordinators (PCs) work with groups participating in funded projects. These DDFs must keep in touch with FEDOMA and the funder, meet the reporting requirements and have regular contact with the PC. As indicated in Action's statement above, it can be more difficult to obtain reports from DDFs in districts without a funded project. In addition to reporting directly to the centre, though, DDFs with funded projects' direct communication with PCs is a chance to present a greater diversity of voices to an audience representing the central organisation. PCs visit DDFs in-person, allowing more members to interact with them. These interactions provide FEDOMA staff with a more defined sense of the differences between and within DDFs. When she talked about interactions with DDFs in her project, PC Cecilia (HQ) provided examples of differences between the DDFs:

> *You could find that other districts, people indeed went to school, and the DDF comprises with at least the people who are working or have some status also. And you could find that in the other districts, it's really, most of them are with the status, to be rolling, on the ground.*

The PCs' direct interaction with various DDFs enables them to have a sense of a group's unique needs and challenges, as also emphasised in Phyllomina's earlier comparison of two groups. This relationship presents an understanding of the impact of individuals, place-based schemas, and resources in developing collective identities and collective action. The personalised interactions between PCs and DDFs could provide a model for future interactions between the central headquarters and grassroots groups.

6.4.2 Developing the future of FEDOMA: ideas from the grassroots and headquarters

FEDOMA staff were eager to see the continued development of the DDFs, demonstrating a belief in them as best placed to advocate for their own rights and combat the perception of persons with disabilities as passive recipients of charity:

> *The general community has regarded disability with… the medical and the… charity approach. To say persons with disabilities need things to be done for them. But then, if you build the capacity of the DDFs, they get to understand the human rights perspective of disability. To say… we are rights-holders. We can demand for our rights on our own… So, if they are empowered, they have the knowledge, they have the skills – I think they are the best structure at district level (Nora, HQ).*

DDF members and FEDOMA staff all presented ideas and aspirations for the future of the organisation, based on their perceptions of what schematic changes could help them to move forward and be more sustainable, actively engaging in conscious, deliberate processes of structuration. They included issues discussed in this chapter, i.e., developing schemas to increase material support and better communication. DDFs in particular highlighted that these would help them to reach more remote areas. In turn, members hope to engage persons with disabilities living in these areas in processes of empowerment, in the same ways they 'were empowered', thus building up the organisation's base of support (Int1-22).

On the other hand, the processes involved in the development (or lack thereof) of advocates and collective action at the grassroots can become self-reinforcing, reproducing structures that enable some DDFs to develop further and/or faster than others:

> *The last criteria will also be to do with… capacity. So, we have formed this, but then there are others where we feel that a project of a certain magnitude cannot… be handled by certain*

> *DDF… so we look at those that have capacity. That's when we have challenges, because we might be denying others without capacity, because maybe within that project there is no component of building the capacity of the DDFs. So that's why now we're saying we need special interventions focusing on the DDFs themselves, so it might be a specific project. Just focusing on the DDF – capacity building of DDFs (Action, HQ).*

Those DDFs with greater 'capacity' are more likely to be chosen to participate in projects which in turn continue to build capacity. In order for a DDF to demonstrate 'capacity', they have to engage in local advocacy activities and report their activities to FEDOMA HQ. However, as discussed in this chapter, the DDFs that are more engaged and confident are those that already feel supported by FEDOMA. Beginning to focus specifically on the best way to engage a particular group may help to break this cycle, creating pathways toward altering constraining schemas and aiding in the development of stronger collective leadership, as espoused by Foster-Fishman et al. (2007). This change may involve responding to a variety of "reactive" (Bosco, 2007) negative emotions, such as those expressed by some D3 DDF members. However, in most of the examples given, the same action by FEDOMA could mitigate against a range of negative emotions. For example, sending the bank letter to D3's DDF could help to dispel Doreen's anger *and* Taonga's disappointment. Emotions are part of relational processes, which can change over time as schemas are altered to address the more specific needs of local collectives and the individuals within them. Attention should be paid to how implementing future policies will draw emotional reactions from individual DDFs and impact their development. Focusing on the most engaged and confident DDFs in implementing new projects may in fact further alienate those who already feel less heard, reproducing and exacerbating imbalances in empowerment processes and access to resources throughout the organisation.

Most of the staff and management also highlighted the need for better *listening* on the part of the organisation and the necessity of frequent and reliable communication between FEDOMA HQ and the DDFs. Staff felt that this would help them to provide support to the DDFs in a timely manner. Staff members also made a point that more frequent contact was the most common thing grassroots advocates asked for, and several felt that if it were given the DDFs would be more engaged advocates: *"Basically, because these are* *the very things that they normally request. I think they will be happy. Because it will be like an answer to their request"* (Cecilia, HQ). Improving communication could help demonstrate that HQ agents are hearing and *listening* to the voices of the DDFs.

One of the suggestions from the management of FEDOMA was to use mobile phones to facilitate communication between the grassroots and HQ in a more formalised way, and this approach was also 'pre-piloted' through questions during the interviews in this project. (See report in Appendix C.) All of the DDF members interviewed felt that a mobile system for reporting to FEDOMA could help to overcome some of the issues with communication. (Though there was some variation in definitions of reporting, with the DDF members suggesting more frequent, informal approaches than staff.) Increasing mobile contact could be a step in repairing relationships and facilitating meaningful performances of hearing and *listening*.

FEDOMA staff indicated that a formal mobile reporting system would work better than the more informal approach suggested by DDF interviewees. FEDOMA staff work with multiple DDFs, as well as reporting to funders, completing administrative tasks and aiding with one another's project activities (FNs, 2018/19). Having a set schedule for receiving and responding to reports could aid them in keeping their work organised. A formal system could help FEDOMA to further develop the knowledge base it draws from in national-level advocacy:

> *We feel that… without a formal kind of system in place, we kind of losing out. At times, we hear cases, some have been solved already, in the village… in a way… that's not satisfying. Maybe it's a rape case, and the Chief just say… "Well, I think what you have done you've done wrong, but this is your relative, so you have to pay the goat, or you have to pay three chickens," and the case ends there. But if we had… a system, it might not be really a real-time system, but something that's workable, where we get the cases, even if they are to be handled at that level, at village level. But we have some kind of feedback, and also we have… sort of a database, where we, you know, record these issues. Then it would help us to say, well, maybe within district "A", cases that are much more prevalent, or violations that are prevalent, are*

> *of this nature. And then we have to dig deep, maybe either have more research done - why is it that we are having more cases of this nature here? We might have more disabilities in a certain district than the other… so this could also be input to our work, as well as to any further research that we can do (Action, HQ).*

In this case, improvements to communication would be mutually beneficial for grassroots advocates and central organisation staff. Overall, it could strengthen the organisation as a whole by reinforcing positive relationships throughout the scales of the organisation and ensuring FEDOMA's work is informed by local knowledge and on-the-ground realities. It is also an issue with broader social utility on which the DDF can break new ground. Traditional justice solutions apply to the broader community as well. In examples such as the rape case, the DDFs can make strides on an intersectional issue, potentially opening up new avenues for collaboration with women's rights or anti-violence groups. In these situations, social movements enable the most marginalised members of society to 'lead' societal change rather than simply striving to gain inclusion in structures which are equally problematic as those which exclude them. However, even in these forward-thinking plans, advocates are constrained by the material realities of their circumstances - such as those which hinder communication between HQ and the districts. For example, DDF members do not always receive timely responses to communications made through formalised procedures. In addition to this, DDF members may not have the time to call or funds for phone minutes at a particular point in time. These obstacles would need to be considered in setting up a new system, again highlighting the tension between participation and formalisation in the organisation.

Even DDF members with a generally positive relationship with FEDOMA felt increased mobile communication would be a good idea. Members of D1's DDF suggested that the use of phone reporting could minimise their visits to headquarters. Despite the advantages of physical proximity to HQ, the financial toll of these visits meant that they were willing to limit their in-person trips, as mentioned by Saba (D1): "*We are happy to give us the phones, because they will minimise the costs of transport, going into FEDOMA head office to report. So, if we had phones, we will just call and communicate easier than before. So, we… welcome that idea.*" Saba's statement suggests a hierarchy of communication based at least in part on the ease of receiving a response weighed against the financial toll; resources are not all equal nor equally easy to mobilise. Writing and mailing reports takes the most time and is the least preferred method. Phone calls are quicker and less expensive than in-person transport, with the added benefit of receiving as quick a response as an in-person meeting - perhaps a faster response, given the long wait times that can sometimes occur at headquarters, particularly if the DDF representative is not expected or does not have an appointment (FNs, 2018/19). However, currently phone calls must be funded by the DDF members. A mobile system, with funding provided for it (which was specifically emphasised by most interviewees) could minimise costs enough to negate some of the ‘proximity advantage’ of in-person visits, facilitating time-space convergence to counteract some of the friction of distance.

Despite the enthusiasm for a mobile communication system, several interviewees, both DDF members and FEDOMA staff, brought up the importance of increasing the frequency of in-person visits to the DDFs. In these cases, the importance of face-to-face contact in reinforcing the connections between geographically distant groups resurfaced. FEDOMA staff visiting the DDFs presented a ‘best of both worlds’ scenario - increased facework without the financial burden (on the DDFs). Several interviewees who had projects running in their districts cited their PCs as crucial points of contact. This is again a potential avenue for bridging the distance and generating time-space convergence, especially since PCs routinely visit the districts in which their projects run. Introducing more (funded) projects through the DDFs, in districts which have not yet run a long-term project, would enable PCs to interact with DDFs that are feeling unsupported.

DDF members and FEDOMA staff and management had other ideas around how to improve FEDOMA in the future. Most of the DDFs wanted increased financial support for their activities. Financial support is the direst need for all of the DDFs and so finding ways to provide it would be an obvious answer to whether FEDOMA is *listening* to their voices. At the same time, most of the staff and managers interviewed said they wanted to ensure that every DDF would have a funded project at some point (even Simon), to support the group’s work and develop capacity. Action (HQ) discussed a plan for the DDFs to begin setting priorities to help FEDOMA determine where to channel funding:

> *We wanted to kind of, I would say, to be focused in our approach. As a district, what is your priority area that you would want to focus? So, what we want to do is… you know, not try to do a lot of things within a district, but to be focused. Yes, so we might do other things, but say if they choose to do economic empowerment, we do economic empowerment as their first priority. And if we do get any, maybe calls [for proposals], or support, then we know where to redirect that support to, to the specific district, you know, where they want to – so that we come up with cases, best practices for each of the… DDFs. So, our priorities in this case as FEDOMA, will not matter much. But what matters is what comes, coming from our constituents.*

These aspirations are challenged by systemic limitations on human and financial resources that constrain FEDOMA and its operations. For example, Action (HQ) discussed the financial considerations of setting up a mobile reporting system: *"You know, they [would] get instant feedback from us. Exactly. That means also in, in ourselves, we also have to look at our own capacity. Are we going to be able to handle that? Do we need a dedicated officer to be handling that, making follow-ups?"*

In addition to limits on available funding, external requirements impact where funding is allocated, potentially conflicting with the policy of enabling DDFs to set priorities. FEDOMA's reliance on external funders remains a critical weakness of the organisation when it comes to directing funds to the DDFs' internally driven priorities and human capacity-building requirements. Many of those at FEDOMA HQ felt that the organisation needed its own revenue stream, to move beyond funders' restrictions. During my time at headquarters, I learned about plans underway to develop businesses, especially in agriculture and real estate/construction, connected to FEDOMA, to help fund the organisation and provide employment and job training opportunities for people with disabilities (FNs, 2018/19). Being able to run increasingly independently may also help FEDOMA to prioritise the felt and expressed needs of its grassroots base and continue to develop as a system of its own, with internal structures which counteract the constraining schemas of national and international financial systems. However, care must also be taken, if these businesses were to be located near the headquarters, to avoid a concentration of resource to those DDFs in close proximity to FEDOMA. For example, if there were opportunities for job training on FEDOMA revenue-generating projects, would those be open to only those who could easily get to Blantyre district? In planning to mitigate one issue, the organisation would have to be mindful of others. Revenue-generating projects, therefore, could potentially be spread out across the country, with careful planning. One of the requirements of this could be the presence of advocates experienced enough to take on a larger role in the execution of such projects. This experience may be something that comes with time but also requires a certain amount of initial capacity at the start. As discussed, this again privileges those who already have funding, experience, and/or strong connections to HQ.

While the limitations of physical proximity may be unintentional, there may be other biases within FEDOMA HQ that constrain the provision of funded projects to every DDF, especially given the limited financial resources available. Some HQ agents admitted to having 'favourite' DDFs whose development they were more invested in than the others (FNs, 2018/19). The idea of establishing DDF funding priorities had already begun and was piloted in a successful group that was a favourite of a manager. In these cases, the reproduction of inequality between DDFs is possible, through the reproduction of internalised neopatrimonialism and patronage structures.

One way to combat these biases could be in increasing inter-DDF communication. The communication within FEDOMA focuses on working across hierarchical scales, but not across the horizontal spectrum the various DDFs span within the organisation. There is little communication between the different DDFs outside of FEDOMA events, even between those in neighbouring districts. This may be due to the focus on moving to increasingly local levels within a district, through the creation of ADFs that report to the DDFs. The districts are the main administrative unit in Malawi, meaning the material resources a DDF has to work with (outside of those provided by FEDOMA) are usually based in their particular district. However, there are other forms of support the DDFs may be able to offer one another.

Events where disability advocates meet in-person, especially ones which bring together different district groups, are important for dispelling feelings of isolation among grassroots groups. These events, such as the

IDoPD celebrations, regional trainings, and FEDOMA’s general assembly, reinforce solidarity and remind individual advocates of the broader movement around them. For example, before, during, and after the IDoPD celebrations in Salima in which I participated, emotional engagement with the movement was clear. The various DPOs and DDFs cheered one another on, performances of songs carried emotional weight, and solidarity was reinforced through a planned protest, singing, dancing, and touching. The open field where the event was held was packed – a stark contrast to the small groups I engaged with in my field visits to the DDFs (FNs, 2018/19). As Bosco (2007) put it, these “symbolic… places create arenas that permit the performance of reciprocal emotional bonds and enhance emotional proximity among participants” (p. 549). The effect of such events is similar to that of a DDF creating spaces for persons with disabilities within the district; these broader spaces create a temporary national space for the groups to come together. It helps to broaden awareness of the participants in the movement beyond an individual DDF and their particular contact at FEDOMA HQ. It also expands local advocates’ notion of ‘the’ collective, increasing interaction and exchange of resource between groups. Interactions such as these could provide critical support to the constitution and evolution of a locally driven, critically aware ‘Malawi-centric’ disability movement.

While in-person meetings such as IDOPD celebrations can help the DDFs to discuss their work with other DDFs, the lack of connection between the districts (faceless or otherwise) is a hole in FEDOMA’s network that has yet to be addressed. Building a network at the district scale could enable advocates to share strategies and support one another. This would also help increase transparency between the districts, potentially counteracting the feeling of some advocates that there is bias about which groups are given support. Additionally, the knowledge that DDFs can discuss HQ agents’ actions amongst themselves may further encourage efforts to actually equalise support. With the DDFs able to support one another, this may relieve some of the pressure on HQ and allow for the direct transmission of ideas and advice from DDFs who have had success on a particular issue to other groups looking to address that same issue in their own district.

6.5 CONCLUSION

The above aspirations for the future are part of how FEDOMA can evolve in its stated mission of creating as participatory a movement as possible. DDFs represent the base from which FEDOMA draws its strength; the organisation relies on its constituent groups' work, particularly given the devolution of rights-implementation to the district level by Malawi's government. As a result, FEDOMA's ability to mobilise support depends upon members' engagement. Additionally, FEDOMA as an organisation prioritises the embodied knowledge of its grassroots members in its external work; to work toward actualisation of its participatory ideals, FEDOMA should do the same in its internal work.

In order for FEDOMA to maintain positive relationships built on trust, the organisation must continue to develop ways to ensure its grassroots base feels heard. Individuals' positive experiences and emotional responses to those experiences can drive them as advocates. On the other hand, less positive experiences and emotions can lead to a loss of drive. Individual experiences, within particular place-based contexts, help to generate local collectives' approaches to advocacy, as demonstrated in this chapter. The work done by local collectives is becoming increasingly central to FEDOMA's organisational system. In order for FEDOMA to continue to move forward and develop a sustainable movement, agents at HQ must perform hearing and *listening* in their relationships with the DDFs in this emerging 'distant-centre' of advocacy work.

Performances of voice, hearing and *listening* produce, reproduce and alter relationships across the scales of FEDOMA. Perceptions of these relationships ultimately affect the work done by grassroots advocates and as a result affect the progress of the DRM in Malawi. Studying movement organisations like FEDOMA helps to problematize the focus on the habitual within structuration theory, drawing out the complex relationships involved in the purposeful alteration of structures by agents with specific outcomes in mind. These complex relationships reflect and expand our understandings of the role played by embodied and relational resources in constituting sustainable social movements. That these relationships occur within other systems and reflect both normative and radical practices helps us to connect the work of disability advocates to broader Malawian society (and beyond), and complicate organisational self-conception and practice. In the next chapter, I probe this tension between the normative and the radical in more depth, as part of an exploration of intersectionality focusing on the role of the women advocates of Malawi’s DRM.

7 FINDINGS 4: FOCUS ON INTERSECTIONALITY - THE WOMEN OF FEDOMA

In this chapter, I explore the experiences of women in FEDOMA. This chapter both reinforces and complicates the discussions presented in previous chapters. It provides a deeper insight into the particular experiences of one of the most important groups within FEDOMA, specifically considering women's role within and outwith the organisation. I consider (i) the internal dynamics of women's spaces within the organisation, (ii) the experiences of women with disabilities and whether these experiences are reflected more generally within FEDOMA, (iii) the ways in which women in particular engage with structures in their advocacy work, and (iv) the ways in which these interactions reproduce and alter structures (RQ4).

Women with disabilities are highlighted within FEDOMA as among the most marginalised of the organisation's members, facing a range of different challenges to men with disabilities. In a review of statistics around the "intersection of gender and disability", Chataika (2017, p. 185) highlights worse outcomes for African girls and women with disabilities when compared to women without disabilities and men with disabilities in: school attendance, literacy, job markets, experiences of violence and sexual assault, access to justice, and mortality (see also: Pal et al. 2015.). Women with disabilities in Malawi face combinations of marginalisation which differ to those faced by Malawian men with disabilities or Malawian women without disabilities. They also differ from one another, depending on other aspects of intersectionality, such as socioeconomic status and age. Exploring the experiences of women can provide greater specificity around the unique ways an individual's positionality and identity impact their engagement with activism, as motivations for activism are structurally constituted. In the previous chapter, I focused on the development of motivation within the organisation. Experiences of structural constraints outwith the organisation also impact motivations. Women with disabilities experience not only the constraints placed on persons with disabilities but also some of those placed on women. However, there are *also* constraints on the extent to which women with disabilities are expected to engage in normative women's roles. While disability and gender are not the only contributing factors to these women's identities, they allow us a glimpse into the diversity of voices within FEDOMA and the DDFs, and how overlapping structural constraints impact whose voices are heard and on what subjects.

As discussed in the literature review, women with disabilities are often denied access to the structurally expected roles of women, such as marriage and childbearing. Normative cultural structures can impact individuals' desires for life. In Malawi, women's sexuality is often tied exclusively to childbearing, and initiation rituals are still widely conducted, especially in the rural communities where most Malawians live (Levandowski et al., 2012). Malawian women are expected to maintain households, conduct subsistence agriculture, and care for children (Paget et al., 2016; Riley and Dodson, 2016). However, women with disabilities are not seen as able - including having the knowledge - to perform these roles (Tefera et al., 2018). As part of their desire for inclusion, many Malawian disability rights advocates seek to engage in these (heteronormative) roles and emphasise their ability as caregivers in their disability work. It is important to note that the participation of women with disabilities in these neo-traditional schemas may serve to reproduce gender inequalities. At the same time, I argue that this same engagement contributes to altering what it means to be a Malawian woman, by (in some cases) catalysing processes of empowerment that extend beyond the achievement of pivotal social roles of wife and mother. Seeking valued, (neo-traditional) social roles can be part of what motivates women with disabilities to overcome constraining schemas. Indeed, some of the foci of their activities include changing institutional structures which constrain opportunities for women and girls. For example, focusing on the inclusion of all children with disabilities, including girls, in school can help to alter schemas which keep girls in general from receiving an education[47]. Through activism, the women of FEDOMA also contribute to subverting cultural and political constraints on women's participation in politics. The potential dangers of political engagement by women mean that in some cases this action must be subversive - especially when it comes to gender's intersection with disability, which compounds marginalisation and danger. By constituting the personal and traditional as political, women contribute to longer-term social change, notwithstanding the tensions and contradictions that remain whilst so doing.

Chataika (2017) suggests that most DRMs consider the issues of women with disabilities to be women's movement issues, and vice versa. However, FEDOMA leadership and grassroots members claim that the organisation is committed to addressing the issues faced by women with disabilities, intentionally integrating women's issues into 'general' movement spaces *and* encouraging the development of women-specific spaces within the organisation. Much of this is the work of women advocates, engaging within the organisation across a multitude of scales and spaces. There are women throughout all scales of FEDOMA's organisation, including on governing bodies and central office staff. Many more women are part of FEDOMA's various DPOs and grassroots groups, including the DDFs. Most of these women have disabilities, and many have children; other women who participate in FEDOMA activities are not themselves disabled but are carers for children or adults with disabilities.

7.1 CHALLENGES FACED BY WOMEN WITH DISABILITIES IN MALAWI: STORIES FROM FEDOMA ADVOCATES

The experiences of Malawian women with disabilities shape their social lives and constrain and enable their performances of agency, including in their advocacy work. Fluri and Piedalue (2017) note that these

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[47] Girls in Malawi spend on average 1.2 fewer years in school than boys (Walters, 2018).

experiences often include, "intimate and systemic forms of violence, and embodied experiences of both direct physical violence and often-invisible violences of deprivation, humiliation, and structured vulnerability" (p. 538), which the authors also note are interconnected. During interviews, both men and women advocates raised issues that are specific to women with disabilities:

> *A lot of the abuse that the people are facing are: people do raped. Early childhood marriages. The young children going marriage… Children drop out from school... They do force the young women to go into marriages. Even though raping system is for – is not only for the young girls. But all the ages… Even the women as well (Taonga, D3).*

The above was Taonga's response when asked to comment on the challenges faced by persons with disabilities generally. Many of the most serious challenges he raised are those faced specifically by women and girls, providing an example of the awareness throughout FEDOMA that women with disabilities often face different and greater challenges than men.

There is little recourse for seeking justice when abuse like that described by Taonga occurs. Often, crimes are not reported, and when they are, police do not respond seriously (FNs, 2018/19). When violence is reported and investigated, it is usually when victims have help and advice from an organisation, as noted in Chapter 6, Section 6.1.1 with the 'Access to Justice' case. In that case, the abuse was committed by a family member but was not reported by the victim's family. Haang'andu (2020) points to "family protectionist tendencies" as a problematic aspect of cultural schemas in which the family is the most important unit: "the greatest stumbling block to fighting sexual violence and rape of women and young girls is not the lack of punitive laws. Instead, it has been that families decide to protect violators to prevent 'family shame'" (p. 289). Here we see a limit to a collectivist notion of rights when it comes to protecting individual bodies. In some cases, there is engagement with the legal system, but it is under-developed, given the impracticalities of the system. Haang'andu (2020) argues that the justice system is "a colonial inheritance... still struggling to entrench itself" (p. 290). Haang'andu presents this as a conflict between colonial structures and cultural specificity, but this is an over-simplification. Alternatively, I argue that the justice system does not suit the emergent, hybrid structures of modern Malawi, which blend the traditional and modern. The formalised justice system does not reflect the importance of local justice systems within Malawian communities. As discussed previously, more traditional approaches to justice can be found in TA*[48] or village governance, however these do not exercise the punitive power of the formal justice system. Malawi's justice system is overly centralised, and while it does highlight the weakness of customary laws, it does not provide a viable alternative; it is ultimately impractical for Malawi's evolving needs. The cultural conflict highlighted by Haang'andu (2020) comes in when considering the actions of some justice system *agents*, who reinforce the patriarchal status-quo discussed previously as a legacy of colonialism. These agents' actions, such as not acting on reports of violence, prevent lay-person engagement with the justice system, making it harder for the evolving legislative resources of Malawi to be used in changing criminal justice structures. The under-developed justice system, combined with cultural schemas, can mean that processes of justice take a long time if they do happen.

Violent acts committed against women with disabilities also take the form of abandonment: "Evidence from Malawi suggests that women with disabilities are exploited both within marriage, and by the promise of marriage, by men who abandon them when they become pregnant" (Barrett and Marshall, 2017, n.p.). In some cases men refuse to marry women with disabilities, because of fear that any children they had would also be disabled: *"It's a big challenge for… disabled women to get married. Because some, they believe that if he marries a disabled woman… the children might also be disabled. So sometimes they might isolate them in terms of loves, or coming together as family" (Rhodah, D3).* The perception of women with disabilities as lower status is reflected in these relationships, especially given the taboo nature of extra-marital sex in Malawi (Levandowski et al., 2012). Men will engage in sexual relationships with women with disabilities but refuse to 'legitimise' relationships through marriage. Additionally, there is the fear of producing children with disabilities, who are seen as less valuable. This fear is the result of cultural beliefs around disability as a failure

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[48] 'Traditional Authority/ies' can refer to both a person and/or a place. For this thesis: 'TA/Tas' = person and 'TA*/TAs*' = place.

or punishment of the mother, combined with understandings of the hereditary nature of some impairments. While sometimes, the isolation of a woman with a disability from her suitor comes before the woman is pregnant, the women of FEDOMA who I spoke to told stories of abandonment by lovers, boyfriends, or husbands *after* the woman becomes pregnant: *'As I have already said, being a woman with disability, most of the men, they just come and... give them pregnant. They deny them. Because they just say: "I will marry". But they will not. So being given a pregnant is also painful'* (Lyness, D2). Stories told by interviewees highlight the complexity of the trauma women with disabilities face. They expressed desires for 'complete', 'traditional', heterosexual families. Being abandoned while pregnant echoes Schriempf's (2001) argument that women with disabilities "are denied the 'choices'" (p. 60) associated with having the traditional family structure - while this is a common experience among women in sub-Saharan Africa, it is even more prevalent among women with disabilities. Barrett and Marshall's (2017) report argues that Malawian women with disabilities have limited choice when it comes to marriage, which is ultimately expected of women in Malawian society, and as such is a thing to which many women with disabilities aspire. However, the lack of choice leads to greater risk of violence in the relationship. Emma (D2) had been abandoned by two different men by the time of her interview. She held out hope, though, saying she would like to form a relationship with a man with a disability, and hoped they would be happy together:

> *I got married in those days, and my... husband denied me because of my nature. Because some people, they were saying, "No – She will bring a big problem on your life. Maybe she can fall on the fire, or in the water, so you better leave her". So, he left me... It was so hard. Being denied by someone whom I trusted... it was painful for me. Now, I am not married, but I got this baby from someone else also. But I live alone... I hope to get married to someone who is also a disabled person. It would be a great joy for me (Emma, D2).*

Emma's story highlights the trauma of being abandoned by her partners. She was married, which may be because as a woman with epilepsy, her disability is less highly stigmatised than other, more visible disabilities. Her (ex)husband divorced her as a result of societal pressure. While he may have resisted negative cultural schemas around disability at first, others' expressions of voice changed his mind. In these expressions of community members' agency, they reproduce cultural schemas which stigmatise women with disabilities. Emma now believes that marriage to a man who shares her disability identity could be a solution. Emma's choices are still constrained – she has adjusted her hopes according to the cultural schemas around her. At the same time, Emma's hopes demonstrate her desire to participate in the strong cultural schemas around marriage and procreation, which is regionally a critical element of personhood and nationally a major aspect of the constitution of womanhood. However, since the cultural schemas around marriage impact men and women differently, this may not be a solution to Emma's problem. Men with disabilities in Malawi do not face the same level of difficulty in finding a non-disabled partner as women (Pal et al., 2015); their identity as a man is still 'above' that of a woman (Addlakha et al., 2017). Due to this, men with disabilities will often choose not to partner with a woman who has a disability (FNs, 2018/19). In the meantime, Emma is left to care for her child on her own. Emma's story highlights a common constraint on women with disabilities – single motherhood. Her story also emphasises the impact of gendered schema on the degree to which women with disabilities' voices are heard and *listened* to, as well as their *perception* of whether they 'have' a voice.

Beyond issues of relationships and abandonment, pregnancy and motherhood can compound financial struggles for women with disabilities. While employment issues for persons with disabilities were discussed in previous chapters, these can be especially challenging for women with disabilities who have children to care for, often on their own. In some cases, such as that of Emma, they can live at home with their parents. The impact of supportive kinship ties on persons with disabilities is discussed later in the chapter. However, sometimes parents are not able to help or have previously abandoned them, often *because* of their disability (FNs, 2018/19). Women with disabilities struggle to gain waged employment, and unmarried mothers may be seen as particularly undesirable employees. Many of the women I spoke to discussed economic issues as a major constraint within their lives. This comes in various forms, including being unable to get hired, but also in the form of limited opportunities for promotion and being fired from jobs once employment is secured. Grace (D4) described women with disabilities' troubles as stemming from a "*lack of capital*". Ester (D3) felt that she was excluded from training in her workplace because of her disability (Int18). Doreen (D3) was fired from her job as a waitress due to her deafness, despite having successfully performed the required tasks (Int16). On the other hand, women interviewed who maintained jobs or ran businesses discussed their economic success as a step toward empowerment through self-sufficiency (though they still emphasised that most women with disabilities struggle to make a living). Economic success had been or could be potentially life-changing for the women with disabilities I interviewed.

Doreen's life story is illustrative of the interplay of various cultural and legal schemas in the lives of women with disabilities. In the extended quote below, Doreen (D3) tells more of her story:

> *At first, I was studying... Then, I was selected to secondary school. So, we were having problems there, at secondary school, because the, specialist teacher was not that easy to have. And they would... mix us up. The Deaf. The Blind. The Disabled Ones. So, the teacher would be talking to us, we can't hear anything, and it wouldn't matter to him. Then, after I wrote the exams, I failed. Then I had to repeat some class. Then my parents told me that they were tired of paying my school fees.*
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> ***
>
> *Then I found a boyfriend. Then I was pregnant.*
>
> ***
>
> *But we had arrangement that we would get married. So, we were staying together. But the mother of the man... Started saying she doesn't like a girl who is deaf as a daughter-in-law… I was receiving some insults from my mother-in-law. Because of my disability.*
>
> ***
>
> *So, after I gave birth, I thought of moving out from their house.*
>
> ***

> *So then, because the man didn't show any changes, I started going – I thought of going to court. Because I had a little baby. So, the man was supposed to give... financial support.*

***

> *Of course, the court said the man should be helping the child out. But he doesn't. So, the child relies on support from me, the mother, only.*

Throughout her story, Doreen discusses various structures which impacted agency throughout her life. These constraints exemplify the problem of dichotomising 'public' and 'private' life. Schooling, arguably part of public life and preparation for future public life in the work force, is in Doreen's case intrinsically tied to her private life - her embodied experience of disability. Her struggles in school informed her parents' decision to withdraw her – a private (home) space decision that had far-reaching implications for Doreen's life as an adult. It is also likely that cultural schemas played a role in this decision - persons with disabilities are viewed as incapable of engaging in school, girls' education is undervalued, and school costs money that many families do not have and/or struggle to make. The intersection of gender, disability, and socioeconomic position in this case raises the question of whether Doreen's parents would have withdrawn her from school had (i) she been a boy (with or without a disability) or (ii) been a girl without a disability. This decision is also impacted by the structural necessity of financial resources for schooling. Cultural and governmental schemas, combined with a lack of resources in the form of school infrastructure, special education teachers, and materials, constrained Doreen from being able to complete school.

No longer in school and struggling to support herself after her parents cut off her school fees, Doreen found a partner. And according to Doreen, this partner was happy to be with her, despite her impairment. However, Doreen's mother-in-law did not want a daughter-in-law with a disability. The mother-in-law did not believe Doreen could provide for her son and his future family to her standards, issues raised in the literature (Addlakha et al., 2017; Frederick, 2017; Tefera et al., 2018). The situation which Doreen describes underlines a complex intersectionality. Within Malawian kinship circles, mothers play a powerful role. In patriarchal cultural schemas, women can feel the need to oppress or control other women in order to gain or maintain status. Doreen's story is not unique to women with disabilities, but her experience is made worse because there is a physical impairment her mother-in-law can apply as a reason for casting her out. In this case, Doreen's womanhood was not the issue for her mother-in-law; it was her disability. In her mother-in-law's eyes, the disability was more constraining than Doreen's (or their shared) womanhood could have been enabling in the role of wife and mother. Cultural schemas about the role of a man's mother, combined with those which question the ability of women with disabilities to engage in traditional roles, created conflict for Doreen's husband. As a result, Doreen and her husband divorced. However, as a woman, Doreen is still expected to care for her child, despite the cultural belief that she should not be able to. Doreen receives no child support from her husband, because despite the court order, there is little possibility of enforcement in Malawi's under-developed legal system. Even if the order were enforceable, women may be hesitant to engage in this process, as fathers have full legal custody over children in Malawi[49] (Semu, 2002). Doreen wants to work to support her child but was fired from her job as a waitress because she is deaf. Now, she tries to make a living selling plastic bags but does not earn enough to cover her child's needs (Int16). Doreen is as much a mother as her partner's mother, but her disability, perceived through cultural schemas, resulted in actions which pushed her further toward the periphery of her community, away from a stable family life. In this example, the role of mother was enabling for Doreen's non-disabled mother-in-law, in altering her son's future. However, the role of mother was constraining for Doreen, a woman with a disability struggling to support her child. This example highlights limitations to the enabling schemas of motherhood for some women, such as those emphasised by Conradsen (2016), especially within a home governed by internal hierarchies dictated by adherence to existing cultural schemas.

Despite the constraints faced by mothers with disabilities, their successes in this role may be a source of some social standing and power. Doreen is driven by a need to provide for her daughter, to be successful in the role of mother, despite the fact that she is not expected to be capable of fulfilling this role. Women with

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[49] In Malawi, the father is the legal guardian of any child under the age of 21. Mothers have to produce a court order or a death certificate for the father in order to legally represent their children - for example, in giving permission for a passport application (Semu, 2002).

disabilities who are successful in the roles of non-disabled women may be viewed positively in broader society - the liberation of women with disabilities partially stems from not being held to the same expectations as non-disabled women. While this reinforces potentially harmful stereotypes about ‘overcoming’ disability, it also helps to alter perceptions of women with disabilities. Tefera et al. (2018) highlight this complexity of expectation:

> The valued roles of… mother lose some of their significance when it comes to the situation of women with disabilities. For example, giving birth without being married is not socially acceptable, and therefore, being an unmarried mother is a devalued role… But, when it comes to women with disabilities, being an unmarried mother becomes a valued social role, as women with disabilities are not expected to get married (p. 89).

In addition, women with disabilities’ marginalisation, and the desire to engage in valued social roles, is part of what motivates them to overcome constraining schemas and continuously express their voice and agency (despite often not being *listened* to), which advocates claim is part of becoming empowered. Women with disabilities seek to engage in these roles in the same ways as their non-disabled peers - successfully raising children out of wedlock is not the ultimate goal for these women. It is, however, a source of internal and external strength. An unintended outcome of the violence committed against women with disabilities can be the creation of emotional and experiential motivators to activism; in these cases, women seek to alter the structures that led to experiences of violence. While women with disabilities seek to change perceptions of themselves as women, they may also reinforce broader oppressive structures based in colonial, post-colonial, and neo-colonial (often religious) patriarchies. However, the use of resource in this way is also borne out of necessity, usually with limited alternatives to seeking inclusion in normative social life.

Disability and womanhood are embodied intersectional identities that impact FEDOMA women’s interactions with structures. These experiences form core emotional drives to movement engagement. Processes of individual and collective empowerment can combat schemas which lead to hurt, struggle, sadness, and anger. Activist women with disabilities’ response to being barred from traditional roles is to change the definition of who can fulfil these roles. Women with disabilities seek to reinforce traditional women's roles despite the different constraints this role may confer on them, because for them these roles are associated with hope, desire, and pride. Part of the activism of women with disabilities is thus engaging in "everyday resistance" (Clothey et al., 2016; Frederick, 2017) - participating in normative roles and spaces from which they would be excluded by society. This forms part of their broader work as advocates within formal FEDOMA spaces. Most of the women interviewed characterised their disability advocate identities as empowering, highlighting these roles as enabling factors in their lives. In the next section, I discuss the ways in which advocacy has furthered women's empowerment through engagement in FEDOMA spaces.

7.2 WOMEN AND MALAWI'S DRM

The women whose stories are presented in this chapter are all members of FEDOMA, the DDFs, and DPOs, in which many of them hold leadership positions. For these women, their embodied experiences of disability and womanhood are central to their advocacy, whether or not they focus specifically on women with disabilities in their work. Advocacy work gives FEDOMA women a platform to centre themselves and their own experiences. Their identity as 'advocate' was described by women as empowering, counteracting negative and dehumanising life experiences. Women described their positions within FEDOMA as making them feel powerful, and like their voices were heard (FNs 2018/19). Participation in the DRM represents both an effect of empowering processes and a continuation of those processes. The senses of self - acceptance, confidence, belief, worth - which Sadan (1997) highlights as both critical outcomes and drivers of individual empowerment processes - aid in the development of positive emotional motivation, which interacts with negative emotional experiences; this combination proved to be a powerful source of ambition and determination for the women of FEDOMA.

Some of the women interviewed initially downplayed the importance of womanhood to their advocacy work. For some, it was important to emphasise that they work on behalf of all Malawians with disabilities, because *"there is no difference"* (Rhodah, D3) in the struggles men and women face. Women advocates focus on the needs of the disability community as a whole and families within that community. The issues that affect men and women with disabilities when seen through this lens are not individually based, giving them less reason to consciously consider gender. Additionally, there may be a fear that if a differentiation is made, women with disabilities may not secure the same rights under any successful campaigns as men. However, *all* of the women advocates had something specific to say relating to women with disabilities, indicating they recognise gender-based differences in experience within the community. Presenting a unified front as a movement, and de-emphasising other identity factors, is part of strategic essentialism - particularly in a new setting, such as an interview. Focusing on one aspect of embodied identity (disability) when telling stories from the movement repertoire may be safer or more useful when performing for a general or unfamiliar audience.

Adherence to a disability-community-focused repertoire may help women advocates de-emphasise their own womanhood, especially those in leadership positions, to ensure the movement is taken seriously. Women in prominent political positions in Malawi can be viewed negatively (Tiessen, 2008). Thus, women use language which focuses on capability without emphasising gender when engaging in public spaces and with local politics and governance. Some women specifically said that they had not gotten to where they were because they were women, focusing on their hard work and reflecting Simon's 'bootstraps' (Chapter 4, Section 4.3) ideology: *"I believe that most of the times, hardworking spirit pays. I am not there because I am a woman, but... because of my work. Because day in and out, my home is like... We have an office for persons with disabilities. Today, one person come, and another day come. Hardworking spirit pays" (Mallory, D1).* Mallory, D1's DDF Chair, emphasises her work ethic as the reason for her leadership roles - initially detaching leadership from womanhood. At the same time, Mallory has 'achieved' many of the traditional ideals of womanhood - she is married (to a non-disabled man), a mother, and holds a job as a teacher, an 'acceptable' (and high-status) job for women. Mallory cannot separate these aspects of her identity from how she is viewed any more than she can her disability. Just by engaging in these roles, she embodies women's resistance. In addition, Mallory's approach to disability advocacy also emphasises traits associated with

Malawian women. For example, in the quote above, Mallory presents her home as a place for persons with disabilities to seek counsel. In this way, Mallory extends her public advocacy work into her private home space - the space traditionally associated with women and their care work. Mallory embraces using women's spaces as spaces of resistance and community care that challenge public/private dichotomies.

Despite emphasising her own "*hardworking spirit*", Mallory (D1) discussed the traditional roles women in general play which she believes makes women well-suited to advocacy work. Mallory (D1) emphasised woman as caretakers and used it as a reason why FEDOMA should focus on women within the organisation: *"Because through what my father did... Oh... [Laughter] I was about to joke that Dads are not good, but Mom... Maybe it is good to empower both but more especially women. Because, they have the spirit of a mother. That I cannot throw this one away. This one is my daughter, my son."* Mallory's father abandoned her family upon finding out that his daughter had albinism – he claimed that her mother must have slept with an English man, a common myth about people with albinism (Int1). This experience - her father's exercise of his agency in leaving, influenced by dominant cultural schemas – affected Mallory's experiences to the extent that it now informs her priorities as an adult activist. Mallory de-emphasised her womanhood when discussing her position as a leader, as a public figure. However, she emphasised womanhood when discussing ideas like care work, its impact on persons with disabilities, and the spaces of the home. These changes to Mallory's performance and storytelling demonstrate a careful consideration of how marginalised individuals are perceived by their audience. It may be that my own position as a woman, combined with interview questions that indicated an interest in her thoughts on women in the movement, enabled Mallory to feel comfortable discussing these topics as the interview progressed. The quote above demonstrates the personal nature of intersecting societal roles in influencing women activists, even those who do not *purposely* perform intersectionality in their public storytelling.

Belief in the power of the mother's (caregiving) 'spirit', introduced by Mallory above, was raised by many participants. Motherhood and the emotional connection that enables a woman to care for her children were seen as natural characteristics, embodied by virtue of simply being a woman (FNs, 2018/19). Women with disabilities claim this identity and its characteristics as part of their claim to womanhood. Some women, including Saba (D1), used this identity, of woman and caregiver, to describe their approach to work on disability issues: *"As a woman, I don't concern… I don't consider myself. But I… see others' problems. So that they can be taken into consideration."* Saba points to women as selfless caregivers in her classification of typical characteristics of women, using it to describe her own motivations for advocacy work. Connecting with and helping others was considered by many advocates as intrinsic to women and thus a 'natural' part of women with disabilities' role, despite the denial of their womanhood in broader society; in using their intersectional identities as motivation for activism and practicing caregiving in their communities, they defy said constraints, engage in everyday resistance, and transform the traditional into the radical.

7.2.1 Women as agents of empowerment processes

Part of women's community engagement is in outreach to other people with disabilities. Spreading knowledge and fuelling processes of empowerment in others was critical to the women's own sense of empowerment. Through being part of a movement and giving back to their communities, their sense of self was positively reinforced; FEDOMA women expressed feeling good about themselves because of their activist identities. Some participants directly related these newer, positive emotions to the struggles they had previously faced. Past experiences of constraints on their agency motivated them (experientially and emotionally) to become advocates. In turn, negative self-images and feelings of helplessness were counteracted by empowerment through advocacy work. These on-going processes strengthen the movement and enable some of the most marginalised members of society to become central figures within the DRM. They found "ways that... women could constitute ourselves – claim ourselves – as subjects... to expand and question definitions of the human" (Mascia-Lees et al., 1989, p. 11). Or in Saba's (D1) own words: *"It has touched me, as a woman. Because as women, we go through difficult situations. So being a woman, I feel it is really good to stand. And to share the responsibility. To empower someone. So, I am feeling good. I am doing a good job."* Like Saba, several of the advocates I spoke to see their work with the DDFs as a responsibility. They believed in their (women's) responsibility of care for others and spreading empowerment as an extension of that. Women advocates apply notions of familial caregiving to DRM activities, substituting and/or extending their ‘mothering’ into movement spaces. Here we see a *chosen/built family* as the basic unit of society. This DRM family is built by and evolves through participation in a collective based around both common critical characteristics and geography; living in the same villages, towns and districts reinforces feelings of closeness and connection with the group and understandings of local structures. Collective empowerment processes also contribute to the strength of the collective or family, and women in particular seek to expand the ‘family’ and include others in the process. For some women, their focus was specifically on empowering other women with disabilities:

> *I fight for the rights of people with disability. But mostly do I fight for the rights of my brethren [referring to other women with disabilities] ... I am happy, because I am fighting for other females with disability. So that they may also have access to education and some other services. I am so passionate about all people with disability... But most especially the women and the children (Lyness, D2).*

Women with disabilities working to empower their peers can speak with the authority of embodied experience, and in speaking they enhance not only other women’s sense of empowerment, but their own.

Lyness’s (D2) concern for women with disabilities is integrated with a concern for children with disabilities. Women and children are connected by being among the most marginalised and in need of care, care which often comes from other women. Women’s rights are in this context intertwined with family rights. In the stories told by many of the women, a concern for women was a concern for the nuclear family, and by extension, the children. For example, Malawian women with disabilities understand the ways in which they have to defy traditional gender roles, particularly when it comes to survival for themselves and their children: *“It is good for us to be empowered, because through us - through that - we will be able to be self-reliant. Because through the work of skills, doing some sort of businesses, so we will be empowered also”* (Emma, D2). Emma underscores the importance of self-reliance for women with disabilities, who often cannot rely on partners or family members to provide for them and their children, despite men’s neo-traditional role as wage-earners. Most persons with disabilities in Malawi struggle to find work, but many women have the additional burden of supporting children on their own. In fact, a woman with a disability who earns her own money may become a *more* attractive prospect for marriage, thus finding a way to circumvent constraining schemas through exercising personal agency and control over her own finances (though there is still a danger that financial stability could also make her a target). All of the married women with disabilities I met had some form of employment or small business (FNs, 2018/19). This point is important to consider when situating women with disabilities along the 'spectrum' of womanhood, determined by schematic notions of women's roles. It complicates the marginalisation of women with disabilities yet again through the introduction of socioeconomic intersectionality and its impact on their 'desirability' as wives and mothers – or engagement in traditional women's roles.

Pushing for the needs, such as economic opportunities, of both themselves and their families is central to the work of women within the DRM. As Mkandawire-Valhmu et al. (2013) found for Malawian women with HIV, when women with disabilities advocate for themselves, they are advocating for their families and motivated by the need to support them. Women with disabilities negotiate the tension between 'African' collectivism and 'Western' individualism to constitute their agency as best they can. They use the range of available resources and schemas to do so. While they can never fully control these structures and thus the extent of their own agency, they can engage in structuration processes in a strategic and critically conscious manner.

Women's role in empowering other women and families reflects the importance of supportive mothers in shaping advocates, whether or not they themselves are engaged with the movement. In these cases, we see processes of empowerment which begin in the home when caregivers emphasise that their children with disabilities are human and deserving of love, care, and support, instead of complying with cultural schemas which would allow them to abandon children with disabilities. These acts of everyday resistance, conducted by mothers outside the DRM, are generally not seen as part of advocacy work, reflecting Conradsen's (2016) point about the internalisation of mothering as domestic responsibility, separate from social change.

However, as advocates made clear in interviews, domestic responsibilities can be part of creating social change, and they have a vital impact on the inclination to self-advocacy among persons with disabilities.

7.2.2 The role of family in developing empowered disability advocates

Many interviewees spoke of the role of family in their development and sense of self. Valentine and Hughes (2012) highlight that "the family is the site where our personhood is cultivated and the lens through which our pasts, presents and futures are often interpreted, acted upon and imagined" (p. 242). Positive familial relationships that transcend the DRM can be critical to identity development, in turn impacting receptivity to social activism and processes of empowerment. Women with disabilities who had supportive kinship networks were often those who expressed the most confidence and who had moved to more central positions within their communities or within FEDOMA, the DDFs, and the DPOs (FNs, 2018/19). Their stories *always* highlighted the role of the mother, though in some cases other family members were also mentioned. For example, Rhodah (D3) is educated and has a job as a hairdresser. She was also one of the most confident and ambitious women I met in Malawi; at the time of the interview, Rhodah (D3) was preparing to run for a seat in Parliament in the 2019 elections and had plans to write a book about women with disabilities: *"I have intentions to publish a book... That will say much more about the challenges that the people with disabilities are facing... But it will talk more about women. I will tell you, the title of the book... Disability and Marriage."* In her interview, Rhodah (D3) specifically highlights her mother and family's role in her personal development:

> *A big support. My mother plays a good role. And lucky enough, she trains me how to do some household chores. As of now, I have taken over from her – I am the mother! Even my father. They are respecting the way I am. There is good relationship between my father's relatives and my mother's relatives. Where they are coming from, there is good unity... Because whenever I am telling, "oh I can't make it"! They come and support me... I am maybe different from other people with disabilities. Because some say that they do abuse their children who*

> *are disabled. But to me, they do take care of me... I am living in a good relationship with my parents.*

Rhodah's story demonstrates how empowerment can be tied to familial support, which is central to schemas of personhood in systems which prioritise the kinship unit. Rhodah's mother trained her in how to take care of a family and a home, despite the societal expectation that Rhodah would be incapable of undertaking these roles. The complexity inherent in this is that expectations of women are still focused on traditional home-based roles. However, Rhodah's parents also represent a change in the way women *with disabilities* are viewed. These changes may lead to further changes in what is expected of women over time. For example, in Malawi, there are many on-going campaigns for girls' education. It is possible that progressive parents of children with disabilities may also be more progressive parents of girls. Despite what she described as a happy life, with steady employment and ambitions for the future, like many women with disabilities, Rhodah is not married. The societal constraints on her undertaking this role are some of the primary injustices which guide and focus the advocacy activities Rhodah engages in most enthusiastically. For example, Rhodah is committed to providing sexual education to young women through her DDF position (Int19). She emphasised that even those who have supportive relationships can miss out on aspects of womanhood because of their status as disabled. However, Rhodah also feels confident that she is deserving of 'normal' relationships and in her capability to run for office. This confidence stems first from the positive support of her familial relationships. During fieldwork, I visited Rhodah's family home. The evening we spent there gave every indication of a close and caring family, with a 'way of being' that did not mark Rhodah out as different from any other member (FNs, 2018/19). Throughout the time we spent together, Rhodah spoke with affection and pride about her family, drawing strength from them and crediting them with her position in life. This was reflected in the practicalities and rhythm of their home environment. For example, Rhodah uses a wheelchair, which cannot be brought into the house due to the stairs. (It is unlikely Rhodah's family would have been financially able to retrofit the house to accommodate a wheelchair.) However, the family has a system and process which enables Rhodah to enter all of the spaces of the home, which is set up to be navigable without the wheelchair, and participate in family gatherings, chores, meals, etc. Rhodah's household is an example of "how... 'relations' are materialised through everyday spatial practices" (Valentine and Hughes, 2012, p. 253) the results of which are "emotional consequences" which impacted the development of Rhodah's agency. The family's support of Rhodah resulted in empowerment as an effect of her relationships, and those processes which continue through her work as an advocate.

In contrast, Ireen (D2) described the slow development of a positive relationship with her family over time, which ultimately progressed into a positive relationship with her whole community:

> *I was born a normal person, as a normal young lady. But I fell sick when I was about 12. My life has been so hard. I was not able to come out and stay with the people – I was just staying indoors... And the community... were isolating me... mocking me, and speaking some sorts of bad things to me... I managed to go to school until I reached at the Form 2 level. Yeah, from there... My family accepted me. And they live with me, in good relationship... No one isolates me, and I am happy. And I am also the first person in the society to be recognised... among the society... So, I am living in good relationship with the people around my area.*

Ireen's performance of agency in attending school and demonstrating her capability in the face of constraints changed her family and community's view of her. As an individual, she made a critical change to the way her community members view persons with disabilities. In doing so, she built relationships with those supporters whose ideas about disability shifted during their acquaintanceship with her. Ireen should not *have* to demonstrate her worth to others. However, in just living her life, she engaged in acts of everyday resistance that impacted an entire community. Now, this is a place from which she draws confidence in her FEDOMA and DDF advocacy work (Int7; FNs, 2018/19). Where Rhodah's family was supportive throughout her life, Ireen's family demonstrated a willingness to change over time. This change over time is part of the "negotiation of difference" within a family (Valentine, Piekut and Harris, 2015, p. 280). Valentine, Piekut, and Harris (2015) point out "that relationships are regularly renegotiated in response to changing social circumstances and opportunities, in which family members exercise agency and try to negotiate or work out the contradictions and paradoxes of their ties to one another over time” (p. 281). These household level changes contribute to a groundswell of support for broader schematic change.

Women as advocates are important for Malawi’s DRM as the people who ultimately care for each subsequent generation of people with disabilities and shape their early lives, emphasising the importance of motherhood in the development of future disability advocates. As Conradsen (2016) discussed, motherhood is for some a “launching point” for deeper involvement in social movements, bridging the private care work of child-rearing with public activism. In the next section, I discuss Parents of Disabled Children Association of Malawi (PODCAM), FEDOMA’s constituent DPO for parents of children with disabilities, and the ways in which motherhood informs grassroots activism. FEDOMA’s work intersects with and intervenes in family spaces as a strategy for changing broader structures.

7.2.3 Mothering in grassroots activism

PODCAM is an influential DDF, given FEDOMA’s emphasis on promoting the rights of children with disabilities and the importance of the family as the primary unit of Malawian society. PODCAM engages parents of children with disabilities in their communities, works with schools, and uses the DPO’s formal networks to establish informal ones, facilitating a wider spread of information (FNs, 2018/19). As a forum, PODCAM organises the caring role which its members embody and formalises caregiving as crucial to disability rights in Malawi. During my fieldwork trips, I met four known representatives from PODCAM; three of them were women. In an interview, Lonely (D4) outlined her journey as a parent, raising four children with disabilities - two her own, two her late sister’s. She became a special needs teacher to support children with disabilities after her own struggles with the children’s education. Lonely (D4) described the work she does through PODCAM:

> *I joined PODCAM... When my child was one year... And I have given awareness to many parents, and I advocated for each. And as of now in [D4], many parents are aware, and have*

> *accepted the disability on their own homes. So during that period, I was doing it at my area where I was staying... And I wrote parents so that they should send their children to… nearby schools, so that they should what?* ***Learn****. So I was standing for, there for those parents with what?* ***Children with disabilities****, that ah – "You can see, myself I am a mother of... children with disabilities. But I am happy, I have accepted it. You should also accept it –* ***you should own it!*** *So that you should live a happy life with your children and give whatever necessary for your children. So that, himself or herself will become an integrated citizen of Malawi."*

Lonely draws on her experiences as a mother to engage other parents of children with disabilities and teach them how to support those children. As a mother, she is an example that they can look to – a fulfilled woman who is happy with her family and has dedicated her life to bettering children's lives. PODCAM uses this as part of their repertoire, presenting parent role-models to the community. The stories they tell are often deeply personal, focused on kinship groups and passionate (whether joyous or angry) in tone (Int21; FNs, 2018/19). Performances of 'ideal' motherhood, such as Lonely's raising her sister's children and sacrificing her previous life goals in order to help her children, are also tied to embodied womanhood.

Lonely does not identify as disabled. She has dedicated her energy as an advocate to working for children with disabilities. This action stemmed from her role as a mother; the participation of non-disabled parents is vital in promoting the care of children with disabilities. The social capital of a non-disabled mother telling other mothers to accept their children can be transformative in altering the schemas which impact non-disabled parents' interactions with their children with disabilities. However, at the same time, it must be noted that as an educated, formally employed, non-disabled woman, Lonely has more social capital than many of the women with disabilities she works alongside. Despite this, none of the interviewees reported conflict between FEDOMA's non-disabled and disabled members. The structure of FEDOMA, with separate DPOs working on their own projects in addition to FEDOMA activities, may allow the work of women with disabilities and the work of women as carers of persons with disabilities to evolve in parallel, instead of in conflict with one another. This may be partially due to the shared constraints of life in a low-resource nation[50]. Parents' and non-parents' objectives converge since the movement is still working towards provision of basic services and rights. The lack of conflict may also stem from the overlap between the two groups - some of the most influential members of PODCAM are persons with disabilities - for example, Lyric, the group leader whose speeches were discussed in Chapter 6, Section 6.1. The position of many women with disabilities as single mothers helps to bring these groups together. PODCAM members raised similar priorities and struggles, regardless of the parent's disability-status; the focus for PODCAM members was the children. Again, the focus on the family in Malawian culture may make this approach more normative and provide insulation against conflicts that may arise in DRMs more focused on individual rights and/or independent living. This difference demonstrates the importance of place and culture in understanding DRMs, emphasising the importance of studying DRMs in-context and moving away from a more general, minority-world understandings of movement needs and strategies.

7.2.4 Women as critical agents for activism

In addition to formal activities undertaken by DPOs like PODCAM, women DDF members also use community outreach to connect with mothers of children with disabilities outside the DRM. Local outreach provides an opportunity to bring together women, focus on the roles of motherhood and caregiving, and alter cultural schemas impacting these mothers' opinions of their children; the acceptance of children with disabilities by their mothers through these relationships is a form of everyday resistance to cultural schemas which devalue children with disabilities. For example, Ester connects with mothers she meets through her job as a health worker. As a woman who knows what to do when a child is born with a disability, Ester (D3)

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[50] It is also possible that there is conflict, but interviewees did not feel they could share this with an outsider. However, during interviews most participants were willing to discuss problems within FEDOMA, and conflict between non-disabled parents and parents with disabilities was not raised. Most of the advocates demonstrated concern for children with disabilities' future prospects in similar ways.

has a measure of social capital with women who seek that knowledge: *"I do go to the community, and chat with the pregnant women and give them guidance. And also see on the date of delivery, if the child was born, with some difficulties... So, I went quite often to help, to take care of the children."* Ester's job as a health worker allows her access to women in the community and enables her to look out for children with disabilities (as well as their mothers) from birth. This informal outreach may have a large impact on a child's life and upbringing. These circumstances highlight women as important critical agents in FEDOMA's continued decentralisation, engaging parents in villages and TAs within a district. FEDOMA women utilise what social capital they have to influence other women in promoting disability rights. These are the spaces that are important to most of the advocates I spoke to – reaching increasingly remote areas and spreading information largely through voice as facework: conversation. Women's focus on sharing empowerment, as discussed previously, encourages relationship-building in peripheral spaces. This in turn supports the empowerment of women in general, contributing to processes of healing from the violence inflicted upon their lives, bodies, and agency. Core to building these relationships are individual women as critical agents, at the grassroots and national levels. Their visibility and the spaces in which these women make their voices heard are critical for a continued focus on issues faced by women with disabilities in Malawi, and for providing persuasive exemplars to expand the movement.

Relationship building and the empowerment it can bring require individuals to exercise their own agency in establishing those relationships. As discussed in previous chapters, well-placed, critical agents can have an outsized impact on structures through their expressions of agency. Women as critical agents help to ensure that women's voices are heard and centred as the movement develops. Take for example, Mallory, whose role as a leader and critical agent was discussed previously. Part of Mallory's (D1) development into a leader was through the actions of another well-placed agent:

> *Previously, there was a person... She was a founder. And that time she got transferred to MACOHA, where she was going to work, and when she was going, I was... I was interested in her. And she told me – "I'm leaving to go to MACOHA – Are you interested to take over?" I*

> *said yes and I took over from her. Doing the same as she was doing up until the committee was established.*

This founder (of APAM's district branch in D1), a woman who was herself moving up through the ranks of disability organisations in taking a job at MACOHA, hand-picked her district-level successor. She acted as a critical agent in ensuring that the work she had begun in the district continued, in this case by another woman. Perhaps she adhered to Mallory's (and other FEDOMA women's) notion that women were natural caretakers in their communities. Now, Mallory is herself a critical agent and leader within her DDF, the broader movement and her community.

The work of women advocates, both individually and as a group, has transformed FEDOMA into a space in which they feel comfortable. All of the women interviewed for this project, even Doreen (D3), whose anger at the organisation was previously discussed, felt that FEDOMA was a welcoming, positive space for women (Int16). As Rhodah (D3) said:

> *They teach us that everyone has his or her own rights. I think we have been encouraged enough. As it was, the day before yesterday, we had a meeting with [FEDOMA Head of Programmes]. And he was encouraging us… We are capable. We can have access to anything, as a non-disabled person can have. For example, we can get married. But we must not get married because someone has a passionate for us. But that, our rights are also being protected. Honoured... So, we see that FEDOMA is focusing much, helping or encouraging us that we can be what we want to be in life.*

Rhodah relayed how meaningful she found this meeting with a prominent FEDOMA figure. The conversation focused on issues important to women with disabilities, allowing for open discussions of both dangers and rights - the current reality versus what women with disabilities *should* be able to have in a more just society. While the specific advice to be careful over who to marry can be read as paternalistic, it is also *realistic* and encourages the women to exercise their agency in demanding better. By choosing not to engage sexually with men who may not commit to them, women are declaring that they have the right to choose their partners and not settle for someone who will commit acts of physical, social, or emotional violence against them. Demonstrating attention to these issues helps the broader organisation perform hearing and *listening* to women members. The complexity of these issues demonstrates the creative tension between Malawian notions of collectivism and the introduction (through colonialism and continuing through today's globalisation) of individualism and individual rights. It also represents evolving conceptualisations of women's rights and agency, including those of women with disabilities. While the term 'feminism', and even the concept of gender, still have largely negative connotations in Malawi (Mwale, 2002; Riley and Dodson, 2016), there have been shifts toward developing a version of women's empowerment that works for Malawi, especially among younger girls, within urban spaces (Walters, 2018). FEDOMA, as an organisation conscious of the marginalisation of women with disabilities, can contribute to the development of this hybridity and to its spread beyond urban areas through the DDFs and ADFs.

The DDFs as drivers of this change were reflected in women's suggestions for what FEDOMA could do to better support them. While they personally felt they were heard within FEDOMA, women activists want the central organisation to focus on outreach to more women, in increasingly remote areas. *"We will feel good if women are empowered and they are taking their responsibility, because we will share their responsibilities easier than before. So, we are empowering women to come here and join"* (Saba, D1). Saba expressed the idea that empowering more women empowers the movement, in turn providing support to other women. During my time in D1, I accompanied Saba on visits to a wide range of people with disabilities in the community. She knew individuals by name, circumstance, story, and village (FNs, 2018/19). She spoke to them gently, with encouragement and care. Saba's approach to advocacy work reflects women's orientation toward the care work and community support which were historically spaces of power for women in Malawi. Networking actions by women with disabilities form bonds of group solidarity within local disability communities, as do more formalised spaces within FEDOMA. In the next section, I discuss more formalised women's group solidarity within FEDOMA, which also reflects relationships built by women within the DRM.

7.2.5 Spaces of women's empowerment: intergenerational solidarity

Women advocates identified their DRM affiliations – FEDOMA, the DDFs, and the DPOs - as important spaces for women's solidarity. The women of FEDOMA have worked to develop internal spaces for women-specific organising. FEDOMA has a women's council and a DPO that is specifically for women with disabilities[51] - Disabled Women in Development (DIWODE) (FNs, 2018/19). DDF guidelines also encourage gender parity when forming DDFs and ADFs, in an attempt to ensure these spaces amplify grassroots women's voices (FNs, 2018/19). Saba (D1) highlights FEDOMA's focus on empowerment of all people with disabilities as a move toward eliminating gender bias: *"I see FEDOMA as taking a good role. She [FEDOMA] is not gender-biased. She takes all people... I think it is good as FEDOMA to incorporate everyone who has a disability, so they can be well-empowered."* Like Saba, most of the people I spoke to, women and men, used woman- or matri- centric terms for FEDOMA, personifying the organisation as 'she', the 'mother organisation', 'our mother', etc. (Int1-22, FNs, 2018/19). FEDOMA's role in caring for the needs of persons with disabilities is thus portrayed within the organisation, by its grassroots membership, as explicitly 'womanly' and 'motherly'. In this characterisation we can see a 'feminisation' of activism, crossing public/private boundaries and emphasising kindness, caring, and nurturing for building a successful movement. The most high-profile and public face of the organisation, FEDOMA as a representative actor of its member-agents, is anthropomorphised as a mother.

This emphasis on nurturing within the organisation can also be found in the ways women express solidarity with one another, especially across another aspect of intersectionality - generational cohorts. Women with disabilities sharing knowledge across generations reflects traditional Malawian practices such as *chinamwali*, demonstrating the continued importance of historical traditions in modern movements and reflecting Malawi's hybrid system(s). Modern spaces echo traditional ones as spaces of sharing knowledge and standard-bearing women's roles. Similarly, movement schema echo normative ones, including respect

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[51] In the past, FEDOMA had another member DPO which focused at least partially on women's issues - Disabled Women and Orphans Organisation of Malawi (DWOOM)

for, and learning from, elders. On the other hand, these are *also* revolutionary spaces of mutual support in which women with disabilities educate one another on the old roles they can 'take back' and the new ones they can create for themselves. Some of the younger women I interviewed were less confident than their older counterparts, though they still expressed a belief in the empowering potential of participation in the DRM (FNs, 2018/19). The older women often had more experience engaging in everyday resistance - living their lives despite constraining cultural beliefs about their limitations. Older women within the organisation again took on a maternal role, guiding younger women through the process of healing through activism. Both Saba and Rhodah discussed their work with younger women as important parts of their activism. In group meetings, younger women pay close attention to the words of the older women with whom they work (FNs, 2018/19). Women with disabilities' mutual empowerment is enacted through this reflection of a mother-daughter relationship, often a more appropriate descriptor for their dynamic than 'sisterhood'.

Emma (D2) described the change she witnessed as the DDF's work took hold amongst women in her community: *"There has been a change. Because now we are seeing women standing and raise up their voices. Because we have advocated for them."* Deference to the wisdom of older generations is part of the broader cultural schemas of Malawi, but in social movement spaces this traditional cultural schema is a resource for the alteration of structures. As more women are engaged in processes of empowerment through advocacy, activists form similar relationships with youth:

> *So, in a local area, I brought together the teenagers. So that I can mentor them. About the sexual reproductive health. So, especially for the women who are disabled, sometimes I might take them into another room and impart them there. Just to motivate them that… I am your model. So, don't worry (Rhodah, D3).*

Like Rhodah, those who have already embraced their more empowered role as rights advocates offer themselves as role models. Rhodah has taken it upon herself to teach young women about sexuality (Int19). She is preparing them for the traditional women's roles of wife and mother. She takes on the role of women elders in a new forum to reach those who may not be included in traditional spaces. At the same time, she presents an evolution of the initiation ritual, which emphasises an individual's right against abuse; this may help her to meaningfully engage her audience of younger women growing up in an increasingly hybridised system.

The relationships between women within the organisation, combined with FEDOMA's personification as woman, is indicative of the powerful imagery of 'mother' for disability advocates. Emphasis on the importance of nurturing for empowerment is underscored through this conceptualisation of FEDOMA. The idea of 'Mother FEDOMA' could thus be seen in two ways: one of motherhood and thus womanhood as empowering, and that of motherhood and thus women as supporters of others' empowerment – of women's 'responsibility', as some participants put it, toward others in their community. However, this role is a heavy burden to place on the most marginalised people within a society, complicating the notion of caring for others as empowering. FEDOMA as a collective has developed a familial structure as part of the support system for advocacy work and as a demonstration of members' adherence to collectivist notions of personhood, even if in practice they actually hybridise and subvert these notions. However, care must be taken with this approach to ensure that the voices of sub-groups with different intersectional identities are heard and to prevent recreating oppressive structures within the organisation. Part of sharing this burden is in continuing to create spaces for women to engage in group spaces and collective support.

7.2.6 Hearing women's voices within FEDOMA

Notwithstanding the positive and empowering feminine imaginaries described above, the responsibilities of women with disabilities (for the care of themselves and their children) and physical and social constraints, can make it more difficult for them to engage in spaces such as FEDOMA HQ, or in national-scale organising. Most of the persons with disabilities who work at FEDOMA headquarters are men. (There are many women who work at FEDOMA HQ, but most of them do not identify as disabled.) While women with disabilities are represented at every level of FEDOMA's central organisation, their numbers and influence increase within the district-level groups (FNs, 2018/19). On the other hand, grassroots groups, and the DDFs in particular, make home the centre of organising, bringing empowerment closer to women's spaces. DDFs are located in the districts, focus on issues relevant to everyday life, and help set-up ADFs which cover even smaller local areas. Women in these spaces move from the periphery of their communities to the centre of these movement spaces, allowing for an emphasis both on women's struggles and empowerment. Many of the DDF members I met were women, and three of the four DDFs I visited had women as Chairpersons (FNs, 2018/19). As FEDOMA continues to focus its energies more on decentralised organising, women's increasingly important role within grassroots spaces may make it easier for women's voices to be heard throughout the organisation.

In addition to emphasising women's participation in DDFs, forums such as DIWODE centre women's voices. DIWODE formalises space for women, similarly to PODCAM's space for parents. They work to ensure FEDOMA focuses on women's issues beyond general integration and parity policies. DIWODE women are not only able to advocate for women's voices to be heard within the organisation, they are also willing to point to what more FEDOMA needs to do and the ways in which it falls short of its empowering promises:

> *As I am talking now... We [DIWODE] have no funds. It would be good if they can focus on that area. Because a lot of women are caught in poverty and... And maybe, because the headquarters… for the Southern region, maybe the funds are not reaching here because of the distance. But it might be good if they can come and reach us as well. Because Disabled Women in Development is under FEDOMA... That means – FEDOMA is our umbrella... It's very difficult... It would be the best platform for women to speak out their voices. But sometimes it takes the Executive Director to sensitise the people. To come and speak out their voices. So that they should know what part they can play (Grace, D4).*

In this story, Grace emphasises the physical spaces within which she and her group conduct their advocacy activities. They have a virtual network that spans the country but, reflecting the concerns of the DDFs presented in previous chapters (particularly in Chapter 6, Section 6.3.1.2), they perceive that their ability to exercise their agency is impacted by the physical distance between the grassroots and HQ. Grace felt that because her district and her more immediate network of local DIWODE women are far from HQ - physically on the periphery - they receive less financial support. This feeling impacts the extent to which she feels women's voices are prioritised within FEDOMA. Grace (D4) feels that DIWODE, more so than FEDOMA, is the "*best platform for women to speak out their voices*." However, in order to do this, DIWODE needs FEDOMA support. In this case, the intersectional voice that a constituent group can provide the broader organisation is not heard to its members' satisfaction. Grace mentioned the absence of the ED's presence as a limitation to their activities. Grace recognised that although her network of women was a source of empowerment and support for her, in order to initiate others into the group, the presence of someone with more authority was required (Int22). Up until that point, the ED of FEDOMA had always been a man.[52] Local women's disability groups still rely on buy-in from the broader movement, the quality of the local connection to the national, and the participation of men. For some women with disabilities, the authority of a central figure and of manhood would be a stronger resource in challenging constraining cultural schemas than DIWODE's women's collective. While belonging to a women's group may be enabling for many of the women involved individually, they are also constrained by their womanhood from expanding their circle, as they are still viewed as peripheral figures by those they seek to draw into the movement, necessitating partnership with 'less' marginalised and/or peripheral individuals. In this, the value for DIWODE of membership in FEDOMA can be seen. This in turn emphasises the importance of advocates like Grace feeling they can raise questions about FEDOMA's practices internally and make their voices heard. In Grace's example above, DIWODE's calls for shifts in FEDOMA's priorities for the future highlight a need for stronger performances of hearing and *listening* to women's voices by agents at HQ. Negotiating these intersectional tensions demonstrates the paradoxical nature of activism, necessitating working between competing and at times contradictory schemas, including in this context those of broader neopatrimonial structures.

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[52] The current acting ED of FEDOMA is a woman.

7.3 CONCLUSION

Grace's point in the previous section demonstrates that while FEDOMA is embraced by its members as a welcoming and supportive place for women, there is work to be done. Despite the positivity expressed by interviewees, the focus of FEDOMA remains disability in general, at times leading women to obscure their gendered qualities in favour of a more focused approach. However, if the organisation continues to decentralise its operations and expand its grassroots base, the collective and individual voices of women may be more strongly heard throughout the organisation. Continued and increased attention on the local and the home, traditional 'women's spaces', can enable women to move to the centre of the movement, sharpening the focus on the most marginalised people within the disability rights movement.

In focusing on the experiences of women with disabilities in Malawi, we can gain a more complex understanding of the mechanisms of marginalisation, resistance, and empowerment. Women with disabilities are both abused because of their embodied womanhood and denied many of the traditional roles that come with womanhood for those who are not disabled. These challenges often centre on sexual and gender-based violence, marriage, child-rearing, and family/home life in general. While many children with disabilities are abandoned by one or both of their parents, it is most often the mother or female relative who takes on childcare responsibilities. Women who are not disabled are at times thus also constrained by the social schemas around womanhood and disability, caring for children and adults with disabilities, often without support. Focusing on intersectionality in social movements, in this case on the experiences of women, can help movements more fully engage with oppressive structures, form relationships beyond the movement and act as part of the vanguard for broader social change.

The intersectionality of constraints on women with disabilities in itself complicates a dualistic reading of gender roles. As Fluri and Piedalue (2017) put it: "centralizing bodies and embodiment helps us to move beyond binaries... in large part because the body crosses over such constructed spatial boundaries" (p. 536). Malawian women with disabilities cross between traditional women's (but non-traditional disabled women's) spaces in their care of children, 'men's' spaces in seeking to support themselves and their families economically, and radical spaces of activism. In moving between and across these spaces, they blur dualistic boundaries between spaces both intentionally and unintentionally. Traditional spaces of care become profound spaces of empowerment and engagement in social movements.

Participation in the DRM can open up spaces for women's voices to be heard, both within FEDOMA as an organisation and in the broader community. Both women and men within the movement attribute a great deal of power to FEDOMA *and* personify the organisation as 'woman'. This underscores the role of the woman, the carer, the mother, in the mythology of FEDOMA – the storytelling that advocates perform for the world. This conceptualisation of FEDOMA as mother underscores the politicisation of the home-space and the transformation of this politicisation into a 'feminine' politics of care which emphasises the 'traditional' (inclusion, caring, nurturing) and the 'modern' (individual rights, women's empowerment, hybridity). In this way, the 'feminised' public performances of the DRM counters mainstream Malawian political discourse's association of women with the purely apolitical 'traditional'. Caring is connected to a 'modern' Malawi which incorporates individualised human-rights into an ethics of community caring, expanding this collective inclusion to the oppressed and marginalised.

8 CONCLUSION

In this thesis, I have sought to understand the role of grassroots voices in reproducing and altering oppressive structures, through the example of FEDOMA and the DDFs. Developing understandings of disability activism in majority-world contexts can enrich and broaden disability studies, integrate contextual nuance into understandings of disability, and assist in the evolution of, and beyond, social/material binaries in models of disability. In this thesis, I have discussed the nuanced tension between minority-world rights discourses and majority-world societal structures; this conversation is important not just for discussions within a Malawian context but for ensuring we continue to understand and learn from the evolving majority-world systems in which most of the world's persons with disabilities live. The analysis in this thesis points to a complex, relational, and hybrid approach to disability organising that can provide one potential model for other majority-world social movements, even as it draws on its predecessors in both minority- and majority-world systems. This chapter will review: (i) the research questions and key findings, (ii) the use of structuration theory in disability studies, (iii) limitations, (iv) contributions to the geographies of disability, and (iv) avenues for future work, before summing up.

8.1 RESEARCH QUESTIONS AND KEY FINDINGS

8.1.1 (1) Can participatory methods be an effective means by which to conduct research with activists in majority-world contexts, especially in the face of severely limited human, capital, and time resources?

I used a participatory design process and ethos in developing this research project. This approach enabled me to engage in "empowering professional practice" (Sadan, 1997, p. 13) and genuine co-production of 'activist research', as espoused by Stone and Priestley (1996) and Kesby (2005) (among others), with benefits to both academic understandings of Malawi's DRM and FEDOMA as an organisation. Using a participatory approach also ensured I that was able to forge strong working relationships which in turn enabled my access to a broad range of FEDOMA activities and personnel. The combination of participatory design, autoethnography, interviewing, and participant observation allowed me to experience and understand the emotional subjectivity involved in advocacy work. It also enabled me to observe and discuss relationality within the DRM from a variety of angles and gain rich insight into the movement's voices and relationships. This thesis contributes to discussions around navigating challenges to participatory methodologies and demonstrates one avenue for practitioners to engage in research with practical relevance as well as academic significance. The methodological contributions of this thesis also suggest that co-production of research design can be a way of engaging in participatory research practice without over-burdening participants in low-resource settings.

8.1.2 (2) What is the role of 'voice' within FEDOMA as an organisation and out-with FEDOMA in the broader Malawian disability rights movement?

In this analysis, I have demonstrated that 'voice' is not a simple phenomenon – it is relational and requires both performance and receptivity by audiences to create impact. Voice is a critical component of how social movement organisations are constituted, built, and sustained. In engaging grassroots advocates in processes of empowerment, FEDOMA immerses them in a critically conscious approach to rights-organising, developing grassroots agents' voices as a movement resource. It also enables them to critique and contribute to the movement and FEDOMA itself. The ability of grassroots advocates to criticise the organisation, the opportunities for informality with managers and the establishment of procedures for reporting problems with leadership all contribute to FEDOMA's perceived role as the supportive 'mother' to its grassroots agents. However, at the same time as being personified as nurturing mother, FEDOMA necessarily engages in practices which echo neopatrimonialism and patronage, particularly in its decision-making around resource provision. The example of FEDOMA demonstrates the complexity in social movement organisations' attempts to balance a democratic ethos and organisational functionality, as well as the ways social movements both alter and reproduce normative structures. Navigating this complexity is a continuously evolving task, demonstrating that social movements are themselves often evolving hybrid systems.

Voice as a resource is invaluable to activists in low-resource settings. It is malleable enough to be constituted differently in different spaces and times, enabling advocates to perform their voice and situated knowledges to effectively make change in a variety of settings, and across scales. The analysis also shows that voice is intrinsically tied to other relational resources, including emotion and trust. These are particularly important for continued engagement in advocacy work. Most of FEDOMA's members felt empowered, supported, and connected to the organisation. FEDOMA initiates DDF members through emotionally charged "facework" (Giddens, 1984; Moore, 2006). These emotional experiences are part of relational processes of trust-building and motivation for activism; the analysis of these experiences expands on Bondi's (2005) conceptualisation of emotions as "constitutive of relationships" (p. 442). However, these embodied, relational resources are not always enough to maintain grassroots engagement, and the materiality of conflicts over resources and physical distance plays an important role in the constitution of a social movement. Sadan's (1997) work on processes of collective empowerment highlights levels of participation by members as the 'test' of a social movement organisation. In this thesis, I have explored examples of how this test plays out differently based on grassroots members' differing experiences, emotional and trust-based relationships, and access to material resources. Through the experiences of D3's DDF, I have discussed how bonds of trust can be broken if members do not feel that their performances of voice are *listened* to, and how this *listening* must be demonstrated in a way that is acceptable to the expresser of voice. At times, disconnects between grassroots outposts and movement headquarters create internal tensions which make some members feel less engaged in the movement, breaking trust [as discussed by Purdue, (2001)] and stalling activities, as in the D3 example. Internal inequalities in whose voices are heard and *listened* to can be damaging to both individuals and the movement, reflecting and supporting Meyers' (2014) argument about the importance of voice within social movements. These insights contribute to a discussion of how social movement organisations can engage with geographically distant bodies in the future, particularly in negotiating the challenges presented by real and perceived advantages of physical proximity to centres of movement power. In this way, FEDOMA provides an example that may be useful to other broadly dispersed social movements, grappling with similar problems in low resource settings. This thesis contributes to addressing Brilliant's (2000) call for further research into striking this balance between structure and passion.

8.1.3 (3) How do disability advocates exercise their agency to reproduce and alter the structures within which they live?

Across the chapters in this thesis, I have explored examples of the ways in which Malawi's disability advocates make change, using voice as a resource. The work of today's advocates continues work which started in earnest with early, disparate, disability activists joining across DPOs to create FEDOMA. Activists in Malawi's early DRM focused on developing 'place-transcending' legal resources, which they were then able to draw on to organise across *all* 'scales' of social life. Malawian leadership's desire to participate in international forums such as the UN enabled the ratification of international legislation and eventually the development of Malawi-specific legislation. While the experiences of past grassroots advocates and those of today are sometimes at odds, in the change over time we can actually witness structuration and hybridisation processes. This example demonstrates the importance of citable, legitimising resources within social movements. Haang'andu's (2020) criticism of the lack of contextual consideration and focus on implementation in introducing internationally influenced legislation in African contexts is important to consider. However, in this analysis I have shown that these resources can be successfully utilised by advocates who understand how to engage them within a given context. Furthermore, organisations like FEDOMA are already engaging in a hybrid approach to organising which fuses place-based, traditional, cultural schemas with an international human-rights based approach.

Implementation of national policy at a grassroots level led to a redefining of FEDOMA's priorities and the organisation's engagement in decentralisation through the establishment of the DDFs. The DDFs engage with communities, TAs, and district officials. They hybridise their approaches, drawing on customary practices, newer legal resources and "strategic emotional labour" (Bosco, 2007, p. 547) in the constitution of voice for their interactions in these spaces, from which they were previously excluded. This is an example of activists' use of "multi-tonal" (Seale, 2017) voices, drawing on their own definitions of voice as relational and processual. This approach is also multi-scalar and produces multi-scalar outcomes, reflecting Sewell Jr. (1992) and Whittington's (2015) insistence on the movement of schemas and resources across social borders. In this thesis, I have explored the precarious spaces that disability activists attempt to occupy between normative structures of society and the radical alternatives possible through social organising. In some cases, 'simply' occupying space can be a radical act. This analysis shows how in working across scales and spaces, advocates often have to compromise and work within normative structures at the same time as seeking to alter them.

Hybridity comes through in this project not just in the theoretical approach but in FEDOMA's approach to advocacy. This hybridity takes into consideration the inter-systemic resources established through the work of other national and international DRMs, such as the UN Convention on the Rights of Persons with Disabilities (UNCRPD), which is a critical resource for FEDOMA. This is despite transnational DRMs and international structures' often minority-world focused, individualised approach to disability rights, which does not always suit the Malawian context. Malawi itself can be described as having hybrid systemic structures, incorporating aspects of minority-world systems through participation in global (capitalist) society and the legacy of colonialism and post/neo-colonialism. FEDOMA works with these inter-systemic, hybrid, and minority-world resources and engages them in particular place-based circumstances. In doing this, they use their knowledge and experience of local cultural structures, adapting resources to suit their context to make change in local communities.

8.1.4 (4) How do intersectional experiences of gender and disability impact women advocates' expressions and perceptions of voice and agency in Malawi?

Considering intersectionality within social movements can force us to think about connections between the specific (an individual and their embodied experience) and the general (the organisation and the movement), again reflecting hybridity; an Afro- or Malawi-centric disability studies should do the same. The analysis of women's roles in Malawi's disability movement complements the work of other feminist disability scholars on the complex, oppressive, differentiated patriarchal expectations of women versus women with disabilities (see for example, Schriempf, 2001) and contributes to a broadening of the nuance and intersectionality with which we conceptualise the roles of majority-world women (as called for by Johnson-Odim, 1991; Day, 2008; Mkandawire-Valhmu et al., 2013, Piedalue, 2016 and others). My research highlights that the way women advocates use Malawian structures to alter systems, upsetting easy considerations of modern versus traditional roles, reflects the importance of Giddens' (1984) "duality of structures" (p. 25) - schemas and resources can be *both* enabling and constraining, depending on the ability and motivation of agents to engage with them. Thus, while the expectation of women's 'duty of care' can constrain and oppress some women, for some women with disabilities, care work can also be a source of empowerment and enablement. This approach enables 'women's' spaces and roles to become constituted as spaces of activism and resistance. Women with disabilities' 'everyday resistance' in engaging in 'traditional' women's roles helps to expand socially-legitimate conceptualisations of person/womanhood and what women and persons with disabilities 'can/cannot' do and helps to bring the movement into spaces of home and community. Intersectionality in identity-driven social movements can thus enable change across various forms of social oppression.

8.2 USING STRUCTURATION THEORY IN DISABILITY STUDIES

The discussions across this thesis have demonstrated the utility of structuration theory (Giddens, 1984) for analysing the complex tension between the social and the material in geographical disability studies. This approach also allows space for considerations of multi-disciplinarity and relationality across the wide expanse of fields of study relevant to disability. In this thesis, I have undertaken an in-depth analysis of the relational resources and enabling schemas that drive intentional alteration of structures, going beyond Giddens' (1984) focus on repetition, habit, and structural reproduction. I have also developed the idea of dormant outcomes to complicate our understanding of the temporal aspect of structural change. My analysis suggests that structuration theory is broad enough to be useful in developing an eclectic, hybrid, and new materialist disability studies, as an evolution of and beyond 'the' social model. The relative newness of disability rights movements in many majority-world settings means that there is potentially a great deal to learn from examining the complex interplay of systems, structures, and agents for challenging oppression within a given society or across societies and communities. This structuration theory-based way of understanding can contribute to building (local and global) DRMs that are sustainable over time, address the needs of constituents and edge ever closer to the ideal of "nothing about us without us" (Charlton, 1998).

8.3 EXPANDING GEOGRAPHIES OF DISABILITY : FOCUSING ON THE COLLECTIVE

The wealth of theoretical nuance discussed in the literature review chapter of this thesis has rarely, if ever, been applied to the study of disability in Malawi - and never to disability activism in Malawi. I attempted to develop a hybrid theoretical framing to explore which aspects of existing literature and theory fit with the project's data, within the constraints of my own perspective and voice. Starting with structuration theory and Sadan's (1997) conceptualisation of empowerment as a base, I drew on various literatures to uncover synergies, fit existing theorising together in relevant ways, and uncover ways in which an Afro- and/or Malawi-centric study might highlight what is missing from current theorising. I soon discovered that a strong social model of disability, such as that which FEDOMA says guides its practice (drawing on more established DRMs in minority-world countries), did not fully fit with the materiality, embodiment, and community focus expressed by participants in this research project. As a result, I used a new materialist ethos as a guide to explore the relationships between materiality, embodiment, and social structures and systems. Drawing on the evolving tradition of hybridity in geographies of disability, engaging the social and material, and considering context, place, and time, I attempted to 'build' a theoretical approach from the data - a 'bottom up' approach to theorising. My version of an eclectic, hybrid disability studies has drawn on organisational studies, empowerment studies, geographies of disability, critical race theory, feminist theories, and emerging Afro-centric disability studies. The theoretical approach in this thesis offers just one example of an attempt at engaging with an eclectic disability studies that does not rely on a single model.

Throughout this thesis, the focus has been on relationships, and especially the relationships between grassroots communities of advocates (the DDFs), their local district communities and families, and FEDOMA as an organisation. This highlights the problem of individualism which is pervasive in disability theorising today. Even those theoretical approaches that emphasise relationality, such as assemblage theory, tend to think about the impacts of relationality within an individual body. However, the Malawian disability advocates I worked with in this project were more concerned with communities than with individuals. Disability is thus located within the community and relationships between groups, individuals, and combinations thereof as much as within the individual body. This reflects normative African social structures - in Malawi, the basic unit of social life is usually considered to be the family or community unit, complicating the application of individual rights discourses in this setting. Embodied experience remains critically important; however, the focus of the advocacy work being undertaken in the Malawian setting is in communities, and in investing in relationships. Highly individualistic priorities, such as those found in minority-world independent living movements, do not manifest in the Malawian setting; they are incompatible with local ways of life and being. While individual human rights are important, there is thus perhaps scope for theorising that locates *disability* within relationships and communities. This approach could build upon the legacy of the strong social model, which sees disability as an issue of society. Instead of separating disability from impairment, however, a community approach to disability could look at the social, material, socio-spatial, scalar, and embodied as part of, and constituted and manifested in, relationships, instead of focusing solely on relationships as vessels for impacting bodies. There is potential here for disability research in Africa that begins with the notion that disability is not individual, as the base unit of society is not the individual. Future explorations could utilise hybrid theoretical approaches to locate disability in relationships and communities without de-emphasising the experiences of individuals. This could help to continue with the “demodeling” (Araneda-Urrutia and Infante, 2020) and centring of majority-world ways of knowing and being within geographic disability studies.

While I attempted not to impose a minority-world disability model and theoretical framing on the data analysis in this thesis, there are limitations to my level of success in achieving this goal. Many of the theoretical approaches I drew on, including structuration theory, were established in minority-world academic contexts. This project used a broad theoretical approach and identified a potential new avenue in geographic disability studies through locating disability in collectives. However, the analysis would have potentially greater validity had the theoretical approaches used been largely drawn from majority-world, and especially African literatures. There is a need for further development of theory from within the majority-world free of imposition of minority-world academics. As a minority-world researcher, my positionality constrains me from truly developing the theory from a majority-world perspective. Ultimately, my role was to try to learn from Malawian disability rights advocates and broaden my thinking around ways to approach disability research.

8.4 LIMITATIONS

My project explored a select sample of four DDFs and looked with specificity at their experiences to enable depth of study. This concentrated focus means there are spaces and relationships within FEDOMA that this thesis does not and cannot address. The study is also limited by my own positionality as an outsider. It is possible that a Malawian researcher would be able to achieve greater access and/or understanding of the processes of everyday life in Malawi. Finally, the extent of the participatory action research undertaken in this study was limited. While I engaged in a ‘participatory design process’, this is the extent to which participants were involved in the ‘work’ of the research project. I had planned to return to Malawi for a ‘data validation' trip[53], to discuss the project findings with participants, which was cancelled due to the Covid-19 pandemic. That trip was intended to provide another participatory aspect to the project, in which participants were given the opportunity to review and provide feedback on the data analysis and findings. I hope to be able to reschedule this trip in the future. However, as of the submission of this thesis, this lack of validation is a further limitation of this study. The limitations of the participatory action research undertaken in this study could be addressed in future work by seeking to find ways to move beyond participatory design and engage grassroots advocates in data collection and analysis, with an eye toward constituting resources for their advocacy work.

8.5 FUTURE RESEARCH

Malawi's disability rights movement has not been widely studied. There are potential avenues for exploration of both FEDOMA and other parts of Malawi's DRM, which could contribute greater understanding of the relationships and processes discussed in this thesis. Beyond the specific opportunity for further study of Malawi's DRM, the processes explored in this thesis could be studied within other types of activist/advocacy organisations, social movements, and/or majority-world contexts. This would provide opportunities to explore to what extent similar types of structures and imaginaries are used in various settings, as well as discover differences. Further study could contribute a broader understanding of ways to 'do' activism (especially in majority-world contexts) and contribute towards the development of contextual, hybrid, eclectic approaches to social movements, including Afro- (and other place-) centric disability studies. In undertaking future research on majority-world disability rights movements, scholars may consider focusing on disability as located in collectives, to see what theoretical developments may emerge from shifting the framing away from individuals. Understanding disability rights movements in majority-world contexts is critical for the continued progression of a global disability studies that is evolving, inclusive, contextually aware, and values intersectional justice. Increasing the emphasis on these aspects of disability

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[53] Funded by a Santander Research Mobility Grant

studies can also broaden the study of disability in minority-world settings, contributing to calls for intersectional justice, the continued evolution beyond rigid models of disability, and the expansion of conceptualisations of disability and inclusion. In these settings (as well as in the majority-world), increasing attention is being focused on intellectual disability as a neglected area for disability-inclusion (including inclusion in research, especially participatory research). Movements to explore the relationship between obesity and disability have also challenged established notions and hierarchies of disability. All of this expanding scholarship could benefit from hybridity of approach, a consideration of the material as well as the social, exploration of relationality and intersectionality, and a loosening of conceptualising disability as strictly falling within a specific model.

8.6 IN SUMMATION

At its core, this thesis is about voice, relationships, hybridity, and processes. Drawing on the creative and productive tension of ever-evolving systems, we can develop new approaches and entities - disability organisations that use the resources of global systems through a place-based lens to address the needs of modern, neo/post-colonial, hybrid societies. Blurring dualities - schemas and resources, grassroots and professional, global and local, past and present - is how FEDOMA works and are strengths of its approach which could be relevant in other settings. Haang'andu's (2020) work calls for the creation of an "Afro-centric" disability studies, but this is already an on-the-ground reality in the work of organisations like FEDOMA, and the actions of agents who use what resource is available to make change in their own communities. Additionally, thanks to the multi-scalar impacts of structure and agency, grassroots advocates' actions can have far wider-ranging implications. This thesis provides a snapshot in time of a particular movement, situated within intersecting systems, impacted by and constituting different structures (schemas and resources). The processes studied here will continue, and Malawi's disability rights movement will develop and evolve over time, a perspective that brings hope and drive to its members. I conclude with Mallory's (D1) words once again:

> *Indeed the voice is changed, and we are able to advocate for everything everywhere… I have also a dream… Maybe for me or for DDF to go even outside Malawi… For me, a person with a disability going to an open place where people… without disabilities are there… But this time, the rights are explained to everybody - with and without disabilities. The owner of the rights are free to move, because they realise that I have the right. And other people, also realise that, "Oh previously, we were killing these people by violating their rights. Now, they are people like us."*

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> *Yes! And maybe, beyond this, because they [youths with disabilities] are growing up whilst they are knowing their rights and looking for us, the elders, that are fighting for their rights, I believe that in future things will change. Yes, completely change.*

POST-SCRIPT[54]

After the conclusion of data collection, FEDOMA was embroiled in an internal financial scandal. As a result, international donors pulled their funding, despite a police investigation finding no proof of wrongdoing. Several members of FEDOMA management left their positions. FEDOMA is in the process of making changes to their leadership and governance as a way of attempting to regain funding (and find new sources). According to informants none of the remaining FEDOMA staff had been paid for the duration of 2019 at least. Despite this, the work continues. Several staff members stayed on and continued working if they could, despite the lack of pay.

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The DDFs I was able to contact are still working. Since the conclusion of data collection, D3's DDF has opened a bank account and written a constitution. They are currently developing a proposal for a Covid-19 awareness campaign aimed at persons with disabilities. Rhodah came second out of five candidates for MP in her area during the 2019 elections and is now considering the next steps for her political career.

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[54] According to informants (and at the time of writing)

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REFERENCES

Act No. 8 of 2012 (Disability Act). [online] Available at <https://www.ilo.org/dyn/natlex/natlex4.detail?p_lang=en&p_isn=104036&p_count=5&p_classification=08> [Accessed 19 December 2020].

Addlakha, R., Price, J., and Heidari, S., 2017. Disability and sexuality: claiming sexual and reproductive rights. *Reproductive health matters*, 25(50), pp. 4-9.

Altermark, N., 2017. The post-institutional era: Visions of history in research on intellectual disability. *Disability & society*, 32(9), pp. 1315-1332.

Amnesty International, 2016. *5 facts about albinism in Malawi*. [online] Available at: <https://www.amnesty.org/en/latest/campaigns/2016/12/5-facts-about-albinism-in-malawi/> [Accessed 29 March 2020].

Amnesty International, 2018. *Towards effective criminal justice for people with albinism in Malawi*. [Online] Available at: <https://www.justice.gov/eoir/page/file/1079266/download> [Accessed 29 March 2020].

Anderson, K. and Smith, S., 2001. Editorial: Emotional geographies. *Transactions of the Institute of British Geographers*, 26(1), pp. 7-10.

Araneda-Urrutia, C. and Infante, M., 2020. Assemblage theory and its potentialities for dis/ability research in the Global South. *Scandinavian journal of disability research*, 22(1), pp. 340-350.

Asaba, E. and Suarez-Balcazar, Y., 2018. Participatory research: A promising approach to promote meaningful engagement. *Scandinavian journal of occupational therapy*, 25(5), pp. 309-312.

Asaki, B. and Hayes, S., 2011. Leaders, not clients: grassroots women's groups transforming social protection. *Gender & development*, 19(2), pp. 241-253.

Ashby, C., 2011. Whose "voice" is it anyway?: Giving voice and qualitative research involving individuals that type to communicate. *Disability studies quarterly*, 31(4), pp. 1-10.

Banks, L. M., Kelly, S. A., Kyegombe, N., Kuper, H., Devires, K., 2017. "If he could speak, he would be able to point out who does those things to him": Experiences of violence and access to child protection among children with disabilities in Uganda and Malawi*. PloS ONE*, 12(9), pp. 1-17.

Barker, C. and Murray, S., 2010. Disabling postcolonialism: Global disability cultures and democratic criticisms. *Journal of literary & cultural disability studies*, 4(3), pp. 219-236.

Barlindhaug, G., Umar, E., Wazakili, M. and Emaus, N., 2016. Living with disabled children in Malawi: Challenges and rewards. *African journal of disability*, 5(1), a254, pp. 1-8.

Barrett, H. and Marshall, J., 2017. *Understanding sexual and gender-based violence against refugees with a communication disability and challenges to accessing appropriate support*. [online] Available at: <https://www.elrha.org/wp-content/uploads/2016/06/sgbv-literature-review.pdf> [Accessed 19 December 2020].

Barry, F. B. and Grady, S. C., 2019. Africana womanism as an extension of feminism in political ecology (of health) research. *Geoforum* 103, pp. 182-186.

Basit, T., 2003. Manual or electronic? The role of coding in qualitative data analysis. *Educational research*, 45(2), pp. 143-154.

Berghs, M., 2010. Coming to terms with inequality and exploitation in an African state: Researching disability in Sierra Leone. *Disability & society*, 25(7), pp. 861-865.

Berman, R.C. and Tyyskä, V., 2011. A critical reflection on the use of translators/interpreters in a qualitative cross-language research project. *International journal of qualitative methods*, 10(1), pp. 178-190.

Blomfield, A. and Mhango, H., 2019. Malawi albinos kidnapped and sacrificed by witchdoctor gangs on the hunt for election charms. *The Telegraph*, 6 April.

Bondi, L., 2005. Making connections and thinking through emotions: between geography and psychotherapy. *Transactions of the Institute of British Geographers*, 30(4), pp. 433-448.

Booth, D., Cammack, D., Harrigan, J., Kanyongolo, E., Mataure, M., Ngwira, N., 2006. *Drivers of change and development in Malawi*. Working Paper 261, London: Overseas Development Institute.

Booyens, M., van Pletzen, E., Lorenzo, T., 2015. The complexity of rural contexts experienced by community disability workers in three southern African countries. *African journal of disability*, 4(1), art. #167, pp. 1-9.

Boris, E., 2002. On grassroots organizing, poor women's movements, and the intellectual as activist. *Journal of women's history*, 14(2), pp. 140-142.

Bosco, F., 2007. Emotions that build networks: Geographies of human rights movements in Argentina and beyond. *Tijdschrift voor economische en sociale geografie*, 98(5), pp. 545-563.

Briggs, J. and Sharp, J., 2004. Indigenous knowledges and development: A postcolonial caution. *Third world quarterly*, 25(4), pp. 661-676.

Brilliant, E., 2000. Women's gain: Fund-raising and fund allocation as an evolving social movement strategy. *Nonprofit and voluntary sector quarterly*, 29(4), pp. 554-570).

Buchanan, I., 2017. Assemblage theory, or, the future of an illusion. *Deleuze studies*, 11(3), pp. 457-474.

Bunnell, T.G. and Coe, N.M., 2001. Spaces and scales of innovation. *Progress in human geography*, 25(4), pp. 569-589.

Burgham, M. and Downward, P., 2005. Why volunteer, time to volunteer? A case study from swimming. *Managing leisure*, 10(2), pp. 79-93.

Butler, J., 1993. Critically queer. *GLQ*, 1, pp. 17-32.

Butler, J., 1999. Performativity's social magic. In: Shusterman, R. ed. 1999. *Bourdieu: A Critical Reader*. Oxford/Malden: Wiley Blackwell. Ch. 7.

Caldwell, J., 2011. Disability identity of leaders in the self-advocacy movement. *Intellectual and developmental disabilities*, 49(5), pp. 315-326.

Carey, A. C., Block, P. and Scotch, R. K., 2019. Sometimes allies: Parent-led disability organizations and social movements. *Disability studies quarterly*, 39(1), pp. 1-43.

Charlton, J. I., 1998. *Nothing about us without us: Disability oppression and empowerment*. Berkeley: University of California Press.

Chataika, T., 2017. Disabled women, urbanization and sustainable development in Africa. In: Lacey, A., ed. 2017. *Women, Urbanization and Sustainability*. London: Palgrave Macmillan, pp. 179 - 198.

Chauluka, S. and Chiumya, E., n.d. *SAFOD Research Programme: Federation of Disability Organizations in Malawi country report*. SAFOD.

Chivandikwa, N., 2013. Participatory theatre for development as action research. *Matatu*, 43(1), pp.

109-123.

Clare, E., 1999. *Exile and pride: Disability, queerness and liberation*. Durham: Duke University Press.

Clothey, R.A., Koku, E.F., Erkin, E., and Emat, H., 2016. A voice for the voiceless: online activism in Uyghur language blogs and state control of the Internet in China. *Information, communication & society*, 19(6), pp. 858-874.

Cluley, V., Fyson, R. and Pilnick, A., 2020. Theorising disability: a practical and representative ontology of learning disability. *Disability & society*, 35(2), pp. 235-257.

Conradsen, S., 2016. Activist mothering. In: Naples, N. A., ed., 2016. *The Wiley Blackwell encyclopedia of gender and sexuality studies*, Wiley Blackwell. [online] Available at: <https://onlinelibrary.wiley.com/doi/book/10.1002/9781118663219> [Accessed 17 December 2020].

CountryReports.org, 2021. *Malawi Geography*. CountryReports. [online] Available at: <https://www.countryreports.org/country/Malawi.htm> [Accessed 22 June 2021].

Crabb, J., Stewart, R.C., Kokota, D., Masson, N., Sylvester, C. and Krishnadas, R., 2012. Attitudes toward mental illness in Malawi: a cross-sectional survey*. BMC public health*, 12(541), pp. 1-6.

Davison, J., 1993. Tenacious women: Clinging to banja household production in the face of changing gender relations in Malawi. *Journal of southern African studies*, 19(3), pp. 405-421.

Day, L. R., 2008. “Bottom power:” Theorizing feminism and the women’s movement in Sierra Leone (1981-2007). *African and Asian studies*, 7, pp. 491-513.

de Clerck, G.A., 2011. Fostering deaf people's empowerment: the Cameroonian deaf community and epistemological equity. *Third world quarterly*, 32(8), pp. 1419-1435.

Deal, M., 2003. Disabled people's attitudes toward other impairment groups: a hierarchy of impairments. *Disability & society*, 18(7), pp. 897-910.

Delgado, R., 1989. Storytelling for oppositionists and others: A plea for narrative. *Michigan law review*, 87(8), pp. 2411-2441.

Delgado, R., 1990. When a story is just a story: Does voice really matter? *Virginia law review*, 76(1), pp. 95-112.

Della Porta, D., 2012. Critical trust: Social movements and democracy in times of crisis. *Cambio*, 2(4), pp. 33-43.

Denzin, N.K. and Lincoln, Y.S., 2000. Introduction: The discipline and practice of qualitative research. In: Denzin, N.K. and Lincoln, Y.S., eds. 2000. *Handbook of qualitative research*, 2nd edition. Thousand Oaks: SAGE. Ch.1.

Dovey, K., Rao, F. and Pafka, E., 2018. Agglomeration and assemblage: Deterritorialising urban theory. *Urban studies journal*, 55(2), pp. 263-273.

Dowse, L., 2001. Contesting practices, challenge codes: Self advocacy, disability politics and the social model. *Disability & society*, 16(1), pp. 123-141.

Economist, 2019. *The killing of albinos is overshadowing Malawi's election*. Economist [online] 11 May. Available at: <https://www.economist.com/middle-east-and-africa/2019/05/11/the-killing-of-albinos-is-overshadowing-malawis-election> [Accessed 3 April 2020].

Eide, A.H. and Instead, B., 2013. Disability and poverty – Reflections on research experiences in Africa and beyond. *African journal of disability*, 2(1), pp. 1-7.

Eide, A.H., Loeb, M.E., Nhiwatiwa, S., Munthali, A., Ngulube, T.J., van Rooy, G., 2011. Living conditions among people with disabilities in developing countries. In: Eide, A.H and Ingstad, B., eds. 2011. *Disability and poverty: A global challenge*. Bristol: Polity. pp. 55-70

Ellis, C., Adams, T.E., and Bochner, A.P., 2011. Autoethnography: An Overview. *Historical Social Research*, 36(4), pp. 273-290.

Englehart, N.A. and Miller, M.K., 2019. Women's rights in international law: Critical actors, structuration, and the institutionalization of norms. *Politics & gender*, pp. 1-25.

European Parliament, 2017. European Parliament resolution on situation of people with albinism in Malawi and other African countries: 2017/2868(RSP). [online] Available at: <https://www.europarl.europa.eu/doceo/document/B-8-2017-0544_EN.html> [Accessed 18 December 2020].

FEDOMA, 2008. *FEDOMA strategic plan*.

FEDOMA, 2019. About our organization. [online] Available at: fedoma.org/about/ [Accessed 13 September 2020].

Feely, M., 2016. Disability studies after the ontological turn: a return to the material world and material bodies without a return to essentialism. *Disability & society*, 31(7), pp. 863-883.

Fiduccia, B. W., 2000. Current issues in sexuality and the disability movement. *Sexuality and disability*, 18(3), pp. 167-174.

Finke, L., 1993. Knowledge as bait: Feminism, voice, and the pedagogical unconscious. *College English*, 55(1), pp. 7-27.

Fluri, J. L. and Piedalue, A., 2017. Embodying violence: critical geographies of gender, race, and culture. *Gender, place & culture*, 24(4), pp. 534-544.

ForeignAssistance.gov, 2020. *Malawi*. [online] Available at: <https://www.foreignassistance.gov/explore/country/Malawi> [Accessed 13 September 2020].

Foster-Fishman, P., Jimenez, T., Valentia, M. and Kelley, T., 2007. Building the next generation of leaders in the disabilities movement. *Disability & society*, 22(4), pp. 341-356.

Fox, N.J. and Alldred, P., 2019. New materialism. In: Atkinson, P.A., Delamont, S., Cernat, A., Sakshaug, J.W. and Williams, M., eds., 2019. *SAGE Research Methods Foundations*. London: Sage.

Frederick. A., 2017. Visibility, respectability, and disengagement: The everyday resistance of mothers with disabilities. *Social science & medicine*, 181, pp. 131-138.

Friedner, M. and Osborne, J., 2013. Audit bodies: Embodied participation, disability universalism, and accessibility in India. *Antipode*, 45(1), pp. 43-60.

Gabel, S. and Peters, S., 2004. Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability. *Disability & society*, 19(6), pp. 585-600.

Ghai, A., 2012. Engaging with disability with postcolonial theory. In: Goodley, D., Hughes, B. and Davis, L., eds., 2012. *Disability and social theory*. Houndmills: Palgrave Macmillan, pp. 270-286.

Giddens, A., 1984. *The constitution of society*. Cambridge: Polity Press.

Giddens, A., 1990. *The consequences of modernity*. Cambridge: Polity Press.

Goodley, D., 2007. Towards socially just pedagogies: Deleuzoguattarian critical disability studies. *International journal of inclusive education*, 11(3), pp. 317-334.

Goodley, D., Hughes, B. and Davis, L., eds., 2012. *Disability and social theory*. Houndmills: Palgrave Macmillan.

Goodley, D., Liddiard, K. and Runswick-Cole, K., 2018. Feeling disability: Theories of affect and critical disability studies. *Disability & society*, 33(2), pp. 197-217.

Goss, K. A., and Heaney, M. T., 2010. Organizing women as women: Hybridity and grassroots collective action in the 21st century. *Perspective on politics*, 8(1), pp. 27-52.

Grech, S., 2012. Disability and the majority-world: A neocolonial approach. In: Goodley, D., Hughes, B. and Davis, L., eds., 2012. *Disability and social theory*. Houndmills: Palgrave Macmillan.

Greenwood, M., Fakih, B., Steff, M., Bechange, S. and Mrisho, M., 2016. Hear my voice: a community-based participatory study gathering the lived experiences of people with disabilities and older people in Tanzania. *Knowledge management for development journal*, 11(2), pp. 63-78.

Groce, N. and McGeown, J., 2013. *Witchcraft, wealth and disability: Reinterpretation of a fold belief in contemporary urban Africa*. London: Leonard Cheshire Disability and Inclusive Development Centre, UCL.

Haang'andu, P., 2020. Towards an Afrocentric disability activism: Opportunities and challenges of transnationalizing disability advocacy in Africa. In: Soldatic, K. and Johnson, K., eds. 2020. *Global perspectives on disability activism and advocacy: Our way*. Oxon: Routledge, pp. 280-297.

Hall, E. and Wilton, R., 2017. Towards a relational geography of disability. *Progress in human geography*, 41(6), pp. 727-744.

Handicapped Persons Act 1971. Lilongwe: Parliament of Malawi.

Haraway, D., 1988. Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist studies*, 14(3), pp. 575-599.

Harding, J. and Pribram, E.D., 2002. The power of feeling: Locating emotions in culture. *European journal of cultural studies*, 5(4), pp. 407-426.

Harrison, F. V., 1991. Women in Jamaica's urban informal economy: Insights from a Kingston slum. In: Mohanty, C. T., Russo, A. and Torres, L., eds. 1991. *Third world women and the politics of feminism*. Bloomington: Indiana University Press.

Hartley, S. and Muhit, M., 2003. Using qualitative research methods for disability research in majority world countries. *Asia Pacific disability rehabilitation journal*, 14(2), pp. 103-114.

Heng-hao, C., 2009. From housewives to activists: Lived experiences of mothers for disability rights in Taiwan. *Asian journal of women's studies*, 15(3), pp. 34-59.

Herda-Rapp, A., 1998. The power of informal leadership: Woman leaders in the civil rights movement. *Sociological focus*, 31(4), pp. 341-355.

hooks, b., 1984. *Feminist theory from margin to center*. Boston: South end press.

hooks, b., 1990. *Yearning: Race, gender and cultural politics*. Boston: South End Press.

Hudson-Weems, C., 1997. Africana womanism and the critical need for Africana theory and thought. *Western journal of black studies*, 21(2), pp. 79-84.

Huque, S. and Amos, A., 2017. District Disability Forums in Malawi - Emerging strengths and weaknesses. *Radical community work journal*, 3(2).

Huque, S., Wånggren, L., Kachali, L. and Remnant, J., forthcoming. Disability in government-controlled media and legislation in Malawi 2012-2019. In: Kent, M. and Rugoho, T., eds. forthcoming. *Disability and media – African perspectives*.

Imrie, R. and Edwards, C., 2007. The geographies of disability: Reflections on the development of a sub-discipline. *Geography compass*, 1(3), pp. 623-640.

International Labour Organization, 2007a. *Strategies for skills acquisition and work for persons with disabilities in Southern Africa: Malawi*. [online] Available at: <https://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_107789.pdf> [Accessed 10 December 2020].

International Labour Organization, 2007b. *People with disabilities: Pathways to decent work*. [online] Available at: <https://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_107785.pdf> [Accessed 10 December 2020].

International Labour Organization, 2017. *Ratifications for Malawi*. [online] Available at: <https://www.ilo.org/dyn/normlex/en/f?p=NORMLEXPUB:11200:0::NO::P11200_COUNTRY_ID:103101> [Accessed 26 July 2019].

Jackson, R. and Kelly, M., 2019. Women researching in Africa: The impact of gender. In: Jackson, R. and Kelly, M., eds. 2019. *Women researching in Africa*. Cham: Palgrave Macmillan, Ch. 1.

Jasper, J. M., 2011. Emotions and social movements: Twenty years of theory and research. *Annual review of sociology*, 37, pp. 285-303.

Johnson-Odim, C., 1991. Common themes, different contexts: Third World women and feminism. In: Mohanty, C. T., Russo, A. and Torres, L., eds. 1991. *Third world women and the politics of feminism*. Bloomington: Indiana University Press.

Kabeer, N., 2003. Growing citizenship from the grassroots: Nijera Kori and social mobilization in Bangladesh. *The Bangladesh development studies*, XXIX(3/4), pp. 1-20.

Kachapila, H., 2006. The revival of nyau and changing gender relations in early colonial central Malawi. *Journal of religion in Africa*, 36(3/4), pp. 319-345.

Kadzamira, E. and Rose, P., 2001*. Educational policy choice and policy practice in Malawi: Dilemmas and disjunctures*. Institute of development studies: Lilongwe.

Kandiyoti, D., 1988. Bargaining with patriarchy. *Gender and society*, 2(3), pp. 274-290.

Kavinya, T., 2011. Is Malawi getting mental health care right? *Malawi medical journal*, 23(3), pp. 98.

Kelly, C., 2010. Wrestling with group identity: Disability activism and direct funding. *Disability studies quarterly*, 30(3/4), pp. 1-17.

Kesby, M., 2005. Retheorizing empowerment-through-participation as a performance in space: Beyond tyranny to transformation. *Signs*, 30(4), pp. 2037-2065.

Kesby, M., 2007. Spatialising participatory approaches. *Environment and planning A*, 39(12), pp. 2813-2831.

Kimball, E.W., Moore, A., Vaccaro, A., Troiano, P.F. and Newman, B.M., 2016. College students with disabilities redefine activism: Self-advocacy, storytelling and collective action. *Journal of diversity in higher education*, 9(3), pp. 245-260.

Kitchin, R. and Wilton, R., 2003. Disability activism and the politics of scale. *The Canadian geographer*, 47(2), pp. 97-115.

Kohler, R.E., Miller, A.R, Gutnik, L., Lee, C.N. and Gopal, S., 2017. Experiences and perceptions regarding clinical breast exam screening by trained laywomen in Malawi. *Cancer causes control*, 28(2), pp. 137-143.

Krumer-Nevo, M., 2009. From voice to knowledge: participatory action research, inclusive debate and feminism. *International journal of qualitative studies in education*, 22(3), pp. 279-295.

Ladson-Billings, G., 1998. Just what is critical race theory and what's it doing in a nice field like education? *International journal of qualitative studies in education*, 11(1), p. 7-24.

Lalthapersad-Pillay, P., 2019. Joyce Banda and Ellen Johnson Sirleaf - confronting the neglect of maternal health and women's rights in Malawi and Liberia. *Agenda*, 33(1), pp. 97-107.

Landsman, G., 2005. Mothers and models of disability. *Journal of medical humanities*, 26(2/3), pp. 121-139.

Lawy, J.R., 2017. Theorizing voice: Performativity, politics and listening. *Anthropological theory*, 17(2), pp. 192-215.

Lazarus, 2019. [short documentary] Directed by David Darg. Malawi/USA: The New Yorker

Documentary. [online] Available at: <https://www.newyorker.com/video/watch/the-new-yorker-documentary-lazarus#> [Accessed 18 December 2020].

Levandowski, B., Kalilani-Phiri, L., Kachale, F., Awah, P., Kangaude, G., Mhango, C., 2012. Investigating social consequences of unwanted pregnancy and unsafe abortion in Malawi: The role of stigma. *International journal of gynecology and obstetrics*, 118(Supplement 2), pp. S167-S171.

Lingard, L., 2019. Beyond the default colon: Effective use of quotes in qualitative research. *Perspectives in medical education*, 8(6), pp. 260-364.

Local Government Act, 1998. Lilongwe: Parliament of Malawi. [online] Available at: <https://www.eisa.org.za/pdf/mal1998localgovernment.pdf> [Accessed 26 July 2019].

Lorenzo, T., 2003. No African renaissance without disabled women: A communal approach to human development in Cape Town South Africa. *Disability & society*, 18(6), pp. 759-778.

Lorenzo, T., van Niekerk, L., Mdlokolo, P., 2007. Economic empowerment and black disabled entrepreneurs: Negotiating partnerships in Cape Town, South Africa. *Disability and rehabilitation*, 29(5), pp. 429-436.

Mack, N., Woodson, C., MacQueen, K.M., Guest, G., Namey, E., 2005. *Qualitative research methods: A data collector's field guide*. Family health international. [online] Available at: <https://www.fhi360.org/sites/default/files/media/documents/Qualitative%20Research%20Methods%20-%20A%20Data%20Collector's%20Field%20Guide.pdf> [Accessed 22 June 2021]

Malawi Human Rights Commission, n.d. *Malawi Human Rights Commission submission of input to the draft general comment: General comment on Article 6 of the CRPD: Women with disabilities.* [online] Available at: <https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx> [Accessed 16 December 2020].

MalawiTourism.com, 2021a. *Central Malawi*. Malawi Travel Marketing Consortium. [online] Available at: <https://www.malawitourism.com/regions/central-malawi/> [Accessed 22 June 2021].

MalawiTourism.com, 2021b. *North Malawi*. Malawi Travel Marketing Consortium. [online] Available at: <https://www.malawitourism.com/regions/north-malawi/> [Accessed 22 June 2021].

MalawiTourism.com, 2021c. *South Malawi*. Malawi Travel Marketing Consortium. [online] Available at: <https://www.malawitourism.com/regions/south-malawi/> [Accessed 22 June 2021].

MANAD, 2012. *Malawi National Association of the Deaf*. [online] Available at: < http://www.manadmw.org/> [Accessed 16 December 2020].

Manda-Taylor, L., Mwale, D., Phiri, T., Walsh, A., Matthews, A. Brugha, R, Mwapasa, V. and Byrne, E., 2017. Changing times? Gender roles and relationships in maternal, newborn and child health in Malawi. *BMC pregnancy and childbirth*, 17(321), pp. 1-13.

Mandala, E., 1984. Capitalism, kinship and gender in the Lower Tchiri (Shire) Valley of Malawi, 1860-1960: An alternative theoretical framework. *African economic history*, 13, pp. 137-169.

Martin, A.W., 2008. Resources for success: Social movements, strategic resource allocation, and union organizing outcomes. *Social problems*, 55(4), pp. 501-524.

Martin, N., 2012. Disability identity - disability pride. *Perspectives: Policy and practice in higher education*, 16(1), pp. 14-18.

Mascia-Lees, F.E., Sharpe, P. and Cohen, C.B., 1989. The postmodernist turn in anthropology: Cautions from a feminist perspective. *Signs*, 15(1), pp. 7-33.

Massah, B.T., Manyozo, C., Msosa, A., Mtambo, T., 2016. *The role of the media in advancing the rights* *of persons with albinism in Malawi. Advancing the rights of persons with albinism in Africa*. A call to action: South Africa, 7-11 November. [online] Available at: <http://chimwemwemanyozo.com/wp-content/uploads/2018/05/1608-The-Role-of-the-Media-in-Advancing-the-Rights-of-Persons-with-Albinism-in-Malawi-1.pdf> [Accessed 18 December 2020].

McBride, R., 2006. Fenced into cycles of deprivation: Orphans, their female carers and education in Malawi. In Yeakey, C.C., Richardson, J.W and Brooks-Buck, J. eds. 2006. *'Suffer the Little children': National and international dimensions of child poverty and public policy*. Amsterdam/Bostin: Elsevier JAI, Ch. 3.

McCracken, J., 1998. Democracy and nationalism in historical perspective: the case of Malawi. *African affairs*, 97, pp. 231-249.

McEvily, B., Perrone, V. and Zaheer, A., 2003. Trust as an organizing principle. *Organization science*, 14(1), pp. 91-103.

McKay, C.L., 2010. Community education and critical race praxis: The power of voice. *Educational foundations*, 24(1-2), pp. 25-38.

Mckenzie, J.A. and Macleod, C.I., 2012. Rights discourses in relation to education of people with intellectual disability: Towards and ethics of care that enables participation. *Disability & society*, 27(1). pp. 15-29.

Meyers, S., 2014. Global civil society as megaphone or echo chamber?: Voice in the international disability rights movement. *International journal of politics, culture and society*, 27(4), pp. 459-476.

Mji, G., Schneider, M., Vergunst, R. and Swartz, L, 2014. On the ethics of being photographed in research in rural South Africa: Views of people with disabilities. *Disability & society*, 29(5), pp. 714-723.

Mkandawire-Valhmu, L., Kako, P., Kibicho, J. and Stevens, P. E., 2013. The innovative and collective capacity of low-income East African women in the era of HIV/AIDS: Contesting Western notions of African women. *Health care for women international*, 34(3/4), pp. 332-350.

Mkutumula, R.K., 2014. *Exploitation, violence and abuse among women and girls with disabilities*. DIWA [online]. Available at: <https://www.womenenabled.org/pdfs/mapping/DIWA%20Exploitation%20Violence%20and%20Abuse%20among%20women%20and%20girls%20with%20Disabilities.pdf>. [Accessed 10 December 2020].

Moore, O., 2006. Understanding postorganic fresh fruit and vegetable consumers at participatory farmers' markets in Ireland: reflexivity, trust and social movements. *International journal of consumer studies*, 30(5), pp. 416-426.

Morris, J., 2001. Impairment and disability: Constructing an ethics of care that promotes human rights. *Hypatia*, 16(4), pp. 1-16.

Morrison, C-A., Woodbury, E., Johnston, L., Longhurst, R., 2020. Disabled people's embodied and emotional geographies of (not) belonging in Aotearoa New Zealand. *Health and place*, 62 (102283), pp. 1-9

Moucheraud, C., Kawale, P., Kafwafwa, S., Bastani, R. and Hoffman, R.M., 2020. "It is big because it's ruining the lives of many people in Malawi": Women's attitudes and beliefs about cervical cancer. *Preventive medicine reports*, 18(101093), pp. 1-6.

Murray. V., 2019. Co-producing knowledge: Reflections on research on the residential geographies of learning disability. *Area*, 51(3), pp. 423-432.

Mwale, P. N., 2002. Where is the foundation of African Gender? The case of Malawi. *Nordic* *journal of African studies*, 11(1), pp. 114-137.

Nakano, D.Y., 2013. An interlocking panethnicity: the negotiation of multiple identities among Asian American social movement leaders. *Sociological perspectives*, 56(4), pp. 569-595.

National Policy on Equalisation of Opportunities for Persons with Disabilities, 2006. Lilongwe: Malawi Government. [online] Available at: <http://www.malawi.gov.mw/images/Publications/policy/Malawi%20National%20Policy%20on%20Equalisation%20of%20Opportunities%20for%20Persons%20with%20Disabilities.pdf> [Accessed 26 July 2019].

National Statistical Office, 2019. *2018 Malawi population and housing census: Main report*. [online] Available at: <http://www.nsomalawi.mw/images/stories/data_on_line/demography/census_2018/2018%20Malawi%20Population%20and%20Housing%20Census%20Main%20Report.pdf> [Accessed 14 June 2020].

Nayeja, R., 2017. *Charles George: Bicycle taxi operator with magical leg*. Thyolo: Malawi News Agency Online, 7 December. [online] Available at: <https://www.manaonline.gov.mw/index.php/national/education/item/7080-charles-george-bicycle-taxi-operator-with-magical-leg> [Accessed 19 December 2020].

Nelson, L., 2003. Decentering the movement: collective action, place, and the ‘sedimentation’ of radical political discourse. *Environment and planning D: Society and space*, 21(5), pp. 559-581.

O’Dell, E.J., 2019. Geographies of disability in the letters of Rimbaud: Mapping colonialism and disablement in Yemen and Ethiopia. *Journal of literary & cultural disability studies*, 13(4), pp. 445-460.

Oliver, M. and Barnes, C., 2010. Disability studies, disabled people and the struggle for inclusion. *British journal of sociology of education*, 31(5), pp. 547-560.

Pal, J., Youngman, M., O'Neill, T., Chandra, P., Semushi, C., 2015. Gender and accessibility in Rwanda and Malawi. *ACM international conference proceedings series*, 15, n.p.

Paget, A., Mallewa, M., Chinguo, D., Mahebere-Chirambo, C. and Gladstone, M., 2016. "It means you are grounded" - caregivers' perspectives on the rehabilitation of children with neurodisability in Malawi. *Disability and rehabilitation*, 38(3), pp. 223-234.

Pain, R., 2003. Social geography: On action-orientated research. *Progress in human geography*, 27(5), pp. 649-657.

Pain, R., 2014. Everyday terrorism: Connecting domestic violence and global terrorism. *Progress in human geography*, 38(4), pp. 531-550.

Park, D.C., Radford, J.P., Vickers, M.H., 1998. Disability studies in human geography. *Progress in human geography*, 22(2, pp. 208-233.

Peters, P. E., 2010. "Our daughters inherit our land, but our sons use their wives' fields": Matrilineal-matrilocal land tenure and the New Land Policy in Malawi. *Journal of Eastern African studies*, 4(1), pp. 179-199.

Piedalue, A., 2016. Beyond 'culture' as an explanation for intimate violence: the politics and possibilities of plural resistance. *Gender, place & culture*, pp. 1-13.

Pilisuk, M., McAllister, J. and Rothman, J., 1996. Coming together for action: The challenge of contemporary grassroots community organizing. *Journal of social issues*, 52(1), pp. 15-37.

Power, A., Bartlett, R. and Hall, E., 2016. Peer advocacy in a personalized landscape: The role of peer support in a context of individualized support and austerity. *Journal of intellectual disabilities*, 20(2), pp. 183-193.

Powers, L.E., 2017. Contributing meaning to research in developmental disabilities: Integrating participatory action and methodological rigour. *Research and practice for persons with severe disabilities*, 42(1), pp. 42-52.

PRB, 2014. *Malawi district infographic fact sheets*. PRB. [online] Available at: https://www.prb.org/resources/malawi-district-infographic-fact-sheets/ [Accessed 22 June 2021]>

Proctor, G., 2001. Listening to older women with dementia: Relationships, voices and power. *Disability & society*, 16(3), pp. 361-376.

Purdue, D., 2001. Neighbourhood governance: Leadership, trust and social capital. *Urban studies*, 38(12), pp. 2211-2224.

Riley, L. and Dodson, B., 2016. 'Gender hates men': untangling gender and development discourses in food security fieldwork in urban Malawi. *Gender, place & culture*, 23(7), pp. 1047-1060.

Rogers, A., Castree, N. and Kitchin, R., 2013. *A dictionary of human geography*. Oxford: Oxford University Press. [online] Available at: <https://www.oxfordreference.com/view/10.1093/acref/9780199599868.001.0001/acref-9780199599868> [Accessed 17 December 2020].

Rohwerder, B., 2018. *Disability stigma in developing countries*. K4D helpdesk report. Brighton: Institute of Development Studies.

Routledge, P., 2005. Grassrooting the imaginary: Acting within the convergence. *Ephemera*, 5(4), pp. 615-628.

Routledge, P., 2009. Transnational resistance: Global justice networks and spaces of convergence. *Geography compass*, 3(5), pp. 1881-1901.

Sadan, E., 1997. *Empowerment and community planning: Theory and practice of people-focused solutions*. Tel Aviv: Hakibbutz Hameuchad Publishers [in Hebrew]. English translation available at: http://www.mpow.org/elisheva_sadan_empowerment.pdf

Schriempf, A., 2001. (Re)fusing the amputated body: An interactionist bridge for feminism and disability. *Hypatia*, 16(4), pp. 53-79.

Scotland Malawi Partnership, 2015. *The SMP practical guide to visiting Malawi*. [online] Available at: <https://www.scotland-malawipartnership.org/files/6814/3384/3175/Practical_Guide_to_Visiting_Malawi_2015_Edition_5.pdf> [Accessed 12 December 2020].

Seale, J., 2017. From the voice of the ‘socratic gadfly’: a call for more academic activism in the researching of disability in postsecondary education. *European journal of special needs education*, 32(1), pp. 153-169.

Segal, E. S., 2008. Gender and ethnicity in Banda’s Malawi. *Wagadu*, 6, pp. 1-29.

Semu, L., 2002. Kamuzu’a mbumba: Malawi women’s embeddedness to culture in the face of international political pressure and internal legal change. *Africa today*, 49(2), pp. 77-99.

Setume, S. D., 2016. Myths and beliefs about disabilities: Implications for educators and counselors. *Journal of disability and religion*, 20(1-2), pp. 62-76).

Sewell Jr., W. H., 1992. A theory of structure: Duality, agency and transformation. *American* *journal of sociology*, 98(1), pp. 1-29.

Shapiro, J.P., 1993. *No pity: People with disabilities forging a new civil rights movement*. New York: Times Books/Random House.

Shakespeare, T. and Watson, N., 2001. The social model of disability: an outdated ideology? In: Barnartt, S.N. and Altman, B.M., eds. 2001. *Exploring theories and expanding methodologies: where are we and where we need to go (Research in social science and disability, vol. 2)*. Bingley: Emerald Group.

Sharp, J., 2011a. Gender: Part II. In: Agnew, J.A. and Duncan, J.S., eds. 2011. *The Wiley-Blackwell companion to human geography*, Somerset: Blackwell.

Sharp, J., 2011b. Subaltern geopolitics. *Geoforum*, 42, pp. 271-273.

Sharp, J., 2013. Africa's colonial present: Development, violence, and postcolonial security. In: Huggan, G., ed. 2013. *The Oxford handbook of postcolonial studies*. Oxford: Oxford University Press.

Shawa, L.B., 2012. The big-man syndrome as security threat in Malawi: A critical theory perspective. *Southern African peace and security studies*, 1(2), pp. 44-56.

Smith, B., Bundon, A. and Best, M., 2016. Disability sport and activist identities: a qualitative study of narratives of activism among elite athletes with impairment. *Psychology of sport and exercise*, 26, pp. 139-148.

Spivak, G. C., 1988. Can the subaltern speak? In: Nelson, C. and Grossberg, L., eds. 1988. *Marxism and the interpretation of culture*. Basingstoke: Macmillan Education.

Spivak, G. C., 1999. *A Critique of Postcolonial Reason: Towards a History of the Vanishing Present*.

Cambridge: Harvard University Press.

Spradley, J.P., 1980. *Participant observation*. New York: Holt, Rinehart and Winston.

Sprague, J. and Hayes, J., 2000. Self-determination and empowerment: A feminist standpoint analysis of talk about disability. *American journal of community psychology*, 28(5), pp. 671-695.

Stace, H., 2013. Disability care as women's work. *Women's studies journal*, 27(1), pp. 13-24.

Stephen, L., 1993. Challenging gender inequality: Grassroots organizing among women rural workers in Brazil and Chile. *Critique of anthropology*, 12(1), pp. 33-55.

Stone, E. and Priestley, M., 1996. Parasites, pawns and partners: Disability research and the role of non-disabled researchers. *British journal of sociology*, 47(4), pp. 699-716.

Storper, M., 1985. The spatial and temporal constitution of social action: a critical reading of Giddens. *Environment and planning D: Society space*, 3, pp. 407-424.

Strasser, P. G., 2016-2017. An anti-corruption bureau's inexorable endeavour: A study of Malawi's cashgate scandal. *Washington and Lee law review*, 303.

Sturges, P., 1998. The political economy of information: Malawi under Kamuzu Banda, 1964-94. *International information and library review*, 30, pp. 185-201.

Swanke, J. Zeman, L. D. and Doktor, J., 2009. Discontent and activism among mothers who blog while raising children with Autism spectrum disorders. *Journal of the association for research on mothering*, 11(1), pp. 199-210.

Swerts, T., 2015. Gaining a voice: Storytelling and undocumented youth activism in

Chicago. *Mobilization*, 20(3), pp. 345-360.

Tanabe, M., Pearce, E. and Krause, S.K., 2018. “Nothing about us without us”: Conducting participatory action research among and with persons with disabilities in humanitarian settings. *Action research*, 16(3), pp. 280-298.

Tambala-Kaliati, T., Adomako, E.B. and Frimpong-Manso, K., 2021. Living with albinism in an African community: Exploring the challenges of persons with albinism in Lilongwe District, Malawi. *Heliyon*, 7(e07034), pp. 1-8.

Tarrow, S., 1993. Cycles of collective action: Between moments of madness and the repertoire of contention. *Social science history*, 17(2), pp. 281-307.

Tefera, B., van Engen, M. L., Schippers, A., Eide, A. H., Kersetn, A., van der Klink, J., 2018. Education, work, and motherhood in low and middle income countries: A review of equality challenges and opportunities for women with disabilities. *Social inclusion*, 6(1), pp. 82-93.

Temple, B. and Edwards, R., 2002. Interpreters/translators and cross-language research: Reflexivity and border crossings. *International journal of qualitative methods*, 1(2), pp. 1-12.

Thien, D., 2005. After or beyond feeling? A consideration of affect and emotion in geography. *Area*, 37(4), pp. 450-456.

Thomas, P.D., 2018. Refiguring the subaltern. *Political theory*, 46(6), pp. 861-884.

Tiessen, R., 2008. Small victories but slow progress: An examination of women in politics in Malawi. *International feminist journal of politics*, 10(2), pp. 198-215.

Tilly, C., 2005. Introduction to part II: Invention, diffusion, and transformation of the social movement repertoire. *European review of history*, 12(2), pp. 307-320.

Tilly, C., 2010. Cities, states, and trust networks: chapter 1 of Cities and States in World History. In: Hanagan, M. and Tilly, C. eds. 2011. *Contention and Trust in Cities and States*. New York: Springer. Ch.1.

Tong, A., Sainsbury, P., Craig, J., 2007. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International journal of qualitative health care*, 19(6), pp. 349-357.

United Nations, 2019. *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. [online] Available at: <https://www.un.org/development/desa/disabilities/standard-rules-on-the-equalization-of-opportunities-for-persons-with-disabilities.html> [Accessed 26 July 2019].

United Nations, n.d.a. *International albinism awareness day*. Available online at: <https://www.un.org/en/events/albinismday/background.shtml>. [Accessed 29 March 2020].

United Nations, n.d.b. *United Nations Convention on the Rights of Persons with Disabilities* (CRPD). [online] Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> [Accessed 16 December 2020].

United Nations General Assembly, 2017. *Report of the Independent Expert on the enjoyment of human rights by persons with albinism*. [online] Available at: <https://undocs.org/A/HRC/34/59>. [Accessed 16 December 2020].

Valentine, G. and Hughes, K., 2012 Shared space, distant lives? Understanding family and intimacy at home through the lens of internet gambling. *Transactions of the institute of British geographers, New series,* 37(2), pp. 242-255.

Valentine, G., Piekut, A. and Harris, C., 2015. Intimate encounters: the negotiation of difference within the family and its implications for social relations in public space. *The geographical journal*, 181(3), pp. 280-294.

van der Meulen, E., 2011. Participatory and action-oriented dissertations: the challenges and importance of community-engaged graduate research. *The qualitative report*, 16(5), pp. 1291-1303.

van Niekerk, L., Lorenzo, T., Mdlookolo, P., 2006. Understanding partnerships in developing disabled entrepreneurs through participatory action research. *Disability and rehabilitation*, 28(5), pp. 323-331.

Waite, G., 1987. Public health in pre-colonial east-central Africa*. Social science and medicine*, 24(3), pp. 197-208.

Walters, R., 2018. Reading girls’ participation in Girl Up as feminist: club members’ activism in the UK, USA and Malawi. *Gender & development*, 26(3), pp. 477-493.

Warren, C. A. B., 2004. Interviewing in qualitative research. In: Lewis-Beck, M.S., Bryman, A. and Futing Liao, T. (2004). *The SAGE encyclopedia of social science research methods*. Thousand Oaks: SAGE. pp. 521-524.

Washington Group on Disability Statistics, 2016. *Short set of disability questions*. [online] Available at: <http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/> [Accessed: 19 December 2020].

Wasili, 2017. *Using alms to take children to school*. Blantyre: Malawi News Agency Online, 3 November. [online] Available at: <https://www.manaonline.gov.mw/index.php/national/agriculture/item/6567-using-alms-to-take-children-to-school> [Accessed 19 December 2020].

Whittington, R., 2015. Giddens, structuration theory and strategy as practice. In: Golsorkhi, D., Rouleau, L., Seidl, D. and Vaara, E., eds. 2015. *Cambridge handbook of strategy as practice, second edition*. Cambridge: Cambridge University Press.

Wickenden, M., 2011. Whose voice is that?: Issues of identity, voice and representation arising in an ethnographic study of the lives of disabled teenagers who use Augmentative and Alternative Communication (AAC). *Disability studies quarterly*, 31(4), pp. 1-20.

Wilton, R. and Horton, J., 2020. Disabling and enabling geographies: Celebrating 20 years of research in Social and Cultural Geography. *Social & cultural geography*, 21(7), pp. 1021-1028.

World Bank, 2020. *GDP Ranking: Gross domestic product 2019*. [online] Available at: <https://databank.worldbank.org/data/download/GDP.pdf> [Accessed 19 December 2020].

APPENDIX A

CONTENTS:

- SYSTEMATIC REVIEW PROTOCOL
- SELECTED REVIEW BIBLIOGRAPHY: “AFRICAN CONTEXT” PAPERS
- DELPHI STUDY ETHICAL APPROVAL

Participatory Approaches to Disability Research: Protocol for a Rapid Review & Meta-Synthesis (Abbreviated for PhD Thesis)

I. Objectives

The objectives of this review are to determine to what extent participatory/community-based action research has been used in qualitative disability studies as a method for research and intervention-design, and to investigate what synthesising the data from any studies found may contribute to the understanding of disability from a social lens.

II. Methods

A. Criteria for including and excluding studies

Types of study designs

Qualitative studies of any kind that identify their methodology or intervention as participatory and/or community-based action research will be included, as well as qualitative components of mixed-methods studies that do the same. To avoid potential duplication, other systematic reviews or meta-syntheses will not be included, (though the reference lists of relevant reviews may be consulted for any studies not returned via electronic search).

Types of participants

Participants must be defined in the study as disabled persons (self-identified or otherwise), and may also include disability activists, disability caretakers, and any other personnel that work or engage with disabled people. Samples which include non-disabled individuals will be included, provided that findings with respect to disabled persons are clearly delineated.

Types of interventions

Studies must include a participatory or community-based research methodology or intervention, as self-identified within the paper.

B. Search Strategy for Identification of Studies

Electronic search

A wide range of disciplines may include pertinent studies and grey literature, as the topic of this review spans social sciences, medicine, politics, global health, and service provision. Taking this into consideration, a broad range of topical databases will be included in the initial search, as a means of gathering as many potentially relevant studies as possible from any discipline. A search strategy consisting of terms pertinent to participatory/community-based research and disability will be run in the following databases:

Academic Search Complete
Africa-wide Information
British Education Index

Child Development and Adolescent Studies

EBSCOhost*

ERIC

Global Health

Google Scholar

JSTOR

ProjectMUSE

Proquest Dissertations and Theses with Full Text (PQDT)

PsycARTICLES

PsycINFO

Psychology and Behavioral Sciences Collection

Research Repository (St Andrews Research Repository)

Scopus

Web of Science (Medline/PubMed)

*EBSCOhost databases searched include: Academic Search Complete, Africa-wide Information, British Education Index, Child Development and Adolescent Studies, EBSCOhost, ERIC, PsycARTICLES, PsycINFO

Search Terms

The following search terms will be used to undertake electronic database searches, with search strategies adapted for each database depending on its specific functionalities:

Subject	Method
Accesib -ility, -le	Action Research
Chronic	CBPR
Disab –ility, -led, -lement, -ilities	Collaborative research
Handicap	Participatory research
Impair –ed, -ment	

C. Data Collection and Analysis

Selection of studies

The references from all searches will be entered into Elsevier Mendeley reference software. Reviewers will independently screen all of the records over three rounds: title, abstract and full paper, and exclude ineligible studies based on intervention, research methodology and population, at each round. Both reviewers will review all studies in the ‘title’ and ‘abstract’ rounds. For the ‘full paper’ round, 75% of the studies will be read by each reviewer, with 25% overlap in studies read to standardise decision-making. Any disputes or discrepancies regarding inclusion will be resolved via consultation with a separate reviewer.

Assessment of study quality

Each included study will be assessed for quality. For the quality assessment, a modified version of the COREQ (consolidated criteria for reporting qualitative research) checklist will be utilised

(Tong, Sainsbury & Craig, 2007). Specific guiding standards for low, high, and unclear quality (Quality Assessment) in each domain were established, as demonstrated below. Using these guidelines, texts will be awarded a point value for each domain in the checklist. The overall scores for each text will be used to compare the quality of the studies include in the meta-analyses. (A separate Delphi study of University of St Andrews social scientists was conducted to establish the relative importance of each item on the checklist and determine the highest possible point value for each item.)

(Adapted) COREQ Checklist (Tong, Sainsbury & Craig, 2007)

Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer / facilitator	Which author/s conducted the interview or focus group? **Quality Assessment** *-High*: Interviewers/facilitators were kept consistent across the study. *-Low*: Interviewers/facilitators varied across the study. *-Unclear*: No information on interviewer(s) is given nor is this information attainable from contact with the study authors.
2.	Credentials	What were the researcher's credentials? **Quality Assessment** *-High*: Researchers have appropriate credentials to undertake/understand the research process, subjects, and cultural context.

		-Low: Researchers have little or no training relevant to undertaking/understanding the research process, subjects, or cultural context. *-Unclear*: Researchers' credentials are not provided.
3.	Occupation	What was their occupation at the time of the study? **QUALITY ASSESSMENT** *-High*: Researchers' occupations allow them access to and understanding of the issue under study. *-Low*: Researchers' occupations allow for only a cursory level of access or understanding of the issue. *-Unclear*: Information on the researchers' occupations is not provided.
4.	Gender	Was the researcher male or female? **QUALITY ASSESSMENT** *-High:* Research team's gender distribution makes sense with regard to study participants' comfort, a necessity for building trust and gaining access. *-Low:* Research team's gender distribution does not account for comfort of the participants. *-Unclear*: Information on research team's gender-specific interactions with participants is not provided.
5.	Experience and training	What experience or training did the researcher have?

		QUALITY ASSESSMENT -*High*: Researchers have experience/training in the study methodology. -*Low*: Researchers are unfamiliar with the study methodology. -*Unclear*: Information on the researchers' experience/training is not provided.
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement? **QUALITY ASSESSMENT** -*High*: Enough of a rapport was established to develop trust with participants, which can help extract deeper information. -*Low*: No rapport was established with the participants; alternatively, the participants were known to the researchers before the start of the study. -*Unclear*: No information or information lacking in detail is provided on the relationship between participants and researchers.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? **QUALITY ASSESSMENT** -*High*: Participants were aware of enough information on the researcher/study to ensure their comfort and agency, but not so much as to be “coached” in the “correct” answers. -*Low*:

		Participants were given no information about the researcher/study; alternatively, the participants knew a great deal, especially regarding the researchers’ personal hopes or opinions on the outcome of the study. *-Unclear*: No information on the extent of the participants’ knowledge of the interviewer is provided.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? **QUALITY ASSESSMENT** *-High*: Any characteristics about the interviewer that may have affected the outcomes of the study were reported; additionally, none of the characteristics reported are likely to bias the results unduly. *-Low*: No characteristics of the interviewer were reported; alternatively, reported characteristics may have affected the results of the study. *-Unclear*: It was unclear whether there were potentially biasing characteristics attributable to the interviewer.
Domain 2: Study design		
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? **QUALITY ASSESSMENT** *-High*: There is a methodological orientation that is appropriate to investigate the outcomes of interest.

		-Low: The methodological orientation is unsuited to investigate the outcomes of interest. (Ex: conducting focus groups when the outcome of interest is usual interactions between members of a community; in this case, ethnography may be a better methodology.) *-Unclear*: It was unclear whether methodological orientation was suited to outcomes of interest.
Participant selection		
10.	Sampling	How were participants selected? **QUALITY ASSESSMENT** *-High*: Utilized the most appropriate and/or accessible sampling method depending on outcomes, comparators, and population of interest. *-Low*: The sampling method creates bias in conclusions drawn regarding the population being studied (Ex: snowball sampling in a male-dominated workplace may bias samples in studies interested in the different economic realities of men and women with disabilities). *-Unclear*: The sampling method is not mentioned; alternatively, it is unclear how the sampling method may have affected the study data/conclusions.
11.	Method of approach	How were participants approached? **QUALITY ASSESSMENT** *-High*: Participants were approached in ways that would generate a wide variety of experiences within the target population.

		-*Low*: Participants were approached in ways that are biased toward certain groups within the target population while excluding others. -*Unclear*: Information on approach is unclear or not provided; there are questions as to whether the approach would be biasing for a particular population.
12.	Sample size	How many participants were in the study? **QUALITY ASSESSMENT** -*High*: Study included a variety of participants with different backgrounds, experiences, etc.; alternatively, study includes a large enough sample to support conclusions drawn across a group. -*Low*: Study included little variety in participant experiences, and a very small sample. -*Unclear*: Sample size and/or its effect on the outcomes of the study is unclear.
13.	Non-participation	How many people refused to participate or dropped out? Reasons? **QUALITY ASSESSMENT** -*High*: Drop-outs and refusals were representatives of groups that are included in the study through the perspectives of other members of that group; alternatively, reasons for dropping out were not within the purview of the researchers to amend. -*Low*: Drop-outs and refusals were the only members of particular groups included in the study; alternatively, reasons for dropping out were within the purview of the researchers.

		-Unclear: Information on drop-outs and refusals and/or reasons was not provided.
Setting		
14.	Setting of data collection	Where was the data collected? **QUALITY ASSESSMENT** *-High*: Location was comfortable and safe for participants and researchers. *-Low*: Participants or researchers’ safety and comfort was not considered. *-Unclear*: Location was unclear/ not discussed.
15.	Presence of non-participants	Was anyone else present besides the participants and researchers? **QUALITY ASSESSMENT** *-High*: No individuals besides the participant and researcher were present. *-Low*: Other individuals were present. *-Unclear*: No information was provided on presence of non-participants.
16.	Description of sample	What are the important characteristics of the sample? **QUALITY ASSESSMENT** *-High*: Detailed demographic information was collected and considered during data analysis. *-Low*: Limited or no demographic information was collected; alternatively, demographics were not considered during analysis.

		-*Unclear*: Information on demographic data collection/consideration was not provided.
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested? **QUALITY ASSESSMENT** -*High*: Interview guide was appropriate to elicit the information of interest, and was pilot tested. -*Low*: Interview guide was inappropriate to elicit the information of interest, and/or was not pilot tested. -*Unclear*: Information on interview guide/pilot testing was not provided.
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many? **QUALITY ASSESSMENT** -*High*: Repeat interviewing was appropriate and necessary to the study interests, and risk of repeat interviewing was taken into consideration during data analysis. -*Low*: Repeat interviewing was inappropriate to the study interests, and/or risk of repeat interviewing was not taken into consideration during data analysis. -*Unclear*: Appropriateness/consideration of repeat interviewing unclear.
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data? **QUALITY ASSESSMENT**

		-*High*: Audio or visual recording was utilised appropriately within the study goals. -*Low:* Audio or visual recording was utilised inappropriately within the study goals. -*Unclear:* Audio or visual recording's appropriateness to study goals unclear.
20.	Field notes	Were field notes made during and/or after the interview or focus group? **QUALITY ASSESSMENT** -*High*: Field notes taken in a timely manner. -*Low*: No field notes taken or taken in an untimely manner. -*Unclear*: No information on field notes provided.
21.	Duration	What was the duration of the interviews or focus group? **QUALITY ASSESSMENT** -*High*: Duration of the interview sufficient to collect data but not cause participants discomfort. -*Low*: Duration insufficient to collect data or did cause participants discomfort. -*Unclear*: Duration's effect on data collection and/or participants' comfort unclear.
22.	Data saturation	Was data saturation discussed? **QUALITY ASSESSMENT** -*High*: Data saturation reached/discussed.

		-*Low*: Data saturation not reached/discussed. -*Unclear*: Data saturation unclearly discussed.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction? **QUALITY ASSESSMENT** -*High*: An appropriate number of transcripts returned for comment/correction. -*Low*: Transcripts not returned for comment/correction. -*Unclear*: Information on transcript returns not provided.
Domain 3: analysis and findings		
Data analysis		
24.	Number of data coders	How many data coders coded the data? **QUALITY ASSESSMENT** -*High*: Data coders kept consistent across study. -*Low*: Data coders varied across study. -*Unclear*: Information on data coders not provided.
25.	Description of the coding tree	Did authors provide a description of the coding tree? **QUALITY ASSESSMENT** -*High*: Description of coding tree provided. -*Low*:

		Description of coding tree not provided. *-Unclear*: Partial/unclear description of coding tree provided.
26.	Derivation of themes	Were themes identified in advance or derived from the data? **QUALITY ASSESSMENT** *-High*: Guiding themes identified in advance but additional themes were derived from data; alternatively, all themes derived from data. *-Low*: No themes derived from data. *-Unclear*: No information on theme derivation provided.
27.	Software	What software, if applicable, was used to manage the data? **QUALITY ASSESSMENT** *-High*: Appropriate software was utilised, if any. *-Low*: Inappropriate software was utilised, if any. *-Unclear*: No information provided on software utilization.
28.	Participant checking	Did participants provide feedback on the findings? **QUALITY ASSESSMENT** *-High*: An appropriate number of participants provided feedback on findings. *-Low*: Too few or no participants were given the chance to provide feedback; alternatively, no participants agreed to provide feedback.

		-*Unclear*: No information provided on participant feedback.
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? **QUALITY ASSESSMENT** -*High*: Participant quotations are identifiable to a particular participant; quotes used to support themes. -*Low*: Participant quotations are unidentifiable to a particular participant; quotes not used to support themes. -*Unclear*: Unclear which participants provided which quotations, but quotations used to illustrate themes.
30.	Data and findings consistent	Was there consistency between the data presented and the findings? **QUALITY ASSESSMENT** -*High*: Data and findings are consistent. -*Low*: Data and findings are inconsistent. -*Unclear*: Not enough information provided to link data and findings.
31.	Clarity of major themes	Were major themes clearly presented in the findings? **QUALITY ASSESSMENT** -*High*: Major themes are clearly presented, explained, and related back to data.

		-*Low*: Major themes are unclear, poorly explained, and not related back to data. -*Unclear*: Contains aspects of both the low and high ROB categories described above.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? **QUALITY ASSESSMENT** -*High*: Diverse cases and minor themes are described/discussed. -*Low*: Diverse cases and minor themes not explored. -*Unclear*: Information on diverse cases and minor themes not provided.

Synthesis (on-going)

A multi-component synthesis of the data will be conducted, using first-order constructs in the form of direct participant quotations, second-order constructs consisting of individual reviewers' interpretations, and third-order constructs consisting of the reviewers' analysis and synthesis of data from all included studies.

Using the concept cards containing participant quotations and author interpretations, the researchers will analyse the data for parallel and conflicting opinions, thoughts, perceptions, etc. pertaining to disability and the use of participatory research; from this analysis, themes will be developed. The demographic data of participants whose data fits into a particular theme will be analysed, and all participant demographics within said theme will then be compared, again looking for parallels and conflicts. From these steps, reviewers will develop synthesised results and discussion around the use of participatory action research in a disability studies context, the issues that relate to disabled persons and communities, and the ways in which the results of qualitative studies have been or could be utilised in policy and programme design and implementation, and the reduction of social stigma and disabling social conditions.

References

Tong, A., Sainsbury, P. & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32- item checklist for interviews and focus group. *International Journal of Qualitative in Health Care*, 19(6), pp.349 -357. [online] Available at: http://intqhc.oxfordjournals.org/content/intqhc/19/6/349.full.pdf

Selected Bibliography (Systematic Review Results): "African Context"

Chappell, P., Rule, P., Dlamini, M. and Nkala, N. (2014). Troubling power dynamics: Youth with disabilities as co-researchers in sexuality research in South Africa. *Childhood*, 21(3), pp. 385–399. doi: 10.1177/0907568214525427.

Chivandikwa, N. (2013). Participatory Theatre for Development as Action Research. Methodological, Theoretical and Ethical Challenges, Tensions and Possibilities with Specific Reference to an HIV / AIDS and Disability Project. *Matatu*, 43(1), pp. 109–123. doi: 10.1163/9789401210539.

de Clerck, G. A. (2011). Fostering deaf people's empowerment: The Cameroonian deaf community and epistemological equity. *Third World Quarterly*, 32(8), pp. 1419–1435. doi: 10.1080/01436597.2011.604516.

Greenwood, M., Fakih, B., Steff, M., Bechange, S., Mrisho, M. (2016). Hear my voice: a community-based participatory study gathering the lived experiences of people with disabilities and older people in Tanzania. *Knowledge Management for Development Journal*, 11(2), pp. 63–78. Available at: http://journal.km4dev.org.

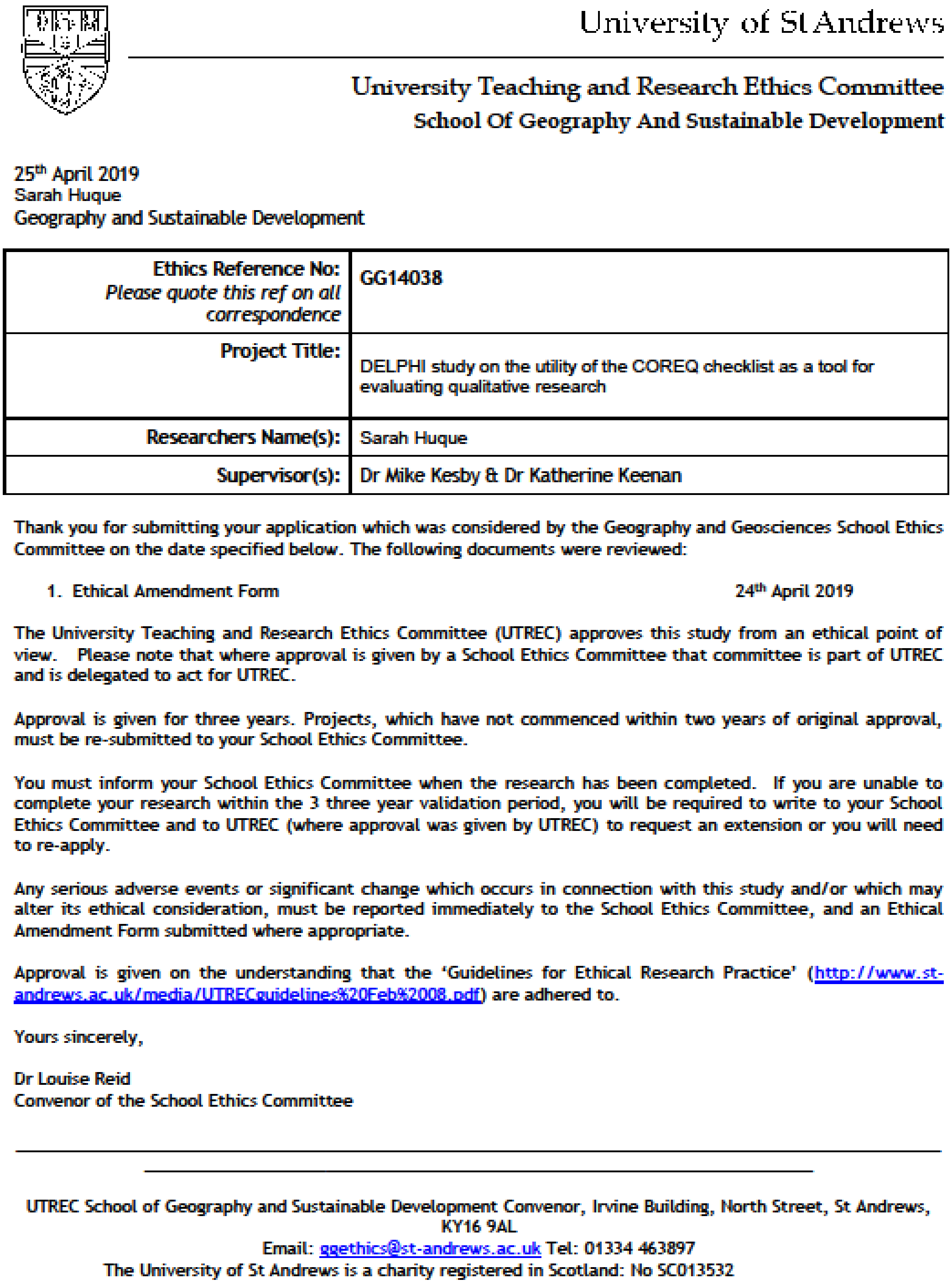
Jones, I., Marshall, J., Lawthom, R. and Read, J. (2013). Involving people with communication disability in research in Uganda: A response to the World Report on Disability. *International Journal of Speech-Language Pathology*, 15(1), pp. 75–78. doi: 10.3109/17549507.2012.743175.

Lorenzo, T. (2003). No African Renaissance without Disabled Women: A communal approach to human development in Cape Town South Arica. *Disability and Society*, 18(6), pp. 759–778. doi: 10.1080/0968759032000119505.

Lorenzo, T., van Niekerk, L. and Mdlokolo, P. (2007). Economic empowerment and black disabled entrepreneurs: Negotiating partnerships in Cape Town, South Africa. *Disability and Rehabilitation*. Taylor & Francis, 29(5), pp. 429–436. doi: 10.1080/09638280600841190.

van Niekerk, L., Lorenzo, T. and Mdlokolo, P. (2006) 'Understanding partnerships in developing disabled entrepreneurs through participatory action research. *Disability and Rehabilitation*. Taylor & Francis, 28(5), pp. 323–331. doi: 10.1080/09638280500166425.

Stewart, R. and Bhagwanjee, A. (1999). Promoting group empowerment and self-reliance through participatory research: A case study of people with physical disability. *Disability and Rehabilitation*, 21(7), pp. 338–345. doi: 10.1080/096382899297585.



University of St Andrews

University Teaching and Research Ethics Committee
School Of Geography And Sustainable Development

25th April 2019
Sarah Huque
Geography and Sustainable Development

Ethics Reference No: *Please quote this ref on all correspondence*	GG14038
Project Title:	DELPHI study on the utility of the COREQ checklist as a tool for evaluating qualitative research
Researchers Name(s):	Sarah Huque
Supervisor(s):	Dr Mike Kesby & Dr Katherine Keenan

Thank you for submitting your application which was considered by the Geography and Geosciences School Ethics Committee on the date specified below. The following documents were reviewed:

1. Ethical Amendment Form	24th April 2019

The University Teaching and Research Ethics Committee (UTREC) approves this study from an ethical point of view. Please note that where approval is given by a School Ethics Committee that committee is part of UTREC and is delegated to act for UTREC.

Approval is given for three years. Projects, which have not commenced within two years of original approval, must be re-submitted to your School Ethics Committee.

You must inform your School Ethics Committee when the research has been completed. If you are unable to complete your research within the 3 three year validation period, you will be required to write to your School Ethics Committee and to UTREC (where approval was given by UTREC) to request an extension or you will need to re-apply.

Any serious adverse events or significant change which occurs in connection with this study and/or which may alter its ethical consideration, must be reported immediately to the School Ethics Committee, and an Ethical Amendment Form submitted where appropriate.

Approval is given on the understanding that the 'Guidelines for Ethical Research Practice' (http://www.st-andrews.ac.uk/media/UTRECguidelines%20Feb%2008.pdf) are adhered to.

Yours sincerely,

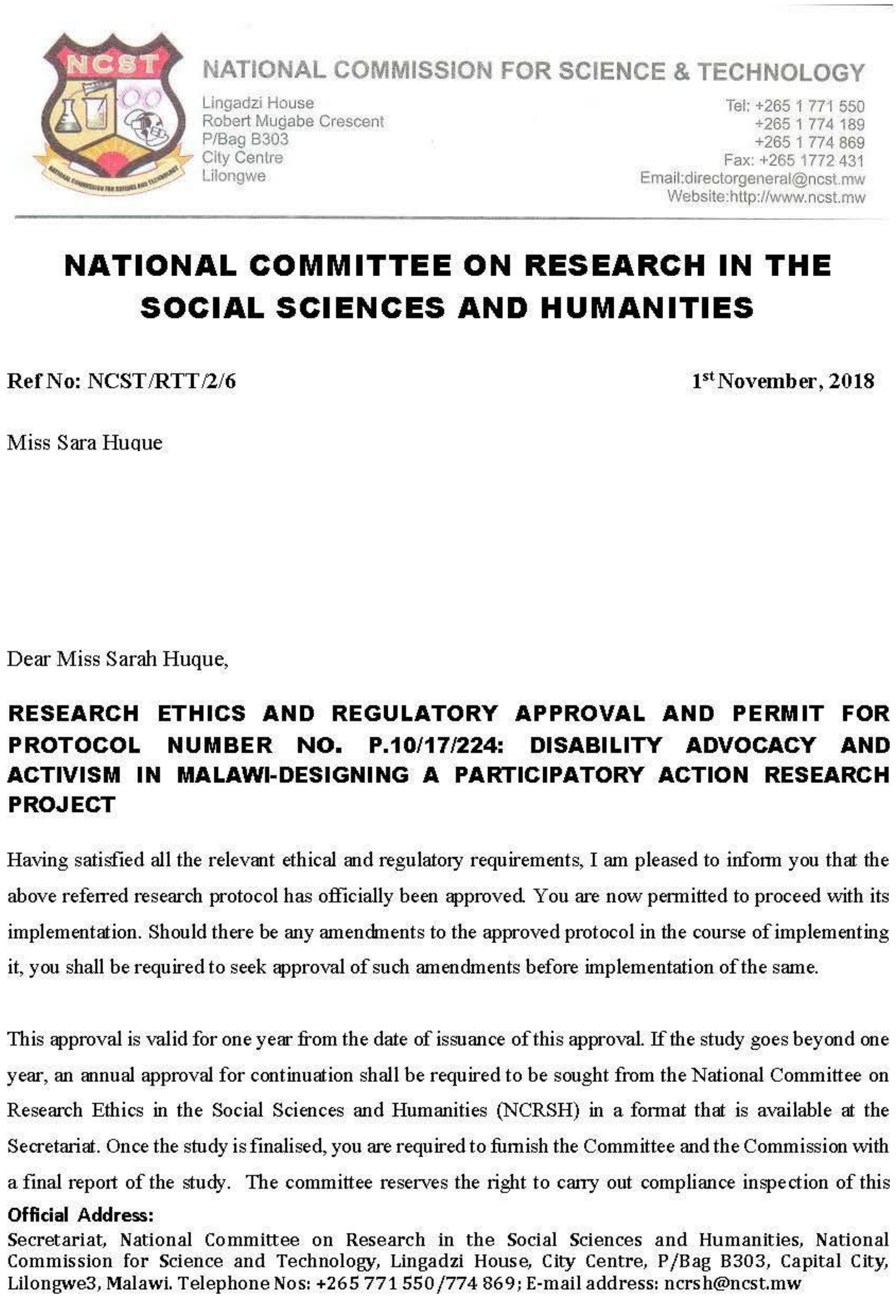
Dr Louise Reid
Convenor of the School Ethics Committee

UTREC School of Geography and Sustainable Development Convenor, Irvine Building, North Street, St Andrews, KY16 9AL
Email: ggethics@st-andrews.ac.uk Tel: 01334 463897
The University of St Andrews is a charity registered in Scotland: No SC013532

APPENDIX B

CONTENTS:

- STAGE 2 DATA COLLECTION ETHICAL APPROVALS
- STAGE 2 (APPROVED) ETHICAL APPLICATION, INCLUDING: DATA COLLECTION DOCUMENTS



NATIONAL COMMISSION FOR SCIENCE & TECHNOLOGY
Lingadzi House
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Lilongwe

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Website:http://www.ncst.mw

NATIONAL COMMITTEE ON RESEARCH IN THE SOCIAL SCIENCES AND HUMANITIES

Ref No: NCST/RTT/2/6 **1st November, 2018**

Miss Sara Huque

Dear Miss Sarah Huque,

RESEARCH ETHICS AND REGULATORY APPROVAL AND PERMIT FOR PROTOCOL NUMBER NO. P.10/17/224: DISABILITY ADVOCACY AND ACTIVISM IN MALAWI-DESIGNING A PARTICIPATORY ACTION RESEARCH PROJECT

Having satisfied all the relevant ethical and regulatory requirements, I am pleased to inform you that the above referred research protocol has officially been approved. You are now permitted to proceed with its implementation. Should there be any amendments to the approved protocol in the course of implementing it, you shall be required to seek approval of such amendments before implementation of the same.

This approval is valid for one year from the date of issuance of this approval. If the study goes beyond one year, an annual approval for continuation shall be required to be sought from the National Committee on Research Ethics in the Social Sciences and Humanities (NCRSH) in a format that is available at the Secretariat. Once the study is finalised, you are required to furnish the Committee and the Commission with a final report of the study. The committee reserves the right to carry out compliance inspection of this approved protocol at any time as may be deemed by it. As such, you are expected to properly maintain all study documents including consent forms and data collection tools for a period not more than five years. Wishing you a successful implementation of your study.

Yours Sincerely,

Mike Kachedwa

HEAD OF NCRSH SECRETARIAT
For: CHAIRMAN OF NCRSH

Official Address:
Secretariat, National Committee on Research in the Social Sciences and Humanities, National Commission for Science and Technology, Lingadzi House, City Centre, P/Bag B303, Capital City, Lilongwe3, Malawi. Telephone Nos: +265 771 550/774 869; E-mail address: ncrsh@ncst.mw

University of St Andrews

University Teaching and Research Ethics Committee

School Of Geography And Geosciences

20th August 2018
Sarah Huque
Geography and Sustainable Development

Ethics Reference No: *Please quote this ref on all correspondence*	**GG13884**
Project Title:	Disability Advocacy in Malawi: Part 2
Researchers Name(s):	Sarah Huque
Supervisor(s):	Dr Mike Kesby & Dr Katy Keenan

Thank you for submitting your application which was considered by the Geography and Geosciences School Ethics Committee on the date specified below. The following documents were reviewed:

1. Ethical Application Form	20th July 2018
2. Participant Information Sheet	20th July 2018
3. Consent Form	20th July 2018

The University Teaching and Research Ethics Committee (UTREC) approves this study from an ethical point of view. Please note that where approval is given by a School Ethics Committee that committee is part of UTREC and is delegated to act for UTREC.

Approval is given for three years. Projects, which have not commenced within two years of original approval, must be re-submitted to your School Ethics Committee.

You must inform your School Ethics Committee when the research has been completed. If you are unable to complete your research within the 3 three year validation period, you will be required to write to your School Ethics Committee and to UTREC (where approval was given by UTREC) to request an extension or you will need to re-apply.

Any serious adverse events or significant change which occurs in connection with this study and/or which may alter its ethical consideration, must be reported immediately to the School Ethics Committee, and an Ethical Amendment Form submitted where appropriate.

Approval is given on the understanding that the 'Guidelines for Ethical Research Practice' (http://www.st-andrews.ac.uk/media/UTRECguidelines%20Feb%2008.pdf) are adhered to.

Yours sincerely,

Dr. Kim McKee
Convenor of the School Ethics Committee

UTREC School of Geography and Sustainable Development Convenor, Irvine Building, North Street, St Andrews, KY16 9AL
Email: ggethics@st-andrews.ac.uk Tel: 01334 463897
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Sarah Huque
School of Geography & Sustainable Development

In Malawi:
Tel: +265 995 49 92 90

Ms. Martina Chimzimu
Mr. Mike Kachedwa
Health, Social Sciences and Humanities Division
National Commission for Science and Technology
Lingadzi House
Lilongwe, Malawi

27th September 2018

Dear Ms. Chimzimu and Mr. Kachedwa,

Please find attached a submission for consideration for ethical clearance, with changes made as required by the initial ethics review for the application, submitted on 12th October 2017. The proposed project is a participatory action research-project to be conducted as part of my, Sarah Huque's, PhD research at the University of St Andrews in Scotland. This student project is being undertaken with research partner FEDOMA, with whom a research agreement has been established, again with updates as required by the Committee's previous comments. (A copy of the updated agreement, with changes established through a Variation Letter, is included in this package.) The project has been granted ethical approval by the University of St Andrews UTREC, through the School of Geography and Sustainable Development.

To assist the Committee with the review of specific changes made in line with the previous comments, we have included an itemized list of the changes which relate to said comments at the beginning of the application.

Please do not hesitate to contact me if you require anything further, or have questions, comments, or concerns.

Thank you for your time and consideration.

Sincerely,

Sarah Huque
PhD Student
School of Geography & Sustainable Development
University of St Andrews

List of NCRSH Comments and Related Revisions:

(a) Signed agreement between FEDOMA and St Andrews

The research agreement has been renegotiated and redrafted in line with the issues raised by the Committee. In response to the comment about vetting the agreement, Mr Action Amos reached out to the NCST directly, as we were unable to find information on this procedure elsewhere, and spoke to Mr Kachedwa regarding the application. We were asked to resubmit the agreement with the changes to the NCRSH< so that the additional vetting could take place during the ethical review. If the Committee believes further vetting is required, we respectfully ask that instructions be provided on where/to whom to send the agreement, so that we may proceed in the appropriate manner. The revised agreement, which consists of the original agreement and changes made via Variation Letter, can be found in **Appendix A, which begins on page 13 of the revised application**.

(b) Budget

Based on the Committee's comments, the budget has been raised to £4,000. A complete budget breakdown is provided here and can also be found beginning on **page 11** of the revised application:

Budget & Budget Justification

Due to the fact that this is a student project, available funding is limited. However, based on the comments from the initial ethical application, additional funding has been sought. The previous budget of £3,000 has been raised to £4,000 to include all costs outlined in this breakdown, as well as other costs that may arise, including but not limited to NCRSH fees, fuel costs, and provision of refreshments for interview participants. The student researcher will be covering her own personal subsistence costs. We feel that this budget is reasonable, considering the small scale of the project and the lack of a need for any specialised equipment.

Total Budget: £4,000 = (approx.) MK 4,450,000

Item	**Estimated Cost (£ and approx. MK equivalent) *except visa fees, which are payed in USD**	**Notes**
Flights	£1,084 = MK 1,040,000	Based on most recent availability.
Transport to secondary field sites	£540 = MK 600,000	Vehicle arrangement through FEDOMA: per diem flat rate
Lodging in Blantyre	£840 = MK 806,000	Based on £15/day x planned duration of field visit. This rate is from lodging previously used in Blantyre.
Lodging at secondary field sites	£450 = MK 432,000	Based on £15/day/person for researcher and field assistant, for 5 days in each of the 3 districts.
Visa fee upon entry	*$75 = £56 = MK 54,000	First month
Visa extension fee	£5 = MK 5,000	Second month
TOTAL BASELINE EXPENDITURES	**£2,975 = MK 2,937,000**	

(c) Indicate all the sites/locations/districts in which the study will be implemented

This information is provided here, and can also be found on **page 8** of the revised application:

Study sites/locations

- Based in Blantyre, with visits to several districts within which FEDOMA works across Malawi. The districts to be visited have been chosen by the Executive Director of FEDOMA, and are as follows: Kasungu, Nkhatabay, and Mulanje.

(d) Consent form/Information sheet

(i) The details of NCRSH reporting have been added to the forms, which can be found in **Appendix C, which begins on page 31 of the revised application.**

(ii) Language relating to the maintenance of images and recorded data has been removed from the Consent form, which can be found in **Appendix C, which begins on page 31 of the revised application**.

(e) Sample size

Details about the sample size are provided here, and can also be found on **page 8** of the revised application:

<u>Sample size</u>

- Interviews will be conducted with the elected leaders of three of FEDOMA's District Disability Forums, for an overall interview sample size of 15 people.

- Participant observation will be carried out among FEDOMA's staff and activities, specifically following the fieldwork and programming of at least 7 project coordinators, as well as members of FEDOMA who assist with and/or participate in such events.

(f) Define the type of mixed methods that are referred to in the protocol

Definitions of the mixed methods are provided here, and can also be found on **page 9** of the revised application:

This research uses mixed qualitative methods in the form of interviewing and participant observation.

(g) **Data collection tools**

The data collection tools have been included in the revised application, and can be found in **Appendix B, which begins on page 26 of the revised application**.

NCRSH CHECKLIST

[*To accompany research proposals submitted to the committee for review*]

Note: Before submitting a research proposal to the Committee, an applicant must complete the following checklist by ticking each item in the box. Do not submit the proposal, unless you have provided a tick in all the boxes. Incomplete submissions will not be processed.

TITLE OF PROPOSAL:
Disability Advocacy in Malawi

PRINCIPAL INVESTIGATOR:
Sarah Huque, PhD Candidate, University of St Andrews

I declare that the following items are included in this submission;

1. Covering letter of introduction from the investigator [X]
2. Two (2) hard copies of the study proposal prepared and bound in the required NCRSH format appearing in the Framework of Guidelines for Research in the Social Sciences and Humanities. [X]
3. A soft copy of the proposal with all the required information as specified below;

Proposal Title (on cover page) [X]
Names of Investigators and their Qualifications [X]
Institution of affiliation(local or international) [X]
Introduction/Literature review [X]
Problem statement/Justification [X]
Main and Specific Objectives

[X]
Description of Methodology/Materials and Methods

- Study design [X]
- Study sites/locations [X]
- Study participants [X]
- Study period [X]
- Sampling methods [X]
- Sample size [X]
- Data collection instruments [X]
- Data management methods [X]
- Data analysis method [X]

Research dissemination strategy [X]
Ethics

- Risks and strategies for obviating them to enhance protection of rights and welfare of study participants [X]
- Informed consent form/sheet/assent in English and/or translated into an appropriate local language containing

  standard elements of an informed consent form/sheet/assent [x]

Work plan (including roles of collaborators clearly defined) [X]

Budget (*that include a **10%** research compliance and capacity building fee when study is approved*) [X]
Budget justification [X]
Bibliography [X]

4. Data collection instruments translated into appropriate local language and referred to in the annex [X]

5. Letter(s) of permission of entry/support from relevant DHO/Head of Health Facility, if the study is going to be conducted in a health facility [N/A]

6. Letter of approval from foreign ethics committee (for all studying in foreign universities) [X]

7. Application/Processing fee of U$ 150 or its MKW equivalent [X]

8. Curriculum vitae (CVs) for all the investigators (in annex) [X]

SIGNATURE:

NAME (PRINT): Sarah Huque

DATE: 12 October 2017

Disability Advocacy and Activism in Malawi

Researcher:
Sarah Huque, PhD Candidate
School of Geography & Sustainable Development and School of Medicine, University of St Andrews
Supervisors:
Dr Mike Kesby, School of Geography & Sustainable Development, University of St Andrews
Dr Katherine Keenan, School of Geography & Sustainable Development, University of St Andrews

In Partnership with:

Federation of Disability Organizations in Malawi (FEDOMA)
Executive Director: Mr Action Amos

Introduction

This ethics application is for a collaborative research project between Sarah Huque, a PhD researcher at the University of St Andrews, and the Federation of Disability Organizations in Malawi (FEDOMA). The project would be undertaken as part of a PhD research project, wherein the researcher's academic goal is the submission of a doctoral thesis. A research agreement, fully signed by all parties involved, is attached as Appendix A, with changes made in a Variation Letter, as per the Committee's previous review of this project.

This project explores the needs, work, experiences, and voice of disability advocates in Malawi, using participatory approaches. The project will involve dialogue with FEDOMA, including its district-level affiliates, through participant observation and interviewing. Discussions with FEDOMA have led to a decision to focus on investigating the effectiveness of communication around advocacy activities, and the implications the organisational structure has for voice within the disability community.

Literature Review

Before this project was begun, a general review of the academic disability literature was conducted. However, this was not written up in a formal manner, as the specific topics within the literature that are relevant to this project continue to evolve, based on the open, participatory nature of the project. At the moment, a thorough systematic review of the literature relating to disability and participatory research as a methodology is being undertaken by the researcher, following on from the development of a search protocol designed to capture the breadth of the literature across all relevant fields. The systematic review is currently still underway, as the search returned more than 60,000 unique results.

Problem Statement/Justification

Recent legislation, in particular the 2012 Disability Act, and movement on disability rights in Malawi represent great potential strides forward for the actualization of these rights. However, implementation of this legislation remains a challenge and research is needed on the face of the issue. Furthermore, bespoke research on disability and the rights of persons with disabilities within a particular community can provide useful information for use within that community, as well as informing a better understanding of the experience of disability globally. At its core, this project aims to increase awareness of the work of FEDOMA in Malawi, and help to further the goals of the organisation toward the realisation of social and economic justice, and the reduction of harm and stigma perpetuated against people with disabilities

Objectives

- To produce knowledge that helps to further the movement for the human, social, and economic rights of people with disabilities in Malawi;
- To understand the views of Malawians with disabilities about the utility of advocacy work, the nature of their needs, and the ways these needs might best be met;
- To investigate whose voices are heard and in what capacity within disability advocacy circles;
- To improve communication between members of disability advocacy organizations;
- To generate meaningful insight into the experience of disability in the majority world.

Methodology

- Study design: participatory action research, utilising qualitative research methods, in the form of participant observation and interviewing.

- Study sites/locations: based in Blantyre, with visits to several districts within which FEDOMA works across Malawi. The districts to be visited have been chosen by the Executive Director of FEDOMA, and are as follows: Kasungu, Nkhatabay, and Mulanje.
- Study participants: any disability advocates who wish to participate as members of FEDOMA and/or its constituent organizations will be encouraged to do so. Participants will be recruited from the existing membership of FEDOMA, its constituent organizations, its partners, and FEDOMA's and the researcher's contacts in other organizations and government bodies.
- Study period: at least seven weeks, to commence once ethical approval has been obtained, ideally between 1 October 2018 and 31 December 2018.
- Sample size:
  - Interviews will be conducted with the elected leaders of three of FEDOMA's District Disability Forums, for an overall interview sample size of 15 people.
  - Participant observation will be carried out among FEDOMA's staff and activities, specifically following the fieldwork and programming of at least 7 project coordinators, as well as members of FEDOMA who assist with and/or participate in such events.
- Data collection instruments: the main method of data collection will be participant observation, with detailed field notes and/or recordings and photos being taken by the researcher; some formal interviews will also take place, but these interviews will be as organic and conversational in nature as possible, and will not necessarily have a strict question set, though a guide will be followed to ensure that the conversations are comparable.
  - For the specific data collection instruments to be used, please see Appendix B.
- Data management method: data will be collected on the researcher's computer, and stored on a University of St Andrews run cloud service (Microsoft Exchange). Hard back-ups will be saved on physical memory cards, external drives, and flash drives belonging to the researcher and designated solely for use in this project. While in Malawi, hard documents, including signed consent forms, will be kept in the researcher's locked accommodation or on her person. While in Scotland, hard documents will be kept in a file under lock and key. Transcripts of interviews will be anonymised, and will be preserved for entry into the St Andrews research repository. Recordings will be destroyed after a period of three years from completion of the PhD.

  -Data analysis method: Interviews will be fully transcribed by the researcher. Notes from participant observation will be coded and grouped thematically, to draw out the major points of interest, commonality, and difference. Data analysis software Nvivo will be utilised when undertaking data analysis. This will then be compiled into an anonymised report, which will be shared with FEDOMA.

Research Dissemination Strategy

The results of this research will be shared with FEDOMA and decisions as to the dissemination of the results will be made jointly. The hope is that the results may be shared both locally and internationally, in the form of academic papers, reports for FEDOMA and its affiliates, and production of materials that can be used at every level of the organisation.

Research partners have drafted an agreement which includes provision for both parties to mutually notify the other of any outputs, and which acknowledges the necessity for academic outputs on the researcher's end. The research and university will retain rights to academic outputs. An objective of the research is to identify what other outputs might emerge from the project. Any individuals contributing to the collection of research in this stage will be credited appropriately in any outputs. The aforementioned agreement provides sufficient time for any party to object/clarify/seek additional credits in outputs if need be.

Ethical Considerations

1. Research Agreement

The research will be governed by the research agreement between Sarah Huque, FEDOMA, and the University of St Andrews, which sets out the rights and responsibilities of both parties, and provides an initial layer of protection against any form of ethical misconduct.

2. Proposed Consent Protocol

The research uses mixed qualitative methods (consisting of participant observation and interviewing), and as such will be undertaken with adherence to the following proposed consent protocol:

Interviews

- Participant Info Sheet
- Informed consent in written or oral form
- Participant debrief

Participant Observation (Ethnography)

- In organizational setting/offices/protests/programmes:
  - Ex: Within FEDOMA offices
  - Announcement and Statement of Researcher's Purpose
    - See attached participant information sheet in Appendix C
  - For strictly observational work: "opt-out" consent: anyone uncomfortable with my taking notes on them can notify myself or a member of FEDOMA/organizational staff that they do not wish for any information about them to be recorded/noted.
  - For informal conversations: notes will be taken, but speaker will be notified that notes are being taken and asked to confirm that they are okay with that. (No identifying information will be kept with the records: participant will be given a pseudonym and the key will be kept separately.)
- In more personal settings
  - These will be voluntary, recruited based on group ethnographic encounters and/or voluntary "self-recruitment."
  - Ex: "day-in-the-life"
  - Participant Info Sheet
  - Informed consent in written or oral form
  - Participant debrief
- Children will not be recruited as participants in this research project.

*Note: Consent forms and participant information sheet are attached in Appendix C.

3. Voluntary Participation

The main project and procedures will be explained to all participants in advance, so that they can make an informed decision about participating. Participants will be clearly informed about issues of data storage, access, and destruction. All participants will be informed that their participation is voluntary, and that if they choose to participate, they may withdraw from participation without having to give a reason. Separate consent will be sought from all participants for any audio or video recording or photography.

a. Data will be stored on a university-run cloud service (Microsoft Exchange) and hard back-ups will be saved on physical external drives and flash drives. Transcripts of interviews will be anonymised, and will be preserved for entry into the St Andrews research repository. Recordings will be destroyed after a period of three years from completion of the PhD.
b. Photographs/videos: Video or audio recordings will be taken of the formal interviews.
   i. Video would be preferred because facial expressions and body language can be used to help interpret the actual words being spoken. (And because being able to see those expressions holds the researcher even more accountable for the effects of the questions they ask.)
   ii. Audio recordings will be taken for those uncomfortable with video in order to still be able to create a full transcript.

    iii. If participants are uncomfortable with both, detailed notes will be taken in place of a full transcript.
    iv. Photographs will be taken of any programme activities/protests/outreach activities that are conducted while I am in the observational phase, to help to illustrate points and capture what is already being done and how. (Assuming participants consent to images being taken.)
    v. Images will be anonymised as much as possible for use in the thesis. (Blacking out of eyes, blurring faces.)
    vi. Images taken by FEDOMA or constituent organizations may be sought as well, and these will be anonymised as far as possible in the thesis.

4. Ethical Risk

None of the participants in this study are in a dependent relationship with the investigator. We do not believe that any aspect of the research contains significant risk of causing any damage, harm, or other problems for the people in the study area.

5. Ethical Statement

On both academic and ethical grounds, the proposed project seeks to involve interested parties in all phases of the research process. An outline of the proposed project has already been presented to the Board of Trustees and Executive Council of FEDOMA to seek their assent for collaboration on the project. The proposal has been approved, and a research agreement has been approved and signed by all involved parties.

While FEDOMA will be a research partner and while other stakeholders are being engaged: (i) within organizations briefing and consent must be individualized so as to avoid any 'forced recruitment' and: (ii) Because conversations may transition to interviews and/or generate information useful to the research project, briefing and consent procedures will be followed. (Please see proposed consent protocol outlined above.)

We acknowledge that some stakeholders outside of FEDOMA may be unable to discuss matters related to their institution without permission. In these cases, decisions will be made on a case-by-case manner, with an understanding of the rules surrounding said circumstances. This may take the form of participants choosing not to discuss their institutional work, remaining anonymous, anonymizing the organization they work for, or speaking strictly from a personal point of view.

Participants will be asked to sign attributable data forms – because they will be briefed that the small size of the sample, organizations within the sample, and the prominence of the positions held by stakeholders, may make their responses recognizable to others. Furthermore, while raw, un-anonymized data will not be shared with research partners, general findings will be, again compromising complete anonymity. Participants will be offered the protection of a pseudonym if they wish, but will be briefed that this is not a guarantee that their responses will remain anonymous to those who know them, and they will be asked to participate only in this knowledge.

Most participants will already be involved in advocacy and activism, so this should also ensure an established degree of comfort in discussing the issues under study. However, many of the research partners and stakeholders consulted will have disabilities, and the co-design of the research project may result in a focus on the needs and experiences of special groups. Thus because participants and/or those drawn into consultation, may be considered vulnerable adults and/or children, the researcher discussed the research to be undertaken with the Director of Student Services at the University of St Andrews - (the University's designated point-person for student Protection of Vulnerable Groups [PVG] issues.) The Director of Student Services has determined that there is no need for additional background checks for the stage of the project presented here, as required by Scottish law.

There is no significant risk associated with the participatory design of a research project, as proposed here. Nevertheless, participants may recall difficult past experiences and/or identify problematic and controversial current practice in the course of participating in the project. Furthermore, advocacy is an inherently political activity. Thus briefing, consent, and briefing about the significance of consent for attributable data will be necessary. Participants will be briefed that they will not be asked to elaborate on personal experiences, or controversial topics, if they become distressed by doing so. People with learning or communicative difficulties will be approached through their existing work with FEDOMA, and discussions as to approach and/or interpretation will be undertaken with the individual, their caregivers and the organization as needed. This is due to the wide range of potential learning and communicative difficulties, the lack of a one-size approach to disability, the range of adaptations required, and a dedication to not infantilizing individuals with disabilities. (A translator from FEDOMA who speaks both English and Chichewa will accompany the researcher on district visits.) Working within the organization system established by FEDOMA, and within the parameters set out by FEDOMA within the research agreement, as well as participants' voluntary engagement with FEDOMA is meant to form a layer of protection for the participants, and provide a standard to which the research will adhere.

Work Plan

The researcher, Sarah Huque, will spend time in the headquarters of FEDOMA in Blantyre. This time will be spent observing, engaging in conversations with members of FEDOMA, and attending staff meetings and activities/events. The researcher will also visit at least 3 districts in which FEDOMA works, one in each region of Malawi, to conduct formal interviews with elected District Disability Forum leaders. On these visits, the researcher will be accompanied by a translator employed by FEDOMA. After the completion of this work, the researcher will return to Scotland to compile the data. Using this data, the researcher and FEDOMA will jointly discuss outputs, with an eye toward implementation of a useful strategy for advancing FEDOMA's advocacy activities, internal communication, and impact.

Projected Timeline

Week 1: Arrival in Malawi, re-acclimatisation for researcher, participant observation at FEDOMA offices and on FEDOMA projects.

Week 2: Visit to first district, in-depth interviews with DDF committee, participant observation on any DDF/FEDOMA activities that are going on.

Week 3: Participant observation at FEDOMA offices and on FEDOMA projects.

Week 4: Visit to second district, in-depth interviews with DDF committee, participant observation on any DDF/FEDOMA activities that are going on.

Week 5: Participant observation at FEDOMA offices and on FEDOMA projects.

Week 6: Visit to third district, in-depth interviews with DDF committee, participant observation on any DDF/FEDOMA activities that are going on.

Week 7: Participant observation at FEDOMA offices and on FEDOMA projects.

Budget & Budget Justification

Due to the fact that this is a student project, available funding is limited. However, based on the comments from the initial ethical application, additional funding has been sought. The previous budget of £3,000 has been raised to £4,000 to include all costs outlined in this breakdown, as well as other costs that may arise, including but not limited to NCRSH fees, fuel costs, and provision of refreshments for interview participants. The student researcher will be covering her own personal subsistence costs. We feel that this budget is reasonable, considering the small scale of the project and the lack of a need for any specialised equipment.

Total Budget: £4,000 = (approx.) MK 4,450,000

Item	**Estimated Cost (£ and approx. MK equivalent) *except visa fees, which are payed in USD**	**Notes**
Flights	£1,084 = MK 1,040,000	Based on most recent availability.
Transport to secondary field sites	£540 = MK 600,000	Vehicle arrangement through FEDOMA: per diem flat rate

Lodging in Blantyre	£840 = MK 806,000	Based on £15/day x planned duration of field visit. This rate is from lodging previously used in Blantyre.
Lodging at secondary field sites	£450 = MK 432,000	Based on £15/day/person for researcher and field assistant, for 5 days in each of the 3 districts.
Visa fee upon entry	*$75 = £56 = MK 54,000	First month
Visa extension fee	£5 = MK 5,000	Second month
TOTAL BASELINE EXPENDITURES	**£2,975 = MK 2,937,000**	

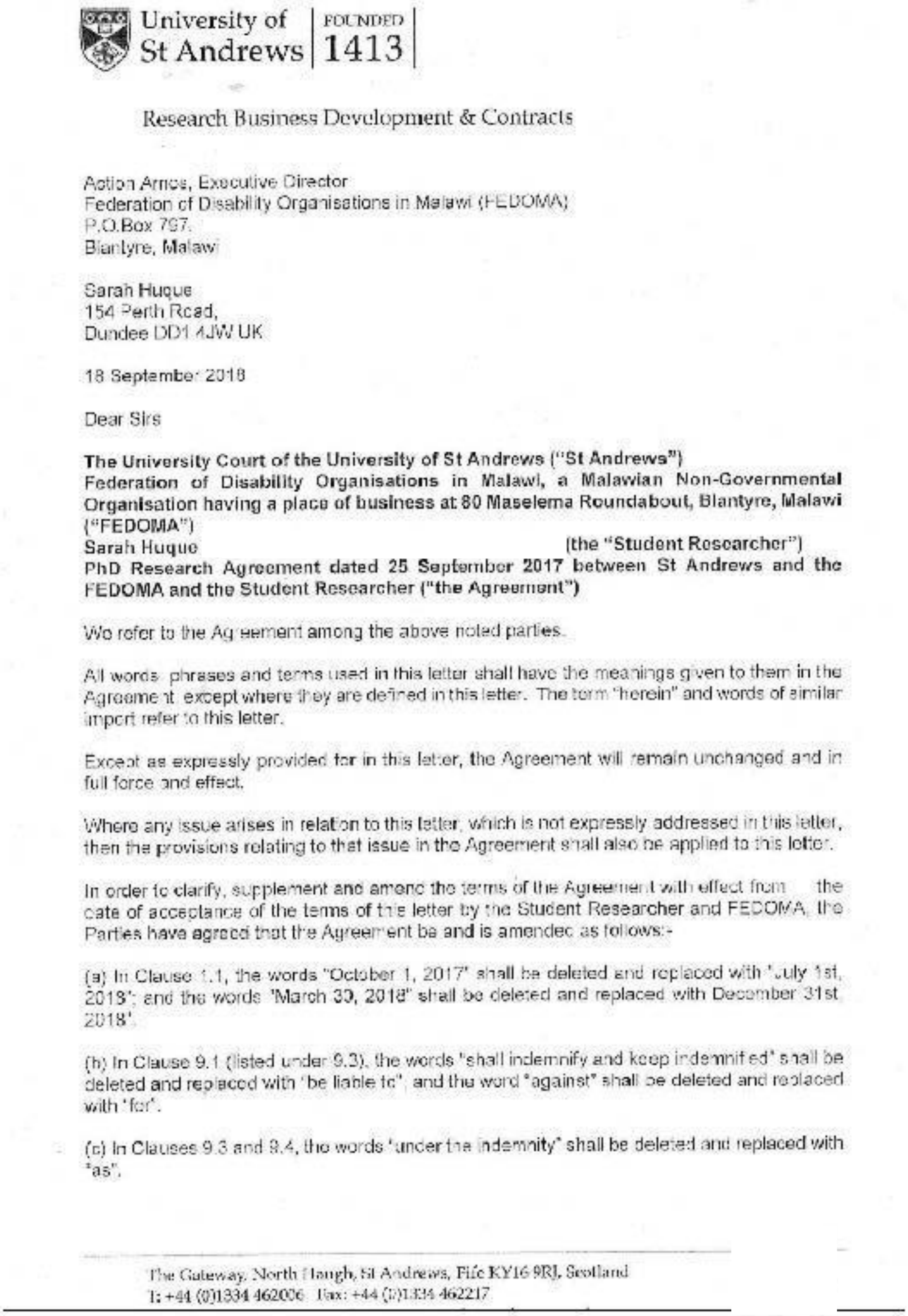
Bibliography

1) Sources (besides St Andrews UTREC and Malawi NHSRC guidelines) used to develop this proposal and accompanying documents include the following.
    a. CIOMS/WHO: International ethical guidelines for health-related research involving humans
    b. Valentine, G. (2013). Geography and ethics: in pursuit of social justice – ethics and emotions in geographies of health and disability research. Progress in Human Geography, 27(3), pp. 375-380.
    c. Iphofen, R. (2015). Research ethics in ethnography/anthropology. European Commission.
        i. This piece in particular was used as a guide when developing the included consent protocol.

Appendix A:

Revised Research Agreement between Sarah Huque,
FEDOMA,
& the University of St Andrews

Note: Changes to the Research Agreement were made and agreed via Variation Letter. All changes as outlined in the Variation Letter take precedence over the wording of the original Research Agreement, which is appended here as well, for reference.



University of St Andrews | FOUNDED 1413

Research Business Development & Contracts

Action Arnos, Executive Director
Federation of Disability Organisations in Malawi (FEDOMA)
P.O.Box 797.
Blantyre, Malawi

Sarah Huque
154 Perth Road,
Dundee DD1 4JW UK

18 September 2018

Dear Sirs

The University Court of the University of St Andrews ("St Andrews")
Federation of Disability Organisations in Malawi, a Malawian Non-Governmental Organisation having a place of business at 80 Maselema Roundabout, Blantyre, Malawi ("FEDOMA")
Sarah Huque (the "Student Researcher")
PhD Research Agreement dated 25 September 2017 between St Andrews and the FEDOMA and the Student Researcher ("the Agreement")

We refer to the Agreement among the above noted parties.

All words, phrases and terms used in this letter shall have the meanings given to them in the Agreement except where they are defined in this letter. The term "herein" and words of similar import refer to this letter.

Except as expressly provided for in this letter, the Agreement will remain unchanged and in full force and effect.

Where any issue arises in relation to this letter, which is not expressly addressed in this letter, then the provisions relating to that issue in the Agreement shall also be applied to this letter.

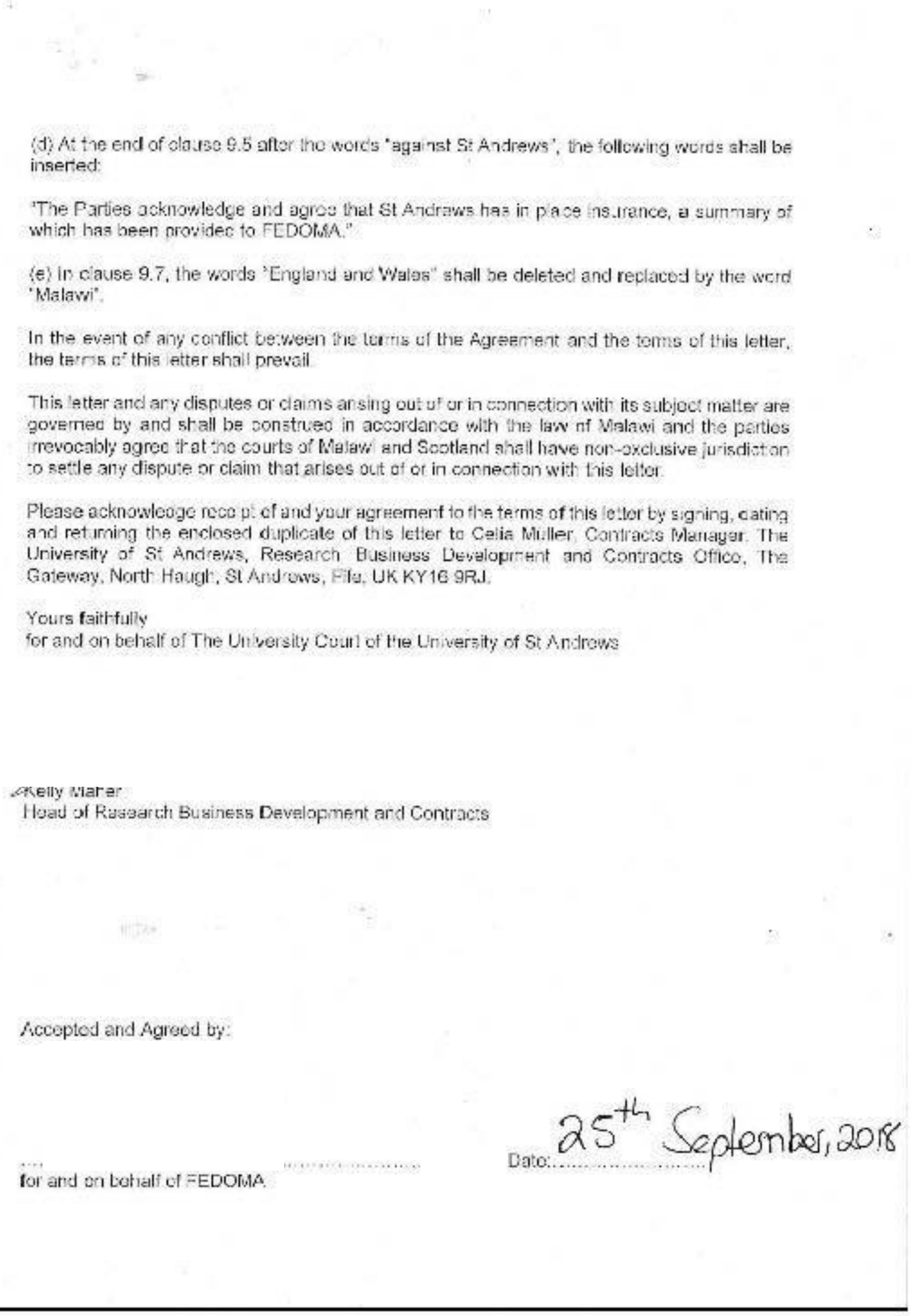
In order to clarify, supplement and amend the terms of the Agreement with effect from the date of acceptance of the terms of this letter by the Student Researcher and FEDOMA, the Parties have agreed that the Agreement be and is amended as follows:-

(a) In Clause 1.1, the words "October 1, 2017" shall be deleted and replaced with 'July 1st, 2018'; and the words 'March 30, 2018" shall be deleted and replaced with December 31st 2018'.

(b) In Clause 9.1 (listed under 9.3), the words "shall indemnify and keep indemnified" shall be deleted and replaced with 'be liable to"; and the word "against" shall be deleted and replaced with 'for'.

(c) In Clauses 9.3 and 9.4, the words 'under the indemnity' shall be deleted and replaced with "as".

The Gateway, North Haugh, St Andrews, Fife KY16 9RJ, Scotland
T: +44 (0)1334 462006 Fax: +44 (0)1334 462217



(d) At the end of clause 9.5 after the words 'against St Andrews', the following words shall be inserted:

"The Parties acknowledge and agree that St Andrews has in place insurance, a summary of which has been provided to FEDOMA."

(e) In clause 9.7, the words 'England and Wales" shall be deleted and replaced by the word 'Malawi'.

In the event of any conflict between the terms of the Agreement and the terms of this letter, the terms of this letter shall prevail.

This letter and any disputes or claims arising out of or in connection with its subject matter are governed by and shall be construed in accordance with the law of Malawi and the parties irrevocably agree that the courts of Malawi and Scotland shall have non-exclusive jurisdiction to settle any dispute or claim that arises out of or in connection with this letter.

Please acknowledge receipt of and your agreement to the terms of this letter by signing, dating and returning the enclosed duplicate of this letter to Celia Muller, Contracts Manager, The University of St Andrews, Research Business Development and Contracts Office, The Gateway, North Haugh, St Andrews, Fife, UK KY16 9RJ.

Yours faithfully
for and on behalf of The University Court of the University of St Andrews

Kelly Maher
Head of Research Business Development and Contracts

Accepted and Agreed by:

.... Date: 25th September, 2018
for and on behalf of FEDOMA

Accepted and Agreed by Sarah Huque

Date:....19/9/18....

PHD RESEARCH AGREEMENT
BETWEEN
FEDOMA AND THE UNIVERSITY COURT OF THE UNIVERSITY OF ST ANDREWS AND SARAH HUQUE

This Research Agreement is made by and between Federation of Disability Organisations in Malawi, a Malawian Non Governmental Organisation having a place of business at 80 Maselema Roundabout, Blantyre, Malawi ("FEDOMA") and

THE UNIVERSITY COURT OF THE UNIVERSITY OF ST ANDREWS, a charitable body registered in Scotland under registered number SC013532 and incorporated by the Universities (Scotland) Act 1889, as amended by the Universities (Scotland) Act 1966, and having its principal office at College Gate, North Street, St Andrews KY16 9AJ, United Kingdom ("St Andrews"); and

Sarah Huque vho is matriculated as a PHD Student at St Andrews.

Research Agreement

Article 1 - Definitions

As used herein, the following terms will mean:

1.1 "Contract Period" means October 1, 2017 through March 30, 2018.

1.2 "Confidential Information" means any confidential or proprietary information of a Party related solely to the Research, including any information related to any compound, research project, work in process, future development, business plan, financial or personnel matter relating to such Party, its present or future research, products, services, employees, funders, or business, whether in oral, written, graphic or electronic form. Notwithstanding the foregoing, Confidential Information does not include any information that the receiving Party can prove by competent written evidence: (a) is now, or hereafter becomes generally known or available through no unlawful act or failure to act on the part of the receiving Party; (b) is known by the receiving Party at the time of receiving such information as evidenced by the receiving Party's records; (c) is hereafter furnished to the receiving Party by a third party as a matter of right and without restriction on disclosure; (d) is independently developed by the receiving Party as evidenced by the receiving Party's records, without knowledge, aid, application or use of the Confidential Information of the disclosing Party; (e) is the subject of a written permission to disclose provided by the disclosing Party; or (f) does not employ or involve technology described in the Research.

1.3 "Effective Date" means the later date upon which an authorized representative executes this Research Agreement on behalf of a Party.

1.4 "Extended Term" means any agreed extension beyond Contract Period in written form.

1.5 "Party" or "Parties" means Student Researcher and FEDOMA and St Andrews individually and collectively, and in the case of FEDOMA its principal investigators, trustees, directors, officers, members, employees, faculty, students, fellows, graduate assistants, postdoctoral associates, agents, volunteers, subcontractors, representatives, designees, successors and assigns.

1.6 "Student Researcher" means **Sarah Huque.**

1.7 "Research" means each and every element of the research and work performed in the University's efforts to achieve the objectives identified in Exhibit A which is incorporated herein by this reference.

1.8 " Research Agreement" means this Research Agreement for the Research.

Article 2 - Research

2.1 The Student Researcher will use reasonable endeavours to commence performance of the Research promptly after the full execution of this Research Agreement, and will use reasonable efforts to perform the Research substantially in accordance with the terms and conditions of this Research Agreement. Notwithstanding anything contained herein to the contrary, the Parties may at any time amend the scope of the Research by mutual written agreement.

2.2 In the event the Student Researcher becomes unable or unwilling to continue the Research, any Party may terminate this Research Agreement upon written notice to the other Parties.

2.3 During the performance of the Research, FEDOMA may have the opportunity to utilize Student Researcher presence at FEDOMA in areas that the latter sees fitting into the proposed study, acting reasonably. All such use of Student Researcher must be under the guidance and supervision of the FEDOMA Executive Director (Action Amos) in line with the Research. The Student Researcher undertakes to comply with all works rules and safety and other regulations communicated to her by FEDOMA and which FEDOMA may reasonably prescribe during the Contract Period. For the avoidance of doubt, the Student Researcher will not be an employee of FEDOMA during such period and FEDOMA will not require the Student Researcher to sign any contract of employment or other such legally binding agreement.

Article 3 - Reports and Conferences

3.1 St Andrews will provide FEDOMA with Research status reports on dates and times to be mutually agreed upon by the Parties. St Andrews will provide FEDOMA a final Research report within thirty (30) calendar days after the earlier of the: (a) submission of the Student Researcher's PhD thesis or (b) termination of this Research Agreement.

3.2 During the Contract Period and if applicable the Extended Term, the Student Researcher will meet with FEDOMA Executive Director at times and places to be mutually agreed upon to discuss the progress, ongoing plans, changes to, and results of, the Research.

Article 4 – Payments

4.1 FEDOMA will NOT pay the Student Researcher any monies for work performed on the Research during the Contract Period.

Article 5 - Publicity

5.1 No Party will use the name of any other Party in any publicity, advertising, news release or other media without that other Party's prior written approval.

Article 6 - Confidentiality

6.1 Confidentiality. During the Contract Period and if applicable the Extended Term, and for a period of five (5) years after the latter thereof, each Party will maintain in strict confidence all Confidential Information disclosed by the other Parties. No Party will use, disclose nor grant use of such Confidential Information except as expressly authorized by this Research Agreement. To the extent that disclosure is authorized by this Research Agreement, the disclosing Party will obtain prior agreement from its employees or agents to whom disclosure is to be made to hold in confidence and not make use of such information for any purpose other than those permitted by this Research Agreement. Each Party will use at least the same standard of care as such Party uses to protect such Party's own Confidential Information to ensure that such employees or agents do not disclose or make any unauthorized use of such Confidential Information. Each Party will promptly notify the other Parties upon discovery of any unauthorized use or disclosure of the Confidential Information.

6.2 Authorized Disclosure. Each party will have the right to disclose the Confidential Information to the extent such disclosure is reasonably necessary to protect intellectual property, prosecuting or defending litigation, or complying with applicable laws, statutes, rules, governmental orders and regulations; provided however, that if such Party is required to make any such disclosure of Confidential Information, such party will to the extent practicable give reasonable advance written notice to the other Parties and, except to the extent inappropriate in the case of protecting intellectual property, will use such Party's reasonable endeavours to secure confidential treatment of such information required to be disclosed.

Article 7 - Publications

7.1 St Andrews, as a Scottish public institution of higher education, engages only in research that is compatible and beneficial to, and consistent with, its academic role and mission. Therefore, results of this research activities must be reasonably available for publication. FEDOMA agrees that St Andrews including without limitation St Andrews' students and postdoctoral associates working on the Research, may publish the methods and results of the Research in journals, theses or dissertations, and present at symposia, national or regional professional meetings, or otherwise, at its discretion; provided however, that St Andrews and/or St Andrews' students and/or postdoctoral associates working on the Research will furnish FEDOMA with copies of all proposed publications and presentations at least thirty (30) calendar days before submission of such proposed publications and presentations. FEDOMA will then have thirty (30) calendar days after receipt of said copies, to object to such proposed publications or presentations in whole or in part, in writing, because said copies contain patentable subject matter. This Agreement shall not prevent or hinder the Student Researcher from submitting for degrees of St Andrews theses based on results generated within the scope of the Research; or from following St Andrews' procedures for examination and for admission to postgraduate degree status (such procedures to include provisions to place the thesis on restricted access within St Andrews' library).

Article 8 – Term, Dispute Resolution and Termination

8.1 This Research Agreement will be in effect from the Effective Date and throughout the Contract Period unless terminated earlier pursuant to the provisions of this Article. The Parties will meet on or before March 30, 2018 to determine if the Research Agreement will be continued for the Extended Term. Notwithstanding anything contained herein to the contrary, the Parties may in writing extend the terms of this Research Agreement for additional or different periods pursuant to mutually acceptable terms and conditions.

8.2 Any Party may terminate this Research Agreement without cause upon forty-five (45) calendar days' prior written notice to the other Parties.

8.3 If a dispute arises between the Parties relating to the interpretation or performance of this Research Agreement or the grounds for termination thereof, and the Parties cannot resolve the dispute within thirty (30) calendar days of a written request by any Party to the other Parties, the Parties agree to hold a meeting (which may be a teleconference), attended by individuals with decision-making authority regarding the dispute, to attempt in good faith to negotiate a resolution of the dispute prior to pursuing termination or other available remedies, legal or otherwise.

8.4 A Party may terminate this Research Agreement prior to the expiration of the Contract Period or if applicable the Extended Term, upon or after a material breach of any provision of this Research Agreement by another Party if the breaching Party has not cured such material breach within thirty (30) calendar days after written notice thereof by the non-breaching Party.

8.5 Termination of this Research Agreement by any Party for any reason will not affect the rights and obligations of the Parties that accrued prior to the effective date of termination.

Article 9 – Representations, Warranties and Covenants

9.1 Binding Agreement. Each Party represents and warrants to the other Parties that this Research Agreement is a legal and valid obligation binding upon such Party and is enforceable in accordance with its terms. The execution, delivery and performance of this Research Agreement by such Party does not conflict with any agreement, instrument or understanding, oral or written, to which such Party is a party or by which such Party may be bound, nor violate any law or regulation of any court, governmental body or administrative or other agency having authority over such Party.

9.2 Beneficiaries. This Research Agreement is for the sole and exclusive benefit of the Parties and no Party intends to create a benefit in favor of any third party.

9.3 Liability.

9.1 FEDOMA shall indemnify and keep indemnified St Andrews and its employees or agents and the Student Researcher against all claims, actions, losses, damages, costs and expenses which may be brought against or incurred or suffered by St Andrews, its employees or agents in connection with or arising out of the Research.

9.2 Nothing contained in this Agreement shall exclude or restrict the liability of any Party for injury, death, loss or damage caused by the negligence of that Party.

9.3 Subject to clause 9.2, and except under the indemnity set out in clause 9.1, the liability of any Party for any breach of this Agreement, or arising in any other way out of the subject matter of this Agreement, will not extend to: (i) loss of business; or (ii) loss of profit; or (iii) to any indirect or consequential damages or losses.

9.4 Subject to clause 9.2, and except under the indemnity set out in clause 9.1, the maximum liability of any Party for any breach of this Agreement, or arising in any other way out of the subject matter of this Agreement, shall not exceed £2,000 (two thousand pounds sterling).

9.5 FEDOMA undertakes to make no claim in connection with this Agreement or its subject matter against the Student Researcher or any other employee, student, agent or appointee of St Andrews (apart from claims based on fraud or wilful misconduct). This undertaking is intended to give protection to individual researchers: it does not prejudice any right which FEDOMA might have to claim against St Andrews.

9.6 Force Majeure. No Party will be liable or responsible to the other Parties nor be deemed to have materially breached this Research Agreement for failure or delay in fulfilling or performing any term of this Research Agreement when such failure or delay is caused by or results from causes beyond the reasonable control of the affected Party, including, without limitation, fire, floods, earthquakes, natural disasters, embargoes, war, acts of war (whether war be declared or not), acts of terrorism, insurrections, riots, civil commotions, strikes, lockouts or other labor disturbances, other acts of God or acts, omissions or delays in acting by any governmental authority or the other Party.

9.7 Governing Law. This Research Agreement will be governed by, and construed and enforced in accordance with, the laws of England and Wales the courts of which will also have non-exclusive jurisdiction to settle any litigation arising out of or relating to this Research Agreement.

9.8 Waiver. The waiver from time to time by any Party of any right or failure to exercise any remedy will not operate or be construed as a continuing waiver of the same right or remedy or of any other of such Party's rights or remedies provided under this Research Agreement.

9.9 Severability. In case any provision of this Research Agreement is determined by a court of competent jurisdiction to be invalid, illegal or unenforceable, the validity, legality and enforceability of the remaining provisions will not in any way be affected or impaired thereby.

9.10 Independent Contractors. The Parties are each an independent contractor and the relationship between the Parties does not constitute a partnership, joint venture or agency of any kind. No Party has the authority to make any statements, representations or commitments of any kind, or to take any action that will be binding on the other Parties, without the prior written consent of that other Party.

9.11 Compliance with Law. Each Party will be separately responsible for compliance with all constitutional, state, local and/or municipal ordinances, regulations and laws, including nondiscrimination laws.

9.12 Notices. All notices and other communications provided for hereunder must be in writing and must be mailed by first-class, registered or certified mail, postage paid, or delivered personally, by overnight delivery service, by facsimile, or by electronic transmission with confirmation of receipt, addressed as follows:

If to the Student Researcher: Sarah Huque at the address at the start of this agreement

If to St Andrews:
Head of Research Business Development and Contracts
The Gateway
North Haugh University of St Andrews
St Andrews
KY16 9RJ United Kingdom

If to FEDOMA :
Executive Director or his/her designee
80 Maselema Roundabout,
Blantyre
Malawi

Any Party may, by like notice, specify or change an address to which notices and communications must thereafter be sent.

9.13 Entire Agreement; Amendment. This Research hereto sets forth all of the agreements and understandings between the Parties with respect to the Research, and supersedes and terminates all contemporaneous and prior agreements and understandings between the Parties with respect to the Research including oral arrangements. There are no agreements or understandings with respect to the Research, either oral or written, between the Parties other than as set forth herein. Except as expressly set forth in this Research Agreement, no subsequent amendment, modification or addition to this Research Agreement will be binding upon the Parties unless reduced to writing and signed by the respective authorized officers of each Party.

9.14 Headings. The captions contained in this Research Agreement are not a part of this Research Agreement, but are merely guides or labels to assist in locating and reading the several Articles hereof.

9.15 Counterparts. This Research Agreement may be executed in three or more counterparts, each of which will be deemed an original, but all of which together will constitute one and the same instrument.

10. Intellectual Property

10.1 Any and all intellectual property rights generated, obtained and developed during the Contract Period in relation to the Research ("**Placement IPR**"): -

10.1.1 by FEDOMA shall be shall be the property of the FEDOMA; and

10.1.2 by the Student Researcher and/or St Andrews shall be the property of the St Andrews.

10.2 FEDOMA hereby grants to St Andrews an irrevocable, royalty-free, paid up non-exclusive right and licence to reproduce, translate and use the Placement IPR for its

10.2 FEDOMA hereby grants to St Andrews an irrevocable, royalty-free, paid up non-exclusive right and licence to reproduce, translate and use the Placement IPR for its own teaching and other academic purposes. For the avoidance of doubt, St Andrews and the Student Researcher shall have the right to publish any and all information relating to the Placement IPR and/or the Placement.

10.3 To give full effect to clause 10.2 above, the Student Researcher hereby assigns, and agrees to assign on demand, her whole right, title and interest in and to the Placement IPR to St Andrews and agrees to execute all documents and assignations and do all such things as may be necessary to perfect St Andrews' title in the same.

IN WITNESS WHEREOF, the Parties have executed this Research Agreement on the date(s) set forth below.

For and on behalf ofFEDOMA

By Executive Director..

Date. 25th September, 2017

By Sarah Huque..

Date: 25/9/17

For and on behalf of the University Court of the University of St Andrews

By Authorised Signatory:

KELLY MAHER
Head of Research Business
Development & Contracts
University of St Andrews

Date 25.09.2017

Appendix B:

Data Collection Instruments

Observation Checklist

During participant observation in this project, I will be using James P. Spradley's (1980) "Descriptive Question Matrix" as a guide, specifically focusing on the nine dimensions of social situations set out in his work. Spradley's inclusion of less physical aspects of observation, for example "goal" and "feeling," set this method apart from other observation guides.

The nine-dimensions as a checklist are as follows:

1) Space: the physical place or places
2) Actor: the people involved
3) Activity: a set of related acts people do
4) Object: the physical things that are present
5) Act: single actions that people do
6) Event: a set of related activities that people carry out
7) Time: the sequencing that takes place over time
8) Goal: the things people are trying to accomplish
9) Feeling: the emotions felt and expressed (Spradley, 1980, p. 78)

In order to ensure that I am capturing as full a picture of the goings-on as possible, I will also incorporate the observational categories for participant observation set out in Family Health International's field guide to qualitative research methods, which suggest some areas of observation not found in other guides (Mack et al., 2005).

The 6 categories as a checklist are as follows:

1) Appearance: includes clothing, age, gender, physical appearance
2) Verbal behaviour and interactions: includes who speaks to whom and for how long; who initiates interaction; languages or dialects spoken; tone of voice
3) Physical behaviour and gestures: includes what people do; who does what; who interacts with whom; who is not interacting
4) Personal space: includes how close people stand to one another
5) Human traffic: includes people who enter, leave, and spend time at the observation site
6) People who stand out: includes identification of people who receive a lot of attention from others (Family Health International, 2005, p. 20)

Other questions may arise from the specific observations undertaken, as well as from continued reading and use of the literature on qualitative research and guidance from supervisors throughout the process.

References

Mack, N., Woodsong, C., MacQueen, K.M., Guest, G., and Namey, E., 2005. Qualitative research methods: a data collector's field guide. *Family Health International.*

Spradley, J.P., 1980. *Participant Observation*. New York: Holt, Rinehart and Winston.

Interview Guide

Method: Semi-structured, in-depth interviews with District Disability Forum (DDF) members

The general aim of these interviews is to get the interviewee to tell their story: of life as a person with a disability or caretaker, of their advocacy work, their hopes for the future, the issues that are important to them, and of course their voice within the DDFs and the broader organisation. What do they want the international world to know about them and their advocacy work? These questions are tools, prompts that may help in getting some of that story out, and help to magnify the voices of grassroots volunteers and local advocates through the outputs that arise from this research project.

Though the topics listed here are presented in question form, the open-ended, story-telling nature of semi-structured interviews means that the interview should develop as organically as possible. This checklist is to help the interviewer guide the interviewee through telling their story if necessary, in order to give them as much agency in the process as possible, while still touching on the topics of interest.

Pre-Interview 'Script'

These guidelines will be followed to ensure that the interviewee is comfortable and made aware of their rights regarding the interview as well as after the interview.

Greeting

Introduction of researcher and research assistant/translator

- Included in introduction will be a chance to ask questions about the researcher and research assistant.

Offer of refreshment

- Interviewer will provide refreshments for participants.

Briefing

- Project will be explained;
- Participant information sheet will be reviewed;
- Information sheet is available in English and Chichewa, and can also be read out loud in either language;
- Opportunity for questions.

Formal ethical consent procedure

- Rights of participant and obligations of researcher will be explained;
- Consent form will be reviewed;
- Consent form is available in English and Chichewa, and can also be read out loud in either language;
- Opportunity for questions;
- Participant will be asked if they would like to consent to the interview;
    - It will be made clear that there will be no negative consequences against the interviewee if they choose not to participate.
- Participant will be asked to provide a signature or verbal recorded consent, depending on their level of literacy and comfort with providing any of the aforementioned information.

Interview Checklist

Section 1 - Introduction

- Participants will be asked to introduce themselves however they see fit.

Section 2 - Advocacy

- How did they get involved with their Disabled Persons' Organization (DPO)?
- Why did they decide to join the DDFs?
- Why did they decide to run for DDF office, if they did?
- What kind of work does the DDF do?
- What are the most important issues they are trying to address?
- How do they feel about the work that the DDFs do?
- How do they feel about FEDOMA as an organisation?

Section 4 - Voice

- How do they define voice?
- Do they feel that their voice, or whether their voice is heard, has changed since joining the DPO/FEDOMA/DDF?
- Do they feel that their voice is heard and respected within the organisation? Why or why not?
- What would they like to see happen within FEDOMA to better make everyone's voices heard, if anything?

Section 3 - Reporting pilot

- Do they think that having a system in place where they could check-in with FEDOMA regularly would be beneficial?
- Do they think such a system would be practical, and if so, on what timescale?
- What would they hope to get out of such a reporting system?
- Do they think a reporting system such as this can help to amplify voices from the grassroots to the broader organisation? Why or why not?

Section 5 - Additional background

*The items in this section may or may not have come out during the previous sections of the interview. These questions are left until the end to allow the individuals' description of themselves and their life to develop as organically as possible. If it feels as though there is more information needed, the researcher may ask:

- Who are they beyond how they introduced themselves?
    - What do they do?
    - Do they have a family?
    - Are they religious?
    - Do they have a favourite pastime, hobby, sports team, etc.?
- What DPO does the individual belong to?
- What is their specific impairment?
- How has that impairment impacted their life up to now?
- How do they feel about their impairment?
- What other groups and/or activities do they participate in, advocacy-related or otherwise?

Section 4 - The rest

- What else do they want me to know, if anything?
- What else do they want FEDOMA to know, if anything?
- What else do they want the world in general know, if anything?

Post-Interview 'Script'

These guidelines will be followed to ensure that the interviewee is comfortable and made aware of their rights regarding the interview that has just been conducted and their rights after the conclusion of the interview.

<u>Participant Debriefing</u>

- Reminder of the participants’ rights;
- Reminder of the purpose of the project;
- Reminder that signed consent forms will be coded and kept separately from data;
- Reminder that notes/recordings of interview responses will be coded and identifying data removed;
- Further opportunity to ask questions.

Farewell and Thanks

Appendix C:
Participant Information Sheets & Consent Forms
(English and Chichewa)

University of
St Andrews

Participant Information Sheet:
Public Participant Observation

General Information

Project Title

Disability Advocacy in Malawi

Section 1: Statement to be read out to the assembled group (and interpreted by a translator as necessary)

My name is Sarah Huque, and I am a PhD student in the School of Geography & Sustainable Development at the University of St Andrews in Scotland. I am working with FEDOMA as part of my research project about disability advocacy in Malawi. In my broader project I am interviewing people, but today I am here just to listen and observe, in order to help me understand FEDOMA as an organisation.

I will be making written notes and taking some photographs today. I will try to make sure that my notes capture who contributes to the meeting, but the notes will not contain anyone's real name.

I have permission to be here as a guest of FEDOMA, but each of you has the right to opt out of the research. That does not mean you have to leave the meeting - you can simply tell me or a member of FEDOMA's staff that you do not want to be included in the research project notes. In this case, I will strike any notes about your contributions from my records. You can choose to opt out now, at any point during the meeting/event, or quietly at the end if you prefer. I also have some handouts which repeat this introduction and provide further details of the project and opting out that will be made available to you. You can also contact me or a FEDOMA staff member to opt out at a later date.

Does anyone have any questions?

Section 2: Further details to be included in hand-out

Do I have to take part/can I opt out?

You can opt out, which in this case means that anything you say during the meeting can be struck from my records.

What is the project about?

This project seeks to investigate 'voice' within FEDOMA as an organisation, especially when it comes to how grassroots volunteers' ideas are integrated into the organisation's practices and priorities. By understanding voice, we help to develop ways to increase communication between the different parts of FEDOMA and encourage a more inclusive approach to advocacy. You are not required to do anything outside of what you normally would - in this case, I would just like to observe and participate in the activities.

Will my participation be Anonymous and Confidential?

I would like to keep notes on any observations or conversations I have with you. I will assign you a pseudonym, a made-up name, so that your personal information is not kept with the data I collect. Pseudonyms will also be used in outputs from the research, such as my thesis. Only the researcher and supervisors will have access to the actual identity of any participant. However, because of the relatively limited number of people I will be working with, the close-knit nature of the disability advocacy community, the visibility of individuals in the sector, and because FEDOMA will have their own record of this meeting (although I will not share any unanonymised raw data with them), it is possible that others who know you in this small community might be able to identify you from your responses. Therefore, while I can give you a made-up name, I cannot entirely guarantee your anonymity. You should only participate in the knowledge of this possibility.

After this briefing, please inform myself or a FEDOMA staff member if you would like to 'opt-out' of participation.

Storage and Destruction of Data Collected

If you agree to any notes being kept by me, they will be kept on the university's Microsoft Exchange server, and backed up to physical drives that will be kept securely in the researcher's possession during data collection in Malawi. Upon return to the UK, the physical drives and any paperwork will be kept under lock-and-key. Three years after completing my PhD, recordings will be destroyed, but paper transcripts will be securely archived in the St Andrews Research Repository for use in further research projects, by other bona fide academic researchers, and/or by disability advocates in Malawi. Only your pseudonym will be kept in this archive, not your true name.

What will happen to the results of the research study?

The results will be finalised by 2019 and written up as part of my PhD Thesis. PhD theses completed by University of St Andrews students are available freely online. Other outputs and products will be a subject of my conversations with you and FEDOMA, and you will have the opportunity to suggest what these might be.

Are there any potential risks to taking part?

Questions of advocacy are often political, so please consider whether any political statements you make could be attributed to you by those who know you, and whether you think this may be a problem for you. Furthermore, during the course of conversation and interviews, personal experiences may come up. If these experiences are emotionally distressing and *EITHER*, you do not wish to discuss them, *OR* you need to take break before you can, please say so, and I will honour this. You do not need to answer every question asked, and can decide to end any conversations at any point in time.

Questions

Do you have any questions? You can also ask questions at any point throughout the process, if you think of one later.

Consent and Approval

This research proposal has been scrutinised and been granted Ethical Approval through the University ethical approval process.

I am from Scotland, where the Scottish Government requires that some projects that work with ‘vulnerable groups’ (hospital patients, children, the elderly, prisoners, people with disabilities that prevent them giving consent, etc.), require that the researcher undergo a police check (called “Enhanced Disclosure Scotland”) to ensure the researcher is not a danger to vulnerable people. In the case of this project, it has been determined that this is not necessary because: I will not be working alone with children or people with severe cognitive difficulties. Any interactions involving such people will include an accompanying parent, guardian, or responsible caregiver, and the majority of people with disabilities that I will be working with will be fully competent to give consent to participate.

This project has also been reviewed by the Malawi National Committee on Research in the Social Sciences and Humanities.

What should I do if I have concerns about this study?

If you desire it, a copy of this document will be provided to you, in either English or Chichewa.

A full outline of the procedures governed by the University Teaching and Research Ethical Committee is available at http://www.st-andrews.ac.uk/utrec/guidelinespolicies/complaints/.

In Malawi, participants may submit any concerns to the National Committee on Research in the Social Science and Humanities. Their contact information is as follows:

Director General
National Commission for Science and Technology
Lingadzi House
City Centre
P/Bag B303
Capital City
Lilongwe 3
Attention: NCRSH Secretariat
Email address: ncrsh@ncst.mw

Contact Details

Researcher: Sarah Huque

Contact Details: sih3@st-andrews.ac.uk

Supervisor: Dr Mike Kesby

Contact Details: mgk@st-andrews.ac.uk; +44 1334 46 2150

Supervisor: Dr Katherine Keenan

Contact Details: klk4@st-andrews.ac.uk; +44 1334 46 3951

University of
St Andrews

PARTICIPANT CONSENT FORM

Identifiable / Attributable Data

General Information

Project Title

Disability Advocacy in Malawi

Researcher(s) Name(s)	**Supervisors Names**
Sarah Huque	*Dr Mike Kesby*
sih3@st-andrews.ac.uk	*Dr Katherine Keenan*

The University of St Andrews attaches high priority to the ethical conduct of research. We therefore ask you to consider the following points before signing this form. Your signature confirms that you are happy to participate in the study.

What is Identifiable/Attributable Data?

'Identifiable/Attributable data' is normally data where the participant is identified, such as when a public figure gives an interview, or where consent is given by a participant for their name to be used in the research outputs. In this project you can *EITHER* give consent for your actual name to be used, *OR* you can request that a pseudonym (made-up name) is used. All raw data will be held confidentially by the researcher (and supervisors), including the actual identity of any participants who choose to be referred to under a pseudonym.

Whether you choose that I use your actual name or give you a pseudonym, there are four features of this project that mean I need to ask for your consent for 'attributable data': (i) The close knit nature of the community that advocate, or provide services for, those with disabilities; (ii) I will consult a relatively small number of people within these communities; (iii) some respondents may hold prominent positions in their organizations; (iv) I will share findings (although not personal information) with research partners in Malawi in order to highlight concerns and priorities raised by participants, especially grassroots advocates, and enable FEDOMA to take action based on the findings. These four features mean that any responses you give to me *may* be identifiable as yours, by people who either know you or your organization.

You should therefore only participate in the knowledge that your responses *will* or *may be* attributable to you.

Questions

Do you have any questions you would like to ask me about this study?

Consent

The purpose of this form is to ensure that you are willing to take part in this study and to let you understand what is involved. Signing this form does not commit you to anything you do not wish to do and you are free to stop and withdraw at any stage.

Please answer each statement concerning the collection and use of the research data.

I have read and understood the information sheet [OR had it read to me].	☐ Yes	☐ No
I have been given the opportunity to ask questions about the study.	☐ Yes	☐ No
I have had my questions answered satisfactorily.	☐ Yes	☐ No
I understand that I can stop and withdraw from the study at any time without having to explain why.	☐ Yes	☐ No
EITHER: I agree to being identified **by my own name** in this interview and any subsequent publications or use.	☐ Yes	☐ No
OR: I agree to being identified **by a pseudonym (made-up)** in this interview and any subsequent publications or use.	☐ Yes	☐ No
I understand that my raw data (information) will be kept securely and will be accessible only to the researcher (and supervisors). I agree that I understand that *either* all data collected will be attributable to me and identified as mine *or* that it may be attributable, even with the use of a pseudonym.	☐ Yes	☐ No
I agree to my data (in line with conditions outlined above) being kept by the researcher and being archived and used for further research projects / by other bona fide researchers.	☐ Yes	☐ No
I agree to my data being provided to disability advocacy organizations in Malawi for future use.	☐ Yes	☐ No
I have been made fully aware of the potential risks associated with this research and am satisfied with the information provided.	☐ Yes	☐ No

Using Photographic, Videoed, or Taped Material

Part of my research involves taking photographic images, tape recordings, and/or videos. These images and recordings will be kept secure and stored with no identifying factors, (i.e. consent forms). Any images used in formal outputs, such as the thesis, papers, or presentations, will be anonymized to the extent possible.

Photographs and recorded data can be valuable resources for future studies, therefore we ask for your additional consent to maintain data and images for this purpose.

I agree to have my photo taken.	☐ Yes	☐ No
I agree to be tape recorded.	☐ Yes	☐ No
I agree to be videoed.	☐ Yes	☐ No
I agree for my photo to be published as part of this research.	☐ Yes	☐ No

Participation in this research is completely voluntary and your consent is required before you can participate in this research. If you decide at a later date that your data should be destroyed, we will honour your request in writing.

I agree to take part in the study. ☐ Yes ☐ No

Name in Block Capitals ______________________________

Your Signature [or mark] ______________________________

Where appropriate – countersigned by the researcher(s) ______________________________

Date ______________________________

University of
St Andrews

ZOMWE MUNTHU OTENGA GAWO AKUYENERA KUDZIWA

Zofunika kudziwa

Dzina la pulojekiti
Disability Advocacy and Activism in Malawi

Section 1: Statement to be read out to the assembled group (and interpreted by a translator as necessary)

My name is Sarah Huque, and I am a PhD student in the School of Geography & Sustainable Development at the University of St Andrews in Scotland. I am working with FEDOMA as part of my research project about disability advocacy in Malawi. In my broader project I am interviewing people, but today I am here just to listen and observe, in order to help me understand FEDOMA as an organisation.

I will be making written notes and taking some photographs today. I will try to make sure that my notes capture who contributes to the meeting, but the notes will not contain anyone's real name.

I have permission to be here as a guest of FEDOMA, but each of you has the right to opt out of the research. That does not mean you have to leave the meeting - you can simply tell me or a member of FEDOMA's staff that you do not want to be included in the research project notes. In this case, I will strike any notes about your contributions from my records. You can choose to opt out now, at any point during the meeting/event, or quietly at the end if you prefer. I also have some handouts which repeat this introduction and provide further details of the project and opting out that will be made available to you. You can also contact me or a FEDOMA staff member to opt out at a later date.

Does anyone have any questions?

Section 2: Further details to be included in hand-out

Kodi ndikuyenela kutenga nawo mbali? Kodi ndikhoza kusiya osatenga nawo mbali?

Mukhoza kusiya osatenga nawo mbali ndipo izi zizathanthauzila kuti china chilichonse chimene munganene pa mkumano umenewu zichotsedwe mmkalembera

Ndikuyenera kuchita chani?

Ntchitoyi ikufunitsitsi kumva 'zolankhulidwa' kuchokera mu FEDOMA ngati bungwe, makamaka kuyangaánira mmene maganizo a anthu a kumudzi makamaka kuchokera kwa anthu amene amangogwira ntchito mozipeleka, kuyangánira kuti amagwiritsidwa ntchito motani munkagwiridwe ntchito ka Bungwe. Munkamvetsetsedwe ka zolankhula za FEDOMA zizathandiza kupeza nnjira zosiyanasiyana zakulumikizanitsa mbali zosiyanasiyana za bungwe la FEDOMA popitaitsa patsogolo njira zogwirira ntchito pamodzi kuti zinthu zisinthe.

Kodi kutenga nawo gawo kwanga kudzakhala kwachinsisi

Ndikufuna ndizilemba pa zokambilana zathu kapena zomwe ndawona ndipo ndingakonde kujambula nawo macheza, Mukhoza kundilola kutero kapena kukana. Ndidzakhala ndikukupatsani dzina lopeka ndicholinga chofuna kutetezani ndipo dzina lanu sindizalisunga pamodzi ndizomwe nditatolere. Dzina lanu lopeka lidzagwiritsidwa ntchito polemba zimene zitatuluke mumkafukufuku ameneyu koma pamene ndidzalembe pepala lalikulu ku sukulu yanga yaukachenjede. Ine ndekha ndi ondithandizila ndi amene tikadziwe mayina eni eni a anthu amene angafune kupatsidwa mayina opeka. Ngakhale zili choncho, chifukwa cha kuchepa kwa chiwelengero cha anthu amene ndi gwile nawo ntchito, kugwirizana kwa anthu amene amagwira ntchito younikila nkhani zaulumali, kudziwika kwa anthu amene akugwira ntchito imenei komanso chifukwa zotsatira za kafukufuku ameneyu azapelekedwa ku bungwe la FEDOMA, ndizotheka kuti anthu amene akukuziwani akhoza kukuzindikilani kuchokera kuzimene kunganene kapena kuyankha. Pazifukwa zimenezi, dzina lopeka limene ndingakupatseni sichitsimikizo choti chinsisi cha dzina lanu chingabisike. Chilolezo chanu potenga nawo mbali muchipeleke izi mutaziziwa.

Ngati simukumvetsa pa zomwe zafotokozedwazi chonde musazengereze ndifunseni kuti nditambasule ndicholinga choti mumvetse bwino.

Kusunga ndi kuwononga zomwe zitoleledwe

Ngati mwavomeleza kuti nditha kusunga zimene takambirana pogwiritsa ntchito ma tepi komanso zolemba, zonse zisasungidwa mu makina a pamwamba a kompyuta osungira zinthu zosiyanasiyana ku sukulu ya ukachenjede. Mukhoza kusankha kupatsidwa dzina lopeka ngati simukufuna kuti dzina lanu lidziwike ndi anthu ena kuoatula opanga kafukufuku yekha ndi owanthandizila.

Pazapita zaka zitatu kuchokera pa nthawi imene ndizasilizire maphunziro anga a ukadaulo , ndipamene ndipamene zonse zojambulidwa zizatayidwa, koma zonse zolembedwa zizakhalabe zikusungidwa ku sitolo ya sukukulu ya St Andrews pofuna kuthandizila ntchito zina komanso akafukufuku a anthu ena pa sukuluyi ku nkhani yokhuza kubweletsa kusintha ku nkhani za ulumali ku Malawi. Dzina lanu lopeka lokn[ha ndi limene lidza sungidwe ku sitolo imeneyo osati dzina lanu lenileni

Kodi zotsatila za kafufufukuyu tidzapanga nazo chani?

Kutolera zotsatila pa ma gawo onse awiri zidzamalizidwa mu mchaka cha 2019 ndipo zidzalembedwa mu Bukhu ngati mbali ya maphuziro anga. Ma Bukhu onse olembedwa ngati mbali ya maphunzilo a anthu ku sukulu yaukachenjedwe yi. Kuchokela apo china chilichonse chimene chingatuluke kuchokela munkafukufuku ameneyu, muzapatsidwa mpata kupelekapo maganizo anu kuti chikhale chani.

Kodi pali zinthu ziti zomwe ndingakumane nazo chifukwa chotenga nawo mbali mu nkafukufuku ameneyu?

Nthawi zambiri mafuso okhudza khani zofuna kusitha kachitidwe kazinthu amalowapondale, chonde ganizilani ngatianthu okudziwani angafanizire zoyankhula zanu ndipo kuti zikhoza kukuikani mmavuto. Kuwonjezera apao, mkatikati mwakuyankhulana, zikhoza kupezeka kuti mwayankhula zinthu zomwe munakumanapo nazo, ndipo nkutheka kuti zimakupatsani maganizo ambiri. Chonde munene ngati zomwe munakumanapo nazo zili zokhumudwitsa ndipo simukufuna kuyankhula za zimenezo. Simukuyenera kuyankha funso lililonse lomwe mwafusidwa ndipo mokhoza kuthetha macheza athu nthawi ina iliyonse.

Mafuso

Mulindi fuso lina lililonse? Mupatsidwa mwayi ofusa mafuso ukhudzana ndi kafukuku musanasaine fomu ya chilolezo.

Chololezo

Kafukufukuyu anawunikidwa bwono ndipo wapatsidwa chilolezo kuchokela ku bungwe limene limapeleka zilolezo ku sukulu yathu yaukachenjede.

Ndimachokera ku Scotland, Boma la kwathu limayembekezera kuti wina aliyense amene akugwira ntchito ndi anthu a magulu omwe ali pa chiopsyezo chachikulu monga (anthu omwe akudwala muzipatala, ana, okalamba, amundende, anthu a ulumali umene ungawakanikitse kupeleka chilolezo, ndi ena ndi ena), akuyeneka kufufuzidwa ndi a polisi (pandondomeko imene imatchulidwa ‘Enhanced Disclosure Scotland’) pofuna kuonetsetsa kuti munthu amene akugwira ntchitoyi sapereka chiopsyezo kwa anthu amagulu amenewa. Pamene ndidzakhale ndikugwira ntchito imeneyi, ndondomeko imeneyi siidzafunika kwambiri chifukwa panthawi imene ndizagwire ntchito limodzi ndi ana komanso anthu amene ali ndi ulumali umene pafupipafupi amafuna chithandizo, ndizakhala limodzi ndi munthu wondithandizila. Ntchito iliyonse imene ndidzagwire ndi anthu amenewa padzayeneka pakhale kholo, womuyangánira kapena wopeleka chisamaliro ndiponso anthu ambiri a maulumali osiyanasiyana amene ndizagwire nawo ntchito adzakhala anthu oti akhoza kupeleka chiloleze paokha kugwira nawo ntchito mu kafukufuku ameneyu.

Kafukufukuyi wawunikidwaso kachiwiri ndi bungwe loyang’anila za kafikufuku m’Malawi.

Ndimgapange bwanji ngati ndikhatakhala ndi madandulo pa kafukufukuyi?

Zoyenerera zones za kafukufuku zikupezeka pa internet http://www.st-andrews.ac.uk/utrec/guidelinespolicies/complaints/

Ku Malawi kuno anthu otenga nawo mbali mu kafukufuku ameneyu angathe kutumiza madandaulo kapena nkhawa zawo ku Komiti yaikulu yoona za kafukufuku (The National Committee on Research in the Science and Humanities). Ndipo adilesi yao ndi iyi:

Director General
National Commission for Science and Technology
Lingadzi House
City Centre
P/Bag B303
Capital City
Lilongwe 3
Attention: NCRSH Secretariat
Email address: ncrsh@ncst.mw

Contact Details

Researcher: Sarah Huque
Contact Details: sih3@st-andrews.ac.uk

Supervisor: Dr Mike Kesby
Contact Details: mgk@st-andrews.ac.uk; +44 1334 46 2150

Supervisor: Dr Katherine Keenan
Contact Details: klk4@st-andrews.ac.uk; +44 1334 46 3951

FOMU YA CHILOLEZO KWA OTENGA MBALI

Zofunika kudziwa

Dzina la pulojekiti

Disability Advocacy and Activism in Malawi: Part One - Designing a Participatory Action Research Project

Researcher(s) Name(s)	**Supervisors Names**
Sarah Huque	*Dr Mike Kesby*
sih3@st-andrews.ac.uk	*Dr Damien Williams*

Sukulu ya Ukachenjede ya St Andrews imachilimika kwambiri pa nkhani za kulemekeza munthu mu ntcito zake za kafukufuku. Pachifukwa chimeneyou tidzakupemphani kuti muyanilepo nfundo izi musana saine fomu imeneyi. Saini yanu ikutsindikiza kuti muli osangalala/ovomela kuti mutenge nawo mbali pa kafukufuku ameneyu.

Kodi zokambidwa zolondolozeka ndi chani?

Zokambidwa zolondolozeka nthawi zambiri ndi zimene zakambidwa kuchokela kwa munthu wozindikilika amene akutenga nawo mabli mu mkafukufuku; chitsanzo akhonza kukhala munthu wamkulu(bwana) amene wafunsidwa mafunso kapenanso pamene munthu wapeleka chilolezo kuti dzina lake likhoza kugwiritsidwa ntchito pamene ntchito yomaliza ikulembedwa. Mu mkafukufuku ameneyu mukhoza kupeleka chilolezo kuti dzina lanu ligwiritsidwe ntchito kapenanso mukhoza kulamula kuti agwiritse ntchito dzina lopeka. Zokambilana zoyambilira zimene zili zosasanthulidwa zizasungidwa mwa chinsinsi ndi amene akupanga kafukufukuyu komanso ndi amene amamuyangánira kuphatikizilapo ndondomeko za onse amene adzatenge nawo mbali pa kafukufukuyu amene ndinso amene adzafuna kuti dzina lawo lisagwiritsidwe ntchito koma pakhale lopeka.

Ngakhale mungasankhe kuti tigwiliotse ntchito dzina lanu lenileni kapena lopeka. Pali zinthu zitatu zomwe ndikuyenera kukufusani kuti mundipatse chilolezo. (i) Ubale wa gulu lomwe limagwila ncthito yoyankhulira kapena kuthandiza anthu olumala (ii)Ndikumana ndi anthu ochepa mma gulu amenewa (iii) Ndidzagawa zotsatila (Zosakhudza munthu payekha) ndi mabunwe ogwila nawo tchito mmalawi ndi cholinmga choti tikonzeso gawo lachiwiri la kafukufuku. Zinthu zitatauzi zikutanthawuza kuti mayankho omwe mungapoeleke akhoza kutengedwa kuti ndi anu ndi anthu omwe akukudziwani kapena bungwe lanu.

Choncho ,mukuyenera kutenga mbali mukudziwa kuti mayankho anu adzakhala komanso akhoza kukukhuzani inuyo.

Mafunso

Muli ndi mafuso omwe mungafune jufusa okhudzana ndi kafukufukuyi?

Chilolezo

Cholinga cha fomu yi ndikuonenetsetsa kuti simukukakamizidwa kutenga nawo gawo pa kafukufufuku komaso kuti mumvetsetse za kafukufukuyu. Mukasayinila fomu yi sikutanthawuza kuti mupanga zinthu zomwe simukugwiliza nazo ndipo muli ololedwa kusiya kutenga gawo pa nthawi iliyonse.

Ndawelenga ndikumvetsetsa zokambidwa pa pepalali.	☐ Yes	☐ No
Ndapatsidwa mwayi/mpata ofusa mafuso pa kafukufukuyu.	☐ Yes	☐ No
Mafuso anga ayankhidwa mokhutitsidwa.	☐ Yes	☐ No
Ndikuzindikira kuti ndi khoza kusiya kutenga nawo gawo pakafukufukuyu nthawi ina iliyonse popanda kufitokoza chifukwa.	☐ Yes	☐ No
Kapena : Ndikugwilizana nazo zonditchula/kugwiritsa ntchito dzina langa lenileni pa kucheza nane komanso mu ntchito ina iliyonse imeneingatuluke mnkuchokela muzokambilana zathu.	☐ Yes	☐ No
Ndikugwirizana ndi zoti agwiritse ntchito dzina lopeka pa nthawi imene tikukambirana komanso pa nthawi imene akakhale akulemba zokambilana zathu.	☐ Yes	☐ No
Ndikumvetsa kuti zomwe ndinene zidzasamalidwa bwinio ndipo zidzakhala ndi ekhayo opanga kafukufuku ndi omuyangánira. Ndikuvomeraza kuti zonse zimene ndikambe ine zizaunikila kwa ine ngakhale pa nthawi imene adzagwiritse ntchito dzina longopeka.	☐ Yes	☐ No
Ndikuvomereza kuti zomwe ndingafotokoze (mogwilizana ndi zomwe zanenedwa mmwambamo) zidzasungidwa ndi opanga kafukufuku ndinso zidzagwilitsidwa ncthito pa kafukufuku wa anthu ena opanga kafukufuku.	☐ Yes	☐ No
Ndikuvomereza kuti zomwe ndingafotokoze zikhoza kupelekedwa ku ma mabungwe a m'Malawi omwe akugwira ntchito pofuna kubweletsa kusintha ku nkhani za maulumali osiyanasiyana kuyangánila ntchito zakutsogolo.	☐ Yes	☐ No
Ndazindilililitsidwa zasotsatlira zomwe zingakhalepo pakutenga nawo gawo pa kafukufukuyu ndipo ndakhutitsidwa nazo.	☐ Yes	☐ No
Ndikuvomereza kutenga nawo gawo pa kafukufukuyi.	☐ Yes	☐ No

Kugwilitsa ntchito zida za zithunzi, Kanema ndinso Kutenga mau

Mbali imodzi ya kafufufuku ikukhudzana ndi kujambula zithunzi, kutepa mau ndinso kujambula ndi kanema. Zithuzi ndi ma tepi zidzasungidwa mosamala popanda choonetsera kuti zachokera kwandani ngati mwini wakeyo sanasaine fomu ya chilolezo.

Zithunzi ndi zonse zokambidwa mu zida zotengela mau ndi mpamba wauukulu kwa anthu amene adzakhale akupanga maphunziro awo mtsogolomu, chifukwa chimenechi tidzakhala tikukupemphanibe chilolezo china kuti tithe kusunga mauthenga amenewa pazithunzi komanso mu zida zathu sotengala mau ndi makanema. ....

Ndikuvomera kutoledwa chithunzi. ☐ Yes ☐ No

Ndikuvomera kutepedwa mawu. ☐ Yes ☐ No

Ndikuvomera kujambulidwa pakanema. ☐ Yes ☐ No

Ndikugwilizana nazo zoti chithunzi change chizagwiritsidwe ntchito pamene zotsatila za kafukufukuyu akutulutsidwa. ☐ Yes ☐ No

Ndikuvomera kuti tepi ya mawu anga idzatulutsidwe ngati mbali ya kafukufuku. ☐ Yes ☐ No

Ndikuvomereza kuti Kanema wanga adzatulutisdwe ngati mbali ya kafukufuku. ☐ Yes ☐ No

Kutenga nawo gawo pakafukufuku sikokakamiza ndipo mukuyenera kupekeka chilolezo musanayambe kutenga nawo mbali. Ngati mungasinthe maganizo kuti zomwe mwanena ziwonongedwe, tidzapanmga mwakufuna kwanu polemba.

Ndikuvomereza kutenga mbali mu phunziroli. ☐ Yes ☐ No

Dzina ______________________________

Siyini ______________________________

Where appropriate - countersigned by the researcher(s) ______________________________

Tsiku ______________________________

University of St Andrews

University Teaching and Research Ethics Committee

School Of Geography And Geosciences

20th August 2018
Sarah Huque
Geography and Sustainable Development

Ethics Reference No: *Please quote this ref on all correspondence*	**GG13884**
Project Title:	Disability Advocacy in Malawi: Part 2
Researchers Name(s):	Sarah Huque
Supervisor(s):	Dr Mike Kesby & Dr Katy Keenan

Thank you for submitting your application which was considered by the Geography and Geosciences School Ethics Committee on the date specified below. The following documents were reviewed:

1. Ethical Application Form	20th July 2018
2. Participant Information Sheet	20th July 2018
3. Consent Form	20th July 2018

The University Teaching and Research Ethics Committee (UTREC) approves this study from an ethical point of view. Please note that where approval is given by a School Ethics Committee that committee is part of UTREC and is delegated to act for UTREC.

Approval is given for three years. Projects, which have not commenced within two years of original approval, must be re-submitted to your School Ethics Committee.

You must inform your School Ethics Committee when the research has been completed. If you are unable to complete your research within the 3 three year validation period, you will be required to write to your School Ethics Committee and to UTREC (where approval was given by UTREC) to request an extension or you will need to re-apply.

Any serious adverse events or significant change which occurs in connection with this study and/or which may alter its ethical consideration, must be reported immediately to the School Ethics Committee, and an Ethical Amendment Form submitted where appropriate.

Approval is given on the understanding that the 'Guidelines for Ethical Research Practice' (http://www.st-andrews.ac.uk/media/UTRECguidelines%20Feb%2008.pdf) are adhered to.

Yours sincerely,

Dr. Kim McKee
Convenor of the School Ethics Committee

UTREC School of Geography and Sustainable Development Convenor, Irvine Building, North Street, St Andrews, KY16 9AL
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APPENDIX C

CONTENTS:

- FEDOMA FIELDWORK REPORT

Disability Advocacy in Malawi: Report on Project Fieldwork

Prepared for: The Federation of Disability Organizations in Malawi

Prepared by: Sarah Huque, PhD Researcher - University of St Andrews

Contact Page

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Table of Contents

1. List of Abbreviations

Federation of Disability Organizations in Malawi - FEDOMA
District Disability Forum - DDF
Disabled Persons' Organisation - DPO
Area Disability Forum - ADF
District Health Officer - DHO
District Education Manager - DEM
District Executive Committee - DEC
District Council - DC
Disability Inclusive Disaster Risk Reduction - DIDRR

2. List of Tables

3.

4. List of Figures

5.

6. I. Introduction

This report is one output of the research study undertaken between 2017 and 2019 by myself, Sarah Huque, a PhD candidate at the University of St Andrews in Scotland. In this report, I present the activities and challenges faced by some of the Federation of Disability Organizations in Malawi (FEDOMA)'s District Disability Forums (DDFs). The contents include obstacles faced by persons with disabilities[55] in the districts, the activities and challenges faced by the DDFs, the DDF members' plans for the future of the DDFs and suggestions for the future of FEDOMA, and the results of a mobile phone reporting system pre-pilot.

The mobile phone reporting system pre-pilot was designed as a way for FEDOMA to gain insight into the potential utility of and enthusiasm for the design and implementation of a regular mobile reporting system between the DDFs and FEDOMA. This report contains the reactions of the interviewees, (DDF members, and FEDOMA staff and management personnel), to the idea, their beliefs on its utility, their suggestions for what it would require, and the researcher's recommendations based on the evidence gathered.

The data contained in this report is based on interviews with District Disability Forum members in four sample districts, as well as several members of staff, all chosen in collaboration with FEDOMA management. During my time with the DDFs and at FEDOMA's Secretariat headquarters, I also got to spend time with the members and participate in their day-to-day activities. While the details of those interactions are not explicitly included in this report, they did help me to come up with the recommendations I made and provide context to the interviewees' responses. However, I do not have first-hand knowledge of the activities described by participants during interviews, and so the information provided by the DDF members is provided here without any interrogation into the truth of what they said; for the purposes of this report, interviewees are taken at their word, and readers can choose to interpret that as necessary when deciding how to use the information.

This report may be periodically updated, as I continue to work with the data from this project, or at the request of FEDOMA. Following on from this report, a thesis dedicated to

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[55] Because person-first language is preferred by disability rights advocates in Malawi, the phrases 'person with a disability,' 'persons with disabilities,' or 'people with disabilities' will be used in this report.

the nature of communication and voice within the organisation will be written by me, in partial fulfilment of the requirements of the PhD programme. This document, however, focuses more on the technical aspects of the DDFs, and considers how they might be approached in the future, particularly in the development of FEDOMA's five-year strategic plan.

Any questions, comments, or concerns may be sent via the contact information at the front of this report.

7. II. Methodology

In September 2017, I travelled to Malawi for a familiarisation visit with FEDOMA, which lasted into November 2017. During this visit, I spent time at FEDOMA's headquarters as well as in the field with FEDOMA project staff. I also worked with the Executive Director on deciding what the research project should focus on. In the end, we decided that the District Disability Forums would be the focus of the project, and that I would conduct a 'pre-pilot' for a mobile phone reporting system – gathering information on whether such a system would be of use to the DDFs, and what suggestions or concerns they would have about it.

Between November 2018 and January 2019, I returned to Malawi and conducted interviews and participant observation with DDF members in four sample districts – one each representing the North, Central, and Southern regions, as well as a district containing an urban centre. FEDOMA and I invited the DDFs' governing committees to be interviewed, and extended the invitation to other members of the DDFs who wanted to participate; as a result, in addition to committee members, I was able to interview lay members and liaisons to other committees in some of the districts. I also conducted interviews with FEDOMA staff and management, for a total of 30 interviews.

The data presented here are part of the results from the interviews, focusing on the aspects that may be useful to FEDOMA in strategizing about the future of the DDFs, especially with regard to the creation of a new five-year plan.

The research plan, interview guides, and all related materials were granted ethical approval by both the University of St Andrews and the government of Malawi.

8. III. Challenges for Persons with Disabilities in Malawi Sample Districts

All interview participants from the four sample districts gave examples of challenges faced by persons with disabilities in their district. Many of these challenges were common to two or more districts, so they are presented below in tables that show which problems were raised by which district's DDF(s). This provides a simple way to look at which issues are most concerning to the DDFs at the moment.

Table 1 below presents challenges raised by the DDFs affecting children with disabilities specifically.

Table 5: Challenges relating to children with disabilities.

Challenge	**District 1**	**District 2**	**District 3**	**District 4**
Children with disabilities kept out of school.		X	X	
Lack of special education teachers and resources.	X		X	X
Children with disabilities passed over for secondary school, even when they have completed primary school. And/or children being held at a particular grade level indefinitely.	X			
Learners with disabilities kept from accessing higher (post-secondary) education.		X		
Inaccessible school structures.			X	X
Early childhood marriages.			X	

As presented in Table 1 above, issues concerning children with disabilities were raised by DDF members in all four sample districts. The most commonly raised issues involved access to education for children with disabilities. DDF interviewees from three out of four districts focused on the lack of special education teachers and resources as an area of concern.

Table 2 presents social and economic challenges described by the DDF members across the four sample districts.

Table 6: Social and economic challenges for persons with disabilities.

Challenge	District 1	District 2	District 3	District 4
Segregation from general public and isolation in homes.		X		
Unawareness of the rights afforded to persons with disabilities through national and international legislation.			X	
Lack of representation in the criminal justice sector.	X			
Lack of employment opportunities.	X	X	X	X
Difficulty obtaining small business loans.	X			X
Inaccessible local institutions (schools, hospitals, police stations, etc.), either through lack of physical (ex: ramps) or other (ex: sign language interpreters) accommodations.	X	X	X	X

Challenge	District 1	District 2	District 3	District 4
Limited awareness around issues of health, disease (HIV/AIDs in particular), and sanitation.	X	X		
Exclusion from national programmes (particularly fertilizer subsidies and disaster preparedness and rebuilding programmes).	X	X	X	X
Exclusion from local programmes (ex: development projects, social cash transfers, food item relief).			X	X
Lack of awareness among persons with disabilities about available products and services (ex: sunscreen lotions in hospitals).	X			
Limited access to assistive devices, medicines, and services.	X	X	X	
Limited access to sanitation facilities (ex: boreholes, toilets)		X		

Challenge	District 1	District 2	District 3	District 4
Unwillingness of local leaders to engage with training on disability issues.		X		
Various seasonal issues (ex: insecure ground during rainy season; sunburn in summer for persons with albinism; natural disasters)		X	X	X
Treatment of women and girls in relationships. (ex: impregnated and left, divorce, intimidation by in-laws)	X	X	X	X

Table 2 shows that there are several issues that concern all four of the sampled districts. Two of these, lack of employment opportunities and exclusion from national subsidies, concern persons with disabilities' ability to support themselves. A third issue all four DDFs raised was barriers to access local institutions. Finally, all four DDFs had members who were concerned with the poor treatment of women with disabilities in relationships. Many had stories of women who were impregnated and then left to raise the child themselves, or men who promise to marry women with disabilities but then disappear.

Table 3 below presents challenges pertaining to violent acts committed against persons with disabilities.

Table 7: Challenges relating to violence perpetrated against persons with disabilities.

Challenge	**District 1**	**District 2**	**District 3**	**District 4**
Physical violence and aggression against persons with albinism.	X	X	X	
Sexual assault against women and girls.	X		X	
Harassment, physical abuse, and human rights violations.	X	X	X	X
Allegations of violence not taken seriously by law enforcement.		X		X

All of the DDFs are concerned with harassment, physical abuse, and human rights violations against persons with disabilities, as presented in Table 3. While two districts specifically brought up sexual assault as a concern, as presented in this table, this issue goes hand-in-hand with the poor treatment of women and girls in relationships (Table 2).

9. IV. District-Specific Interview Responses

In this section, I present the responses of interviewees on three district-specific categories: DDF initiatives and successes, concerns and problems, and suggestions for the future of the DDFs. This section helps the reader understand the DDFs priorities, and their opinions about the best areas of focus for the future. Since each interviewee was asked about the future of their own DDF, they are separated by district. There is some overlap between the districts, which might present an opportunity for focal points in future planning.

10. District 1

11. Initiatives and Successes

The DDF in District 1 has been up and running for a few years, and so had worked on a variety of initiatives. From the start, the interviewees said, they were dedicated to spreading their message as far into the district as possible, even using their refreshment allocation to instead fund transport to visit persons with disabilities further out in the district, to find out about their challenges. DDF members recounted using creative methods such as music and poetry – this DDF has its own choir – to share their experiences and win attention for their cause. The members of the DDF shared various successes they had within the district, and many of these examples were recounted by multiple members of the groups.

Several of the successes discussed during the interviews with District 1 DDF members had to do with creating links – both between the DDF and local institutions and between persons with disabilities and the community. The DDFs ran awareness campaigns in villages, helping them to form relationships with Traditional Authorities and village headmen; this in turn means that the DDF now has a platform to give special presentations during village rallies about topics impacting persons with disabilities. The DDF members reported that after these awareness campaigns, they saw a reduction in violence, rape, and 'defiling' committed against persons with disabilities in the communities where the campaigns have run. The DDF members described how conducting these awareness campaigns in the villages helped open village committees and subcommittees up to membership by persons with disabilities. Through this, they were able to organise farming groups specific to persons with disabilities, growing crops to sell for an income. This was particularly important for persons with disabilities who did not have much education, and as such had limited opportunities for employment. Other small support groups for persons with disabilities were also established, enabling the spread of information, encouragement, and the message of empowerment.

The DDF established ties to district institutions as well. As one interviewee put it, 'we knock to a certain office, the office is opened. If you go to another office, the doors are open. So… we are able to advocate for everything everywhere.' For example, they campaigned for the District Education Department to enable learners with disabilities who had completed primary school to be considered for acceptance into secondary schools. The DDF members said they had seen an increase in the number of children with disabilities who were accepted to secondary schools, and that they went on to run projects with specific secondary schools. Their efforts in getting more inclusive education was the basis for a working relationship that has continued.

The DDF also formed ties to the local courts and established themselves as the organisation to call when a person with a disability needs support on a case, whether they are the defendant or the victim of a crime. Additionally, the DDF members formed a relationship with local police officers to the point where the officers now perform home check-ins with them, in an effort to find out what issues they are facing, or to question them regarding abuses committed against other persons with disabilities.

Some of the work done by the DDF might appear to be smaller-scale, especially when they are working to help a particular individual, but in fact these works have a wider impact in the creation of a sense of support within the community, establishing the DDF as a group that will do whatever they can to help when needed; it is telling that the DDF members often refer to the persons with disabilities in their communities as 'our friends.' The DDF is a safe space, and the members support and counsel one another. In one example, the group was able to assist a young man who had finished school with getting a job through small tasks – helping with his CV and application letters, photocopying his certificates, and contacting the FEDOMA Secretariat for help. This is a critical point as well – the District 1 DDF members' dedication to helping individuals as well as the collective means that they do not seem to see any issue as 'too small' to bring up at the head office.

The District 1 DDF members emphasised their role in providing that safe space. The DDF allows people who might feel unsafe on their own, i.e. persons with albinism, to confront the abuses they experience in their community and speak up for themselves with the support of the group:

> Because we go there as a team with disabilities. And we stand as [a] team with disabilities, saying we are here… we… go there and teach… and that's when they realise, "oh, these are my rights," they are able to stand up. And fight. And also we teach other people… And as they, linking the rights and vivid examples there, they are able to change their minds.
>
> - Quote from District 1 interviewee

The District 1 DDF is also one of the DDFs where Area Disability Forums (ADFs) have been established, for over a year now. The ADFs help the DDFs know what's going on within Traditional Authority areas, and they welcome that connection to the grassroots. The ADFs help local people to identify their challenges, where they come from, what to report, and what to do. This is especially helpful, given that some of the challenges faced by the District 1 DDF revolve around access to individuals in remote areas.

12. Concerns and Problems

The District 1 DDF members were fairly united in the concerns they raised during their individual interviews. All of the concerns can be tied back to a lack of monetary resources. Their concern about the lack of resource is three-fold. Firstly, the lack of funds makes it difficult to visit the more remote areas of the district, since they would need to pay for transport. The issue identified by every interviewee from this DDF was the ability of the members to reach the most remote areas of the district. They are very concerned that there are persons with disabilities in the district who are not at all aware that they even have rights, let alone how to go about obtaining the protections and acceptance afforded by those rights.

Secondly, the lack of funds prevents the members from meeting as often as they would like. This is due both to a lack of available transport and a lack of funds to pay for transport. The group had initially agreed to meet monthly, but at the time of the interviews was settling for meeting at least once every three months.

Finally, the DDF members are concerned with the ability of persons with disabilities in their district to make a living. They would like to be able to provide small business loans or grants to local persons with disabilities to start businesses, but are currently unable to do so. This is one of the initiatives they hope to be able to find resources to support in the future.

13. Suggestions: Future of the DDF

The members expressed several ideas for initiatives and points of focus for the future during their interviews. One such initiative would be to continue to focus on education reform to ensure that children with disabilities grow up knowing their rights and knowing about the movement that fights for those rights. They would also like to continue to expand the ADFs and reach out to the entirety of the district and beyond; the importance of access to information was stressed numerous times throughout several of the interviews.

In addition to continuing with established projects, the DDF would also like to be able to find a way to become financially independent, in order to support and expand their programmes. One idea was to learn to raise animals, another suggested a maize mill. The goal of the methods was the same, though – to create a fund they can use to expand their activities.

Some of their ideas for expansion include: obtaining bicycles to reach more rural areas, especially where people can’t be reached by phone, economic empowerment through providing jobs and/or loans for small businesses, and providing educational opportunities for members of the DDF to expand their capacity as advocates as well as in their professional lives.

14. District 2

15. Initiatives and Successes

In District 2, the DDF members stressed their focus on inclusiveness, both among stakeholders and in local communities more broadly. They count among their successes increasing numbers of participants, including Chiefs and other leaders, in the rallies they have held, as well as door-knocking awareness campaigns. Some of the members spoke about being recognised as ‘freedom fighters’ by community members just out on the streets. One DDF member described how they use their ‘love of people’ – sharing interests, especially music, to show that persons with disabilities are people others in the community can relate to and be friends with. This same person also described how they speak to people about ‘cross-cutting issues:’

> Because the problems that we are facing as people with disabled [sic], they are also the problems which people are facing who are not disabled. They are the same. So when I’m interacting with them, I’m thinking about those problems and how to share them, then to discuss together with them how to solve these problems.’
>
> - Quote from District 2 interviewee

The DDF members noted that this increase in community acceptance has led to a decrease in cases of abuse, rape, and murder committed against persons with disabilities. In particular, one member told us that in some areas, people were beginning to understand that engaging in sexual intercourse with a person with a disability (whether consensual or non-consensual), will not cure HIV/AIDs - a common belief tied to the number of sexual assaults committed against women with disabilities.

Some of the stories the DDF members told demonstrated communities coming together in support of persons with disabilities – for example, one community came together to sew school uniforms for a child with a disability to go to school, and sourced funds for the child’s school fees and transport by bus.

The noise the DDF has been making in the district also includes working with stakeholders in local government and development projects, and hosting roundtables to discuss inclusiveness with said stakeholders. As a result, they are beginning to see some of the issues they have raised concerns about being worked on by district officials. For example, schools in the district have begun installing ramps and using transparent roofing materials to make classrooms more accessible.[56] The group also reported an increase in availability of

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[56] Most classrooms in Malawi do not have electric lights, and the interiors can be very dark. Transparent roofing materials allow more light into the rooms, helping students with visual impairments to see better at school.

large-print books for those with visual impairments. Other DDF members brought up the fact that more persons with albinism are accessing sunscreen and more persons with epilepsy are accessing medications, after the group made recommendations to district officials.

Figure 4: Transparent roofing tiles in a classroom.

The DDF has established themselves as representatives for persons with disabilities. Community members go to them with problems, and the DDF goes to the relevant stakeholders to try to come up with a solution. For example, most of the District 2 DDF members that I interviewed told the story of a young woman with albinism who applied for teacher training college, but was not given an interview because of her disability. The DDF intervened and explained why this was an injustice to the District Education Manager (DEM). In short, that young woman is currently working as a teacher. In another school-related success story, the DDF members said that a school for the blind was set to close, due to an apparent lack of funds, but the group successfully rallied the DEM to find a way to keep it open, and it remained so at least up until the point of the interviews.

On a more technical note, there have been some concrete successes for the District 2 DDF in enabling the participation of persons with disabilities in district groups and programmes. The group advocated for the inclusion of persons with disabilities in a social cash transfer

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These transparent sheets are usually installed towards the front of the classroom, to encourage teachers to place students with visual impairments closer to the board.

programme, and ultimately 1,500 persons with disabilities were enrolled into the programme. Persons with disabilities are now active participants in many district, village, and area committees, and are included in smaller programmes, such as the distribution of flashlights by the District Council (DC). This inclusion means that representatives for the disabled population are part of many of the development activities being undertaken in areas of the district, including farming initiatives, construction projects, and disaster risk reduction.

This DDF has also engaged with the media to promote their message, with members speaking on the local talk radio show and writing songs about the experiences of persons with disabilities. They also invite radio and TV media to their programmes, during which they talk about the initiatives they have worked on, the rights of persons with disabilities, and the challenges they face. One of the ways they have been able to develop a base of knowledge on local challenges was through a baseline survey the group conducted on persons with disabilities in the district. All of the members of the DDF who talked about this survey in their interviews also indicated that it was not yet at the level of information needed, but that it was a start.

16. Concerns and Problems

The DDF in District 2 raised many concerns surrounding economic stability and sustainability of programmes. For example, through a benefactor, they were able to obtain materials for skills training in sewing and carpentry. However, there was limited funding for instructors, and eventually the project phased out. This left the materials, but no one who knows how to use them. A group of women had learned to make handbags to sell, but that is where the skillset ends. Learning how to make and repair more complex items might have made it into a more sustainable economic activity.[57]

The DDF in District 2 is also concerned about communication, both in-person and remote. One interviewee mentioned that network issues can make it difficult to communicate by mobile, because of disruptions to the network and a lack of funds for

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[57] Some DDF members pointed out that the funds the women made from the handbags were used to supply the DDF's meeting place with electricity. Although they had had some initial success, there was concern that the funds were not sustainable, since they did not know how to make anything else.

airtime. Sending reports to FEDOMA via email also presents a challenge. In order to report to FEDOMA, the group relies on local vendors to send emails. Several interviewees described this as an expensive way to communicate, once travel costs, payments to vendors, and the cost of staying in town an extra day if the power is out, are taken into consideration. In this instance, the physical distance of the individual tasked with reporting's home from the nearest town centre exacerbates the issue.

Physical distance also presents a problem for the DDF's ability to reach remote areas of the district, each other, and the office where they meet. Every interviewee talked about how large and hilly the district is, and physical distance as an issue in going about their work. As in District 1, this physical distance presents a problem of resources – transport and funding said transport. Transport issues are further exacerbated depending on the time of the year. One interviewee reported that during the rainy season, the lack of transport or even basic rain gear such as umbrellas, combined with the fact that the ground is sometimes unstable during this time of year, means that DDF members often won't travel to attend meetings, or will wait long hours for breaks in the weather to be able to attend. One of the additional challenges the rainy season brings for the DDF is trying to ensure the inclusion of persons with disabilities in preparations for natural disasters, such as floods and cyclones.

Figure 5: Roads beginning to flood during a storm early in the 2018-2019 rainy season.

While the District 2 DDF members all described their interactions to date with stakeholders as positive dialogues, and many of them felt hopeful about those relationships, they also do face challenges with exacting greater concessions from said stakeholders. The DDF has focused on a push toward inclusive budgeting, but have had difficulties bringing stakeholders on board in a concrete way. This is partially due to a lack of local data on persons with disabilities. Because of this lack of data, it is difficult for the DDF to tell whether stakeholders are really mainstreaming disability issues. One interviewee gave the example of the fertiliser subsidy programme – as of now, they do not have data on how many persons with disabilities are benefitting from this programme in the implementation areas. Even the baseline study they had done, as part of one of FEDOMA's donor-funded programmes, has not yielded the evidence needed to convince stakeholders to take the next steps toward inclusive budgeting. Some of the DDF members described claims of 'no funding' from officials for things like medicines, or barriers to making sure School Improvement Grants, (which often have a portion of the funds earmarked for accessibility improvements), are properly administered.

17. Suggestions: Future of the DDF

The suggestions different DDF members made during their interviews largely seek to address the issues discussed in the previous section. Some of the members would like the DDF to have access to a laptop for writing reports and getting online. The indication seemed to be that this would both ease their ability to submit their reports on time and make it easier for FEDOMA to communicate back to the DDF. Other participants suggested that a laptop and generally better office set-up would help them to improve their record-keeping, especially as they attempt to engage in more data collection. One member opined that a more professional space could help build the community's confidence in the DDF as an effective organisation. Several members of the DDF mentioned needing their own source of funding to run the office, so that they could handle more at the district level, rather than engage in the timely process of reporting issues back up to FEDOMA's Secretariat: '… some problems, some shortfalls… we need to solve quickly.' Funding their office was posited as a way to increase their own capacity, especially since they already have the space.

The DDF members all also talked about their current office space as a place where skills training could be revived. Members talked about using the facilities and supplies they already have to train persons with disabilities in skills that can generate an income – as soon as they can afford to hire someone to teach them. One member mentioned that this is particularly important for those too old to return to school to be able to support themselves.

Investing in these skills could also be a source of income for the DDF to run its programmes, and, critically mentioned by all interviewees, reach those in more remote areas with their awareness campaigns. Another suggestion made several times for how the DDF could generate funds was learning to write proposals and obtain local funding on their own. Economic empowerment for both the DDF members and their constituents was a key issue for all of the interviewees.

The final area the DDF members concentrated on in their ideas for the future of the DDFs was in increasing disability mainstreaming, to combat some of the challenges they had faced in being taken seriously by local stakeholders. Several interviewees would like to concentrate on gaining further government support in the future. Others suggested getting local NGOs invested in disability mainstreaming, especially when it comes to inclusive education, ‘because education is the cure for… everything, for a person to at least reduce challenges… it’s education.’

18. District 3

19. Initiatives and Successes

The DDF in District 3 is a relatively young one, established at the end of 2017. Because of this, many of the DDF members spoke about things they plan to do but admitted that they had not gained much momentum yet. Despite this, there were still some successes discussed during the interviews.

All of the DDF members discussed the awareness campaigns they’ve engaged in, especially those focused on children with disabilities’ access to education. They partnered with one of the local Disabled Persons Organisations (DPOs) to encourage parents to send children to school, and to train non-specialist teachers in including children with disabilities in classroom activities. They also conducted a survey of school age children with disabilities in the community and spoke to parents individually about not locking their children inside and sending them to schools. There was a particular focus on getting children with severe visual impairments into the local school for the blind. According to one of the interviewees, at least 19 boys and girls with disabilities identified by the DDF are now in school.

The DDF in District 3 also engaged in community campaigns with persons with disabilities, and with local leaders. Being able to engage with community members and hear about the problems they are facing will help the DDF to plan for future campaigns; some of the DDF members stressed that they are a human rights organisation, and that these discussions have helped them to identify human rights violations occurring in the community. In some areas, they also introduced small village committees focused on incorporating persons with disabilities in development.

The awareness campaigns have helped to educate Traditional Authority Chiefs, village headmen, and the surrounding communities, so that both persons with and without disabilities gain awareness of the rights of persons with disabilities. The group has engaged in ‘self-acceptance’ campaigns, to help persons with disabilities learn to accept themselves.

Some of the awareness campaigns are more specific, and have been done in conjunction with DPOs to highlight specific issues; as a result, the DDF members reported some changes in the community. For example, one campaign among persons with albinism focused on sun protection, such as wearing long-sleeved clothing, led to a change in behaviour in the communities in which it was undertaken. Another campaign undertaken was to encourage women with disabilities to go and get tested for HIV/AIDs.

Finally, the DDF members reported things they had done to begin gathering support and resources for future programming. Several of the DDF members reported that the group had raised a small amount of money to fund future programmes, building it up among themselves. The group members also talked about establishing connections to local outposts of organisations such as NICE and PLAN Malawi.

20. Concerns and Problems

One of the major concerns of this group seems to be that they are stuck in a waiting pattern with FEDOMA, or even that they may have been forgotten. Multiple members of the DDF reported that they had not received any feedback on their work plan for 2018, as of December 2018. They were already developing the 2019 work plan, but several expressed disappointment and discouragement at the lack of response to the previous plan. The group members also reported not having received any support or resources from FEDOMA, despite having heard about other districts receiving programmes and support that had yet to materialise in District 3. Specifically, DDF members brought up housing and economic empowerment projects. The lack of support has led to a feeling that they cannot yet do much and do not have a real platform.

Multiple DDF members also specifically brought up lacking access to the internet and internet applications such as WhatsApp (before being asked about such things as relate to the mobile phone reporting system). They found that this limited their ability to communicate with FEDOMA, and to keep organised records.

As with Districts 1 and 2, the District 3 DDF members were concerned about being able to reach those in the more remote areas of the district. One of the challenges several members brought up was the difficulty of accessing communities across the breadth of a very large district. Travel across the district is expensive, and the DDF lacks the funds to reach the furthest places. Since DDF members live in different areas across the district, it also makes it difficult for the group to meet, and multiple members admitted that they do not meet as often as they should. This lack of access plus the newness of the DDF meant that some of the members brought up the fact that they do not necessarily feel that they have had an impact yet – one member described the feeling as 'pathetic.'

21. Suggestions: Future of the DDF

Since the District 3 DDF has not yet begun to work on the projects in their work plan, many of the DDF members stressed a preparatory focus for the future. Some of the members brought up receiving training from FEDOMA in advocacy, human rights issues, and health issues as something they would like to see happen; they in turn could conduct these training courses in the community to spread the message. Some of the DDF members also suggested collecting good data in the future, so that they know how many people have disabilities in the district. This data could also be used to identify what those people need by way of assistive devices, and try to get and distribute them accordingly. Other suggestions to set the DDF up for success included: starting a business to raise project funds, opening a bank account, exploring options for direct donor support to the DDF, engaging in collaborations with other organisations, and encouraging those with disabilities to 'work hard.' Some of the DDF members also discussed the group's plans to visit district officials. They hoped to discuss inclusive development projects with the District Council, and discuss the school for the blind, issues faced by teachers with disabilities, and the introduction of Braille and sign language into primary and secondary schools with the District Education Manager.

The DDF members also talked about some of the more specific campaigns they are hoping to run in the future. Many of those campaigns build on activities the DDF has already started to engage with, including advocating for school uniforms to have long sleeve options and hats, encouraging district offices to install wheelchair ramps, and advocating for disability inclusive disaster risk reduction (DIDRR) strategies. Multiple interviewees also brought up ideas to establish vocational training centres for persons with disabilities to learn trades such as tailoring, tin-smithing, carpentry, cooking of mandazi or sweets, animal husbandry, etc. Economic empowerment of the community and the DDFs could also help the DDF to realise some of their more expensive plans, such as the vocational centres, or building shelters for those in remote areas who do not have even the most basic homes.

22. District 4

23. Initiatives and Successes

In contrast with District 3, District 4's DDF is well-established. District 4 also has the difference of containing one of Malawi's major urban centres. The DDF there has thus registered a lot of successes in dealing with government stakeholders. All of the interviewees brought up their engagement efforts with eight line ministries in the district, as well as the judiciary, on issues of inclusivity. The members also provided some examples of the results of that engagement. One member brought up the DDF's engagement with the Ministry of Health as a factor leading to the creation of ombudsman's offices at local hospitals. These offices serve as a point of contact for persons with disabilities to report problems or rights violations in the hospitals. Multiple DDF members also cited the group's successful lobbying for the inclusion of some persons with disabilities in agricultural programmes, contributing to the provision of pesticides, farm inputs, etc. for some individuals, though they also noted that there is much more to be done in that area. Through this work, the DDF has established itself as a valuable resource for disability mainstreaming among the district line ministries.

Figure 6: Farmland in a rural area.

The DDF members have also engaged the district-specific government structures, registering successes with those stakeholders as well. For example, one member brought up their engagement with the District Health Officer (DHO) to use mobile clinic vans to distribute sunscreen lotion in remote areas of the district. Another member brought up that the DDF successfully campaigned for the District Education Manager (DEM) to conduct disability mainstreaming training and capacity building with non-specialist teachers at about ¾ of the district's schools. The DDF also discovered that the inclusive education budget was being diverted, supposedly due to lack of need. The group successfully lobbied the DEM to encourage schools to claim funds from that budget, leading to the discovery of a huge need; the fund actually was not large enough to meet the demand. One DDF member said that they trained the District Executive Committee (DEC) in disability mainstreaming and disability-inclusive budgeting. The DDF also negotiated with district officials for accessible evacuation centres and the institution of a committee of persons with disabilities who focus on disaster relief issues - part of on-going work the group is doing in disability inclusive disaster risk reduction. As part of this work, the DDF has also encouraged persons with disabilities to join district committees, and there are now DDF representatives on the DEC and District Council.

The District 4 DDF has also engaged with Traditional Authorities and local leadership and communities. Some of the DDF members described the village rallies that they have conducted, making sure to point out that many traditional leaders show up and engage with the discussions, as well as youth and other community members both with and without disabilities. These rallies are also a space for persons with disabilities in the community to present their issues for the community at large to hear – the DDF encourages non-DDF members to stand and speak for themselves. Advocacy work done in the community has also led to the inclusion of persons with disabilities in area and village development committees, with an increase in participation over time reported by the DDF members.

Community engagement has also helped the DDF teach parents about acceptance of children with disabilities and that they should be sending their children to school. The DDF members also talked about sensitising teachers, school officials, and district education officials in inclusive education and access, leading to the construction of ramps in some schools, as well as the provision of school uniforms for children in need of them.

Figure 7: Ramps leading up to a school building and into classrooms.

While working in the Traditional Authorities, DDF members reported that they conducted a baseline survey, sampling the TAs to determine gaps in provision of rights for persons with disabilities. This data is given to ministries when they claim they do not have local data to work with in making change.

Finally, District 4 members also reported using their community ties to engage internationally. Some of the DDF members described how they formed a relationship with South Korean disability advocates, after working to resolve inclusivity problems at a church run by a South Korean pastor. One DDF member said that this group is now in the process of reaching out to work with FEDOMA in the future.

24. Concerns and Problems

The concerns expressed by the District 4 DDF members relate to funding and timeframes, with the two often intertwining. One issue raised was in scheduling with district officials, especially when getting approval and funds from FEDOMA tends to happen at the very last minute. (In this case, donor project funds.) The timeframe impinges upon their ability to smoothly implement programmes and include officials, who often need invitations far in advance in order to ensure availability.

Though this DDF does receive funds through its donor-funded project, the members all brought up the problem that there simply is not enough for them to cover the entire district. District 4 is very large, and enough money to fund travel and logistics to reach the more remote areas is difficult to come by. For that reason, the DDF has made a tough decision to focus on areas closest to where the DDF members live and work, to make the limited resources go as far as possible. This issue seemed to make several DDF members uneasy.

The DDF members also raised concerns with professional image, as they lack office space and equipment, and have limited access to the internet. Some of the members use personal laptops or smartphones to get online, others do not use the internet at all. However, all the members interviewed expressed a concern that it is difficult for them to progress and feel professional without these resources.

25. Suggestions: Future of the DDF

The members of District 4's DDF focused mainly on two areas when describing their hopes and plans for the future – continuing and sustaining the work they have already done, and increasing their ability to act independently. All of the DDF members said they would like to continue to follow up on the suggestions they have already made to line ministries, and continue to focus on pushing disability inclusive budgeting. They also want to continue to go further and work in the remote areas of the districts.

All of the members of the DDF who did interviews also expressed a desire to move toward a more independent DDF, beginning of course with building resources. One of the suggestions made was learning to write proposals to source funds for the DDF themselves, and establishing an office space and equipment to work on proposals and reports more efficiently. Another suggested that the members could train in business, management, and networking to improve both their personal lives and be able to pass these skills on to other persons with disabilities. In addition to financial resources, multiple DDF members brought up engaging with additional stakeholders, especially networking with other community organisations. One member gave an example: 'whether those COs [community organisations] are working on [a] WASH[58] project, we should be there. So that we should

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[58] WASH: Water, sanitation and hygiene

see how our friends… persons with disabilities, are accessing water, sanitation.’ The DDF members hope that engaging more stakeholders in disability mainstreaming will help them to sustain the inclusiveness gained by their current project once it is phased out. One DDF member even suggested that the DDF could be its own NGO or district structure one day.

26. V. The DDFs and FEDOMA

Since FEDOMA is beginning to create its five-year organisational plan, I also gathered information from the DDFs on their feelings about the relationship between FEDOMA and the DDFs, as well as their suggestions for what FEDOMA should focus on in the coming year. The following section details the responses from the DDFs.

27. Feelings about FEDOMA

Most of the DDF members interviewed across the four districts expressed positive feelings about the relationship between FEDOMA and their respective DDFs. Many of the interviewees described FEDOMA as an enabler or 'empowerer,' and said that they had previously been too 'shy' or fearful to stand up for themselves, even with advocacy stemming from the DPOs already working in the districts. FEDOMA's role as a liberator, or a 'giver of voice' was repeated over and over during the interviews. A lot of this seems to have stemmed from FEDOMA's role in educating people in the districts about their rights. While the rights were officially conferred by a combination of the United Nations and the national government, FEDOMA is seen by DDF members as the one to bring those rights to the people. Sensitisation and awareness campaigns, enlightenment, and incorporating different people with disabilities to work together as one group were all aspects of FEDOMA's key role brought up by interviewees.

DDF members also described the relationship between the DDFs and FEDOMA in familial terms, with FEDOMA assuming the role of guardian, or more often 'mother.' This role was discussed by DDF members in terms of the way FEDOMA intervenes when the DDFs have a particularly difficult challenge or face internal disputes. Several interviewees also highlighted FEDOMA's role in encouraging the DDFs, offering praise and advice, much like a parent.

FEDOMA as a strong link between the districts and the nation was also emphasised by many interviewees. The DDF members expressed how critical it was that their issues be passed up the ladder, and FEDOMA's role in doing that cements its importance to the majority of DDF members: 'There is a good relationship between FEDOMA and the district here, and also the district and the nation.' One DDF member saw evidence of FEDOMA's advocacy for issues relevant to the district in their televised (and radio-reported) petitions at government meetings. This positive relationship was also expressed in the DDF members' conceptualisation of the DDFs' importance to FEDOMA. One District 2 DDF member described the DDF as the link between FEDOMA and the people, the local conduit for FEDOMA's services and programmes.

FEDOMA's status as a nationally important organisation also helps the DDFs by lending their clout to the smaller groups. FEDOMA was described by some DDF members as the 'power behind the movement.' One DDF member discussed how they introduce themselves as part of FEDOMA, lending legitimacy to the DDF as a representative of the central organisation. Other DDF members also highlighted FEDOMA as the link to funders, which some found to be a positive arrangement, while others found it tiresome, mainly because of delays in communication and resource provision.

Despite their positive inclinations toward FEDOMA as an organisation, many of the DDF interviewees expressed issues and challenges with the practicalities of the relationship between the two. One of the key issues seemed to be a lack of timely communication, brought up by DDF members in all of the sampled districts. Interviewees in multiple districts said that when assistance from FEDOMA comes late, it hurts their programmes, sometimes leading to cancellations. Some interviewees pointed out that the lack of access to the internet in the districts means that communication is slow on both ends, again affecting the timing of DDF programmes. At the same time, many also expressed understanding for the potential reasons behind the delays: '… it is difficult for them to come quickly in times of need, because, as we are crying here for something, others in other districts are also advocating for that.' Many interviewees said that aid from FEDOMA came 'as time goes,' meaning that they are engaging in a waiting game.

On the other hand, some members of District 3's DDF in particular felt that FEDOMA made them promises that never materialised during their communications. One interviewee felt that this rose to the level of lying, and that what the DDF members say does not make a difference to FEDOMA; this same member felt this dishonesty was intentional, and along with some interviewees in other districts, mused that staff spend the funds elsewhere, particularly closer to the Secretariat offices, instead of spreading funding out among the districts. Several members of District 3's DDF felt that they had been left behind or forgotten, and a few used their petition to open a bank account as an example. DDF members said that they were told by the bank that they needed a letter from FEDOMA to open a bank account for the funds the group had raised. According to interviewees, they had been waiting for a response from FEDOMA for months and had not heard anything yet. This same group expressed frustration at not being included in projects or trainings so far. However, members of the District 3 DDF (and others) took the view expressed above, that FEDOMA would support the group when they could.[59]

Others pointed to limited success at the inclusion of persons with disabilities in the implementation of national programmes as an issue. One District 1 interviewee noted that no people with disabilities were included in the fertiliser subsidy programme in their district. FEDOMA's role as connector to the national stage also means that the DDF members place issues with national programmes within the purview of the central organisation. FEDOMA's attempts to advocate at the national stage led one interviewee to note that 'it's also a bit political there.' This same interviewee emphasised the importance of tangible results in determining whether the organisation is having a positive impact, especially when political factors are involved.

Most of the DDFs expressed a desire to be somewhat independent from FEDOMA, though to different degrees in different districts. Within each DDF though, there was a lot of agreement as to how independent they would like to be as a group. Some DDFs hope to become independent organisations, while others want only to be financially independent so that they can run their own programmes on their own schedules. Overall, though, even those interviewees who expressed anger and frustration at some aspects of the DDFs' relationship with FEDOMA are thankful for the knowledge and initiatives FEDOMA has brought; the greatest wish for those who expressed more issues with FEDOMA was to be more included, not less. On the other hand, some of those who have been well-supported and have been able to engage with the work are the ones now looking toward more independence, though still working 'hand-in-hand' with the umbrella organisation.

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[59] It just so happens that FEDOMA included some of the DDF members in a training the same week we were visiting District 3. Those DDF members who attended the training were interviewed after they returned and expressed a more positive view than those who were interviewed earlier and had not gone to the training.

28. Suggestions for the Future of FEDOMA

As part of ongoing efforts to provide opportunities for DDF input into FEDOMA's decision-making, I asked interviewees for their suggestions for areas the organisation should focus on in the future. The responses generally fall into two categories - suggestions that revolve around how FEDOMA can help their DDF, and suggestions for FEDOMA as the umbrella organisation. Again, many of the suggestions were consistent across districts, so the responses are presented in this section in tabular format.

29. Suggestions for FEDOMA to aid the DDFs.

Table 4 presents the suggestions for how FEDOMA might aid the DDFs, and indicates which districts made similar suggestions.

Table 8: Suggestions on how FEDOMA can aid the DDFs.

Suggestion	District 1	District 2	District 3	District 4
Provide scholarships for DDF members to continue their education.	X			
Fund school fees for children with disabilities.	X			
Encourage the DDFs.	X		X	
Communicate more with the DDFs.		X	X	
Communicate honestly with the DDFs, 'not just saying [things] to satisfy them.'			X	

Suggestion	District 1	District 2	District 3	District 4
Provide the DDFs with trainings.	X	X	X	
Engage staff to come out to the districts to partner with the DDFs on district visits.	X			
Focus on longer-term projects.	X	X		X
Focus on projects that can include more districts.				X
Provide DDFs and ADFs with resources for sustainable funding (ex: maize mills, animal rearing, business skills training)	X	X	X	X
Provide links with employment opportunities.	X	X		
Expand provision of resources and logistical support.	X	X		X
Introduce office spaces for DDFs.			X	
Assist with educating Chiefs who are resistant to DDF teachings.	X			

Suggestion	District 1	District 2	District 3	District 4
Train DDFs in proposal writing so they can search for funders themselves.		X		

In Table 4, the issue that all four districts' DDF members raised was sustainable funding. Most of the DDFs expressed a desire to become financially independent, and all of the DDFs had members who presented a DDF-run business as the key to achieving this goal. Three out of four districts also suggested longer-term projects and expanded resource provision, respectively. Based on the interview responses, this is also part of a desire for projects that can be maintained indefinitely, which requires additional funding.

30. Suggestions for FEDOMA as the umbrella organisation.

Table 5 below presents the suggestions made by the DDFs for FEDOMA's organisational development.

Table 9: Suggestions for FEDOMA as the umbrella organisation.

Suggestion	District 1	District 2	District 3	District 4
'Live long' – Ensure that the mother organisation continues to represent local people everywhere.	X	X		X
Prioritise youth projects as a preventative measure for many challenges.				X
Invest in economic empowerment programmes.	X	X	X	X

Suggestion	District 1	District 2	District 3	District 4
Respond to communications and requests for aid in a timely manner.	X		X	
Focus on strategies to spread out to more remote areas.	X	X		
Engage internationally.	X			
Become more financially independent (FEDOMA).	X			
Encourage National Assembly members to visit persons with disabilities in person to see what they face in remote communities.	X			
Work on by-laws that protect persons with disabilities from hate speech and discrimination.	X			
Focus on inclusiveness in national programmes (ex: Farm Input Subsidy programme).		X		
Lobby for better enforcement of existing accessibility statutes.				X

Suggestion	District 1	District 2	District 3	District 4
Lobby government for improvements in the education of persons with disability, (ex. provisions for inclusion in vocational and training centres for persons with disabilities without a school leaving certificate).			X	
Continue to engage in research activities to raise the movement's profile.			X	
Honour promises.			X	

Similar to the focus on sustainable funding discussed above, the DDFs believe that FEDOMA should focus on rolling out economic empowerment programmes. These programmes were presented by interviewees as a way to help persons with disabilities move out of poverty. Many interviewees pointed out that social empowerment can only take people so far, and that the next step is to capacitate growth through economic opportunities.

31.VI. FEDOMA Staff Interview Responses

FEDOMA project staff and management also participated in interviews, and commented on their perceptions of the DDFs and ideas for the DDFs' futures. Many of the responses were similar, so this section will point out some of the major points brought up by the staff members relating to the DDFs. For the purposes of this report, 'staff member' may refer to project staff or managers, to protect identities.

All of the staff members interviewed indicated that the DDFs are important groups for FEDOMA. Some of the DDFs are even personally advised by members of staff, based on their belief in the DDFs as important and capable structures. One staff member commented on the DDF members' affiliations with DPOs, and their understanding of what disability is through experience, as factors that make them good people to advocate for disability rights. Their first-hand knowledge makes them vital to the system in expanding advocacy. Along this same line, another interviewee said that the DDFs are important because most of the implementation of policy is happening at that level, and they are clued in to the district goings-on. The fact that DDFs have been able to hold district duty-bearers to account also makes them important to FEDOMA.

One staff member commented positively on the DDFs' commitment, despite the challenges getting around the districts, which are generally large administrative units. Another described the DDFs as 'best placed' to reach more remote areas. In addition, the DDFs have also helped DPOs not present in districts to find local membership and build district outposts. At the same time, FEDOMA needed a body that could advocate for the rights of all persons with disabilities, not just based around a specific impairment, which is often the case when DPOs are involved. The DDFs provide that body, while maintaining ties to the DPOs.

The DDFs are viewed by the staff as valuable resources themselves, as one interviewee put it: 'We tried to set up a training for four DDFs. And, the way the training was done, was more about experience… Because just among themselves, there is a diversity of approaches they've actually employed. In doing their day-to-day work. That diversity is quite rich in terms of knowledge and experiences.' Staff considered DDF reports important for monitoring efforts, containing data that is used by management to make decisions about what FEDOMA needs to focus on.

When asked about DDF successes, the staff members gave several examples. One said that the evidence of the DDFs' success can be found in their capacity to stand and speak for themselves. They can demand access to development activities in their districts. They are involved in Area Development Committees and are even chairs or leaders of various committees. In that example, the DDF members' engagement is in itself a successful outcome. Another staff member put it this way:

> … the general community has regarded disability with… the medical and the… charity approach. To say persons with disabilities need things to be done for them. But then, if you build the capacity of the DDFs, they get to understand the human rights perspective of disability. To say… we are rights-holders. We can demand for our rights on our own… We can demand for [sic] equality. We can demand for [sic] justice. So, if they are empowered, they have the knowledge, they have the skills – I think they are the best structure at district level.
>
> - Quote from FEDOMA staff interviewee

One staff member listed some of the DDFs' achievements: accessible water points, hospitals, schools, and resource centres. Several of the staff members brought up examples of particularly effective DDFs, especially ones who have achieved much without any resource input from FEDOMA. These examples have produced what the staff consider to be remarkable results, mainly by engaging in working relationships with other civic organisations and finding ways to fund themselves. For example, multiple staff members mentioned a group that was able to raise animals as a source of funding and has used those funds to implement their own district activities. According to the staff interviewees, some of these groups are aided by a particularly vibrant Chair or happen to be comprised of well-educated members.

Staff members also raised issues they have experienced with the DDFs. Several of them brought up the idea that sometimes, DDFs who are given financial support actually become 'lazy,' or 'spoiled,' and won't engage unless there is some financial incentive. Some staff members admitted that when they aren't paid, some DDFs feel like they are being used by

FEDOMA. It was mentioned that some of these DDFs lack the ownership of the 'self-made' DDFs. Multiple interviewees expressed the belief that the DDFs should be self-motivated. Despite this, one of the challenges acknowledged in the interviews was that most of the DDFs were set up without any resources and essentially left to chance. This was intentional in some cases, according to some interviewees, to test the members' passion. A few of the interviewees pointed out that early organisers in the disability rights movement in Malawi managed without funding, and it meant that they could not be cheated or ignored, because they were fuelled by passion. Their early successes are held up as proof that money is not necessary to make change. The development of the grassroots movement has also been an issue with some DDFs, because they don't engage with their ADFs enough, as one staff member pointed out. Since the DDF programme lacked structure at the start, it wasn't necessarily clear that training ADFs to spread the grassroots movement would be part of the job of the DDF, halting what staff members thought would be a 'natural grassroots progression.' They were trained to focus upward, on duty-bearers, 'but then the issue is, how do you hold the hand so the other people, below you, so that they support your work.' Additionally, some DDFs who are doing well reportedly have Chairs with what one interviewee called 'big man syndrome,' and seem to the staff to be more out to build up their own importance than focus on the best interests of the entire movement. This might also contribute to stunting the spread of grassroots advocacy.

Communication between the DDFs and FEDOMA was another area of discussion during the interviews. Some of the staff members felt that reporting was fine, but all of them felt that there was room for improvement. Some of the interviewees pointed out that DDFs who were trained to write reports and have a project with a project coordinator do better at producing reports. Another staff member mentioned that DDFs without any resources from FEDOMA are often late in producing their annual reports. Several staff members talked about some form of phone communication with the DDFs, though many of them also pointed out issues with this form of communication, generally because it lacks structure. Some staff members said that the DDFs that participate in their projects use email, others say that they communicate mainly through phone and post.

Most of the staff members interviewed said that more frequent communication would be an improvement to the current system. Multiple staff members said that increasing regular phone communication, as well as more regular in-person visits would be ideal, although they acknowledged resource constraints would make increasing in-person visits especially difficult. Staff members indicated that they are open to calls from DDF members, and that they tell them if there is no resource to send them when asked. They get feedback from the DDFs and take action when they can, though they are also wary of DDF internal politics. However, a few staff members admitted that at times the Secretariat forgets to get in touch with a DDF, or only gets in touch when they need them. One staff member pointed out that FEDOMA needs to also be reporting to the DDFs, saying 'we could do better.' In these cases, the staff member and others pointed out, FEDOMA is missing out on all of the things the DDF are engaged with, potentially never hearing about 'a great result that is happening in the district,' especially in cases where the focus is on the standardised report required by a donor-funded project.[60] To address gaps in communication, one staff member pointed out that the DDFs would need smartphones to access the internet, which would be too costly for them to do on their own.

In the future, one staff member said they hoped the DDFs would become more 'vibrant,' enabling them to reach more persons in rural communities. Another expressed a lot of hope for the DDFs' success in the future, as long as they are given time, patience, and help to grow. Multiple staff members expressed a hope that all of the DDFs would get a project in their district in the future, for a variety of reasons: so that they feel that they are part of the whole disability movement and gain a sense of engagement with the broader movement, to build their capacity, etc. One staff member hoped that the DDFs become independent and empowered socially and economically. A few of the staff members pointed out the need for the DDFs to have their own spaces to work. This would help them to meet and be more organised, but also host meetings with stakeholders or funders. One staff member summed up most interviewees' thoughts on the future of the DDFs while discussing the expansion of the DDFs into every district as a priority for the FEDOMA Secretariat in the future; saying they should all be:

> … Able to run their advocacy activities without resources from the central office… I know that's not easy. That's quite a vision. And maybe, before that, seeing that each of the DDFs at least is benefiting from one or two projects… because that's the way

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[60] This is one reason that I tried to include as much detail as possible in this report when relaying what the DDFs told me about their activities during the interviews.

DDFs are getting empowered… that's why they reach a point of internalising, understanding their roles much better… the DDFs are the ones that are going to help in the realisation of FEDOMA's vision and dream.

- Quote from FEDOMA staff interviewee

32. VII. Reporting Pilot

Of the 30 interviewees, I asked 29 specifically about the implementation of a mobile phone reporting system between FEDOMA and the DDF[61], and all 30 of the interviewees discussed their opinions on mobile communication between the two.

Firstly, some of the interviewees expressed concerns with mobile communication in general. One participant felt that staff on FEDOMA's end could lie to the DDFs via phone or text, undermining this as a valid way to communicate. This interviewee and a few others stressed the importance of FEDOMA visiting the districts in person more often, to see what they are facing and offer support. For the most part, those who were concerned about this wanted to see a combination of increased mobile communication and in-person visits, though several acknowledged the resource-intensive nature of trips by the staff to the districts. Additionally, despite any expressed concerns about general mobile communication, all 29 of the DDF and FEDOMA staff members asked said that a more formal mobile reporting system would be a welcome thing for the DDFs. The DDF members' reasons for this were: minimising the cost of communication, speeding up communication time, facilitation of in-group communication, and gaining access to the internet and internet-based applications.

Most of the DDFs members interviewed noted that communication between the DDF and FEDOMA is currently inefficient; reporting is slow and can be costly. Most of the DDFs send their reports via email, but without access to internet-enabled devices, they must travel to larger towns to use a vendor to send emails, taking the chance that there will be electricity when they get there. As one District 2 interviewee put it: '... I can travel... maybe from where I am 25 kilometres... to report, and... sometimes you miss the electricity. It means I can stay here, go tomorrow. So it is very hard... communicating to us is about funds.' Other DDFs send their communications via post, which means their reports take a long time to reach their destination, thus slowing down response times. Reporting via phone could help ease this burden.

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[61] One interviewee became upset during the conversation about communication with FEDOMA, so we made the decision to move on from the topic. The interviewee did, however, provide an opinion on mobile communication with FEDOMA during the interview.

Many of the interviewees also mentioned that if phones were provided to multiple or all members of the committee, their ability to communicate with one another would be improved. One District 4 member also pointed out that mobile phones would help them to sustain projects once they are phased out, by easing their communication in the district, especially with emerging stakeholders.

Most of the DDF members and some of the FEDOMA staff members brought up the point that they feel the utility of such a system hinges on the use of smartphones in particular. The DDF members would particularly like to be able to access the internet, in order to send and receive emails, and use platforms such as WhatsApp to communicate with FEDOMA. In particular, DDF members discussed the potential uses of WhatsApp in sending photo and video evidence to FEDOMA about their activities. One interviewee also pointed out that they could use that media when engaging with the community. They gave as an example creating instructional videos for flood evacuation drills. This may prove especially useful for community members with literacy issues.

FEDOMA staff also weighed in on the utility of a mobile reporting system, and again they all concluded that it was a good idea. Several staff members liked the idea that it would give the Secretariat a chance to find out what is going on in the districts more regularly and see whether projects are really having day-to-day impact. Some staff members indicated that the current system encourages under-reporting due to large time-intervals and a focus on donor priorities. Another interviewee pointed out that regular communication would be a responsibility that helps the DDF stay engaged. Keeping FEDOMA engaged as well was another point made by a staff member, helping to make communication more of a 'two-way thing.'

The systematic nature of such a programme also appealed to staff members, who cited confusion with the way calls come in now. This confusion can lead to calls not being returned, or misinformation being passed along. One staff member made the point that the phones would have to be smartphones, allowing communication via messaging apps. This staff member pointed out that the information given in phone calls can often be distorted when passed along, like a game of 'telephone[62].' With a text, the information is re-visitable.

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[62] 'Telephone' is the game also known as 'Chinese Whispers.'

The FEDOMA staff interviewees also all agreed that the DDFs would engage with a mobile reporting system. One interviewee stressed that the DDFs will see this as a way to report their concerns more quickly. Two others used examples of legal cases - FEDOMA frequently hears about a case only after it has been resolved, sometimes unsatisfactorily. A more efficient reporting system might allow them to intervene sooner. One interviewee gave the following example:

> Maybe it's a rape case, and the Chief just says… "Well, I think that you've done wrong, but this is your relative, so you have to pay a goat." Or "you have to pay three chickens," and the case ends there. But if we had that kind of system, it might not be really a real-time system, but something that's workable, where we get cases, even if they are to be handled at… village level.
>
> - Quote from FEDOMA staff interviewee

The same interviewee pointed out that this kind of information could also help FEDOMA gather data on prevalence of human rights violations and develop a database to help further research.

As for concerns about such a system, one staff member brought up the financial burden of such a project as a concern, and a few others indicated that they believed in-person visits would also help to improve communication between the DDFs and FEDOMA. However, they acknowledged, like the DDF members, that these visits could be even more resource-intensive.

33. VIII. Discussion, Recommendations, and Conclusions

34. Mobile Phone Reporting System Pre-Pilot

Based on the interview responses to the idea of a mobile phone reporting pilot, it seems that there is enthusiasm for the idea among the majority of the DDF members surveyed. There are a variety of reasons for this, as well as ideas for how such a programme might run, as described in the section above. In this section, I make some baseline recommendations and suggestions for how such a reporting system might need to be approached to be effective. These suggestions are not exhaustive, and the first suggestion I have is to conduct a review of literature on groups that have already implemented such a programme. Additionally, most of the recommendations below are based on a 'best-case scenario.' I am aware that there are financial implications, difficulty with network connectivity and electricity, and other considerations that could hinder the ability of FEDOMA to implement the ideas presented below. However, they are ideas based on the conversations I had during the completion of this research, and they are offered as ideas for a starting point.

Based on the discussions undertaken during this research, a mobile communication system could greatly improve the connection both between FEDOMA and the DDFs, and within the individual DDFs themselves. Furthermore, it may be a way to open up a channel between DDFs, which is an area where interaction is highly limited at present.

A mobile communication system will require sustainable funding, as well as an established set of guidelines, stated goals, and a designated point person or persons within the FEDOMA offices, to have a chance at being successful. Funding should be secured for DDFs to purchase airtime, both for making and receiving texts/calls, and to enable them to access the Internet, in particular applications for email and platforms such as WhatsApp.

The other large potential financial cost of such a programme would be an up-front outlay to purchase smartphones for use in the programme. Some of the professionals at FEDOMA indicated that they believe that smartphones are available in the districts, already in the possession of the group members. This in fact seems to vary quite a bit across the districts. The other issue with utilising personal phones is that FEDOMA would lose some level of control over possession of the phones. I would recommend that the phones used be purchased by FEDOMA, and be tied to positions on the DDF. This way, when a member leaves their leadership position, the phones will switch hands to the new holder of each position, with messages, email accounts, and files available to the them. This would also mean community members would have a consistent phone number (and if possible, a standardised email address) to use to contact, for example, the DDF Secretary, no matter who is currently holding that position. Using smartphones specifically designated for use by the DDF will also support FEDOMA's new policy of project funding distribution through mobile transfer. These phones could also be pre-programmed with key contacts at the FEDOMA Secretariat and in neighbouring DDFs.

The suggestion of using smartphones stems largely from the potential uses for the phones suggested by DDF interviewees, as described above. Simpler mobile phones, which are likely to become all but obsolete in the near future, also will not provide the same level of usefulness to the DDFs' activities. For example, mobile phones without mobile email capabilities cannot be used for transmission of reports. Many smartphones now have at least simple word processing capabilities, (notes apps), and many can support more advanced word processing applications. With this type of phone, groups without access to computers can generate and submit typed reports quickly and efficiently. The phones could also be used to add visuals to reports, and as one interviewee pointed out in the above section, allow visuals (photographs, video, audio) to be part of the DDFs activities. The DDFs could use these images in their campaigns, with the media, and in developing training materials. This would be the case if, for example, at least one phone was distributed to each DDF. If funding could be secured for multiple (or all) members of a DDF committee to have access to a smartphone, that would expand the usefulness further, allowing DDF members easier communication with one another, and enabling more members of the committee to communicate with FEDOMA directly, instead of relying on a single individual to be available for contacting the head office, or sending reports.

The use of phones with internet access also opens up an opportunity for FEDOMA to distribute materials across DDFs – examples and guides from previously run projects, information on how to replicate initiatives, rallies, and programmes in other districts. This could be done in a variety of ways - from a members-only section of the existing FEDOMA website to simple photos of instructional documents sent through WhatsApp, or copies sent through email. For example, details about the previously run Promoting Access to Justice initiative might be helpful in District 3, where the members raised the issue of child marriages and sexual assaults not being taken seriously by the police. Sharing how that programme was run might help the DDF members to conceptualise a similar one for their district. FEDOMA could also use this system to collect information, developing close to real-time databases for the organisation to refer to, as pointed out in a previous section by one staff member.

On the other hand, the stated original goal of the mobile reporting system was to connect FEDOMA and the DDFs better, allowing FEDOMA to gain insight into what the DDFs are doing, and allowing the DDFs to access support and advice quickly and more regularly. This is still possible to do with the introduction of a simpler mobile check-in through a phone call at a regular interval, without the use of smartphones. This option might be less financially taxing, though the burden on the FEDOMA staff member/s who are in charge of those check-ins might be higher than if the option were presented to check in either via phone call, email, or internet messaging application. This approach would likely allow for the system to be implemented more quickly, but would lack the additional benefits of the DDFs having access to smartphones. Additionally, since the DDF members interviewed almost all indicated that the usefulness of such a system required the use of a smartphone, it might be less well-received.

Either way, the introduction of mobile communication could also be used to facilitate interaction between DDFs. The building of a DDF network is currently a largely untapped resource, especially given the gap in effectiveness between DDFs. Connecting those that have succeeded in finding ways to work around a lack of resource, (or generate their own resources), with struggling or fledgling DDFs could be a way of providing support without a large financial outlay. It will also help to strengthen networks of persons with disabilities and help grassroots activists across the country to feel increasingly connected to and invested in one another. If FEDOMA were to run a mobile reporting system, these reports could also facilitate the network building by creating an opportunity for FEDOMA to give the DDFs insight into what other groups are doing regularly. This might take the form of an update given during check-ins on interesting developments, or if smartphones were used, an email update or newsletter highlighting what different groups had reported.

If a mobile phone reporting system is to be piloted for implementation, however, the governing rules, goals of the programme, amount of airtime to be given, sustainability of the programme, and proper funding should be considered first. If the mobile reporting system was successful, it would hopefully be continued and expanded. This requires both the larger start-up costs to purchase phones at each roll-out, and funding for airtime in between. I believe the largest barrier to the successful implementation of such a programme would be in ensuring it can be properly funded. If a mobile reporting pilot is developed, I also suggest that it be first implemented in the districts who were interviewed for this project, as they have already expressed enthusiasm for the idea and would be likely to engage with it. After that, it would make sense to roll out the system to DDFs that do not have projects, to make them feel invested in, and keep track of what work they are engaging with that might not end up in their year-end report.

35. Future of the DDFs: Researcher Impressions

During the process of conducting this research, I had the chance to speak to FEDOMA staff about potential plans for the future of the DDFs. An upcoming review of the DDFs in the works seems to be one of the positive suggestions for investing in the DDFs going forward. Since the roll-out of the DDFs was relatively unstructured, reviewing what is working and what isn’t, as well as implementing some new policies regarding the governing of the DDFs makes sense. One of the suggestions was the implementation of term-limits for DDF committees, to encourage other members to get involved, and spread the capacity building that comes with leadership roles. This suggestion also included an idea to only cycle out half of the committee members at a time, to ensure some continuity and help the new members to adjust to their roles. I think this idea would be helpful in increasing the knowledge base of DDF members, and may even encourage new members to put themselves forward for positions. Another point of discussion revolved around the fact that there hasn’t been a natural progression of the DDFs training the ADFs, spreading the grassroots base further. This is another area in which FEDOMA having a more concrete set of expectations for the DDFs would be helpful. Since FEDOMA has indicated that it plans to continue to introduce ADFs to the districts, there will be a need to engage with the DDF on what their role in that progression looks like.

Most of the DDF members I spoke to were hesitant to say anything less than complimentary about FEDOMA, but sometimes the difficulties they mentioned suggested that there does need to be a revamping of the way FEDOMA works with the DDFs. The reporting pilot discusses communication to a certain extent, but even if a mobile reporting system isn't implemented, it will be important to address communication gaps between the DDFs and FEDOMA in the future.

As mentioned in the observations section above, the Chair is often the key communicator between the DDF and FEDOMA. While it is good to have a point person for communication, the others on each DDF should feel that they are able to step up to that role when needed, and at least have the appropriate contact information. Additionally, in districts with a busy Chair, when the rest of the group creates a report, they can't send it until they can get it to the Chair. To address this, perhaps the DDFs should be encouraged to set-up a system for covering one another's roles when someone cannot be in attendance.

It is definitely a challenging task for FEDOMA to keep up with the many DDFs, spread so far, and a limit to the financial and personnel resources of the Secretariat. I recommend that going forward, when the office has decided to wait and see what a DDF does on their own, the DDF should be told that. As mentioned above, the expectations of FEDOMA for the DDFs should be made clear, upfront. If the DDFs are unaware that they are being, in a sense, tested, they may be waiting on resources that will not materialise before starting their work, instead of diving in. Gently establishing from the start that FEDOMA has limited resources and would like to see what the DDF can achieve on its own could help to minimise the sense of 'being forgotten about' that some of the interviewees reported.

There should also be a concerted effort to engage with the DDFs regularly, even if they cannot be supported financially. Most of the group members said during interviews that they hold out hope that FEDOMA will help them when they can, but as demonstrated by a few members' descriptions of feeling 'pathetic' or angry, this hope can be fragile. FEDOMA's symbolic role as liberator and 'mother,' is very important to the DDFs, and it can be painful to feel rejected or forgotten by such a critically important mentor. Truthfulness and nurturing may go a long way to gaining the understanding of DDFs that are feeling left out. Additionally, FEDOMA should review the current ways in which it interacts with the DDFs to determine if there is in fact inequality or favouritism. If there is, then the organisation should develop ways to combat this internally. If some DDFs are going to be shepherded by staff members, as reported during the interviews, an effort should be made to provide at least a baseline level of engagement to all of the DDFs. The DDFs already have a sense that staff members ‘play favourites,’ so establishing regular engagement can help to combat this and increase fairness. An effort to support DDFs, especially newer ones, will be necessary in helping them to flourish. Several interviewees discussed personality differences between the DDFs – different DDFs made up of different individuals will naturally require different levels of input. While some DDFs may do very well without guidance, others will need additional help to reach the same level.

Access to phones with internet could be the beginning of the creation of digital resources which can help FEDOMA to tackle some of these issues by spreading knowledge and information-based resources to DDFs which are not currently being financially supported. It could also be a resource for connecting DDFs who are doing well on their own with ones who are struggling, allowing them to mentor one another as well. Again, even if FEDOMA opts not to implement a mobile communication system, encouraging the growth of networks between DDFs may help encourage the DDFs to support one another.

By all accounts, the implementation of DDFs gas been successful as a tool for empowering grassroots advocates at the district level, and their existence in the majority of Malawi’s districts already is an achievement. Both DDF members and the staff that work with them are engaged with and enthusiastic about these structures, and believe they are positive influences in the lives of their membership and their communities. As part of FEDOMA’s five-year plan, a strong effort should be made to prioritise projects and programmes that can build these groups up, as well as enable the formation of Village and Area Disability Forums as well, to better engage with the grassroots areas that the DDFs are trying so hard to reach. If FEDOMA continues to invest in these structures as powerful watchdogs and implementing groups, they have the potential to compound the work already being done. The suggestions and priority areas outlaid by the District Disability Forum members interviewed, included in this report, can be a valuable resource for doing so.