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Women and the Federation of Disability Organizations in Malawi: Experiences of Struggle and Solidarity

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Abstract
Women with disabilities are among the most marginalised members of the Federation of Disability Organizations in Malawi (FEDOMA), facing particular challenges related to sexual and gender-based violence and family/home life; women with disabilities are both abused because of their embodied womanhood *and* denied many socially-valued "traditional women's roles." However, women within Malawi's disability rights movement transgress the boundaries of these social restraints. In this article, I share stories of women disability activists, drawn from an interview and participant observation-based project, co-designed with FEDOMA to explore the experiences of grassroots activists. In telling their stories, the women of FEDOMA detailed processes of empowerment and change, combatting their own and others' experiences of violence, abuse, and exclusion. I discuss the ways in which women activists embodied roles that altered their communities and built activist networks, supporting one another in expressing agency, strength, and solidarity. Their work highlights a politics of care that emphasises the "traditional" *and* the "modern," incorporating individualised human rights discourse into an ethics of community caring and expanding this collective inclusion to the oppressed and marginalised. In focusing on the experiences of Malawi's women disability activists, we gain a more complex understanding of mechanisms of marginalisation, resistance, and empowerment.

Keywords
activism; advocacy; Afro-centric disability studies; disability; feminine politics of care; hybridity; Malawi; women's resistance

1. Introduction

The Federation of Disability Organizations in Malawi (FEDOMA) was founded in 1999 (Chauluka & Chiumya, n.d.) by disability rights activists/advocates to unite Malawi's Disabled Persons' Organisations (DPOs) and form a stronger disability rights movement (DRM) in the country. The organisation foregrounds intersectionality and local relevance in their practices, particularly emphasising women's and youth's issues (FEDOMA, n.d.). FEDOMA engages in extensive grassroots advocacy work, as national legislation is usually implemented at the district level in Malawi. FEDOMA's grassroots work is conducted across Malawi's 28 districts by district disability forums (DDFs) and smaller area disability forums (ADFs), locally based groups consisting of volunteers drawn from constituent DPOs to monitor and advocate for rights implementation at the local level (for more information about FEDOMA's structure and advocacy work see Huque, 2023; Huque & Amos, 2018). Chataika (2017) suggests that most DRMs consider the issues of women with disabilities (the preferred terminology of FEDOMA activists) to be women's movement issues, and women's movements consider these issues for the disability movement. However, FEDOMA leadership and grassroots members maintain that the organisation is committed to addressing the challenges 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. These spaces are a result of the work of women activists, engaging within the organisation across a multitude of scales and spaces, from headquarters to remote grassroots outposts. Their work is specific to the Malawian context and incorporates a hybridisation of cultural understandings and the globalised rhetoric of (individual) human rights.

Malawian women with disabilities face particular challenges related to sexual and gender-based violence and family/home life; women with disabilities are both abused because of their embodied womanhood and denied many socially-valued, "traditional" women's roles. 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. Violent acts committed against women with disabilities in Malawi also take the form of sexual exploitation and abandonment after they become pregnant (Barrett & Marshall, 2017).

Schriempf (2001) notes that women with disabilities are often denied access to the socially expected roles of women, such as marriage and childbearing, but "paradoxically, they are viewed as 'woman enough' to be sexually objectified" (p. 60). 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. 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). However, women with disabilities' practical circumstances often mean that they *do* have experiences of caregiving and supporting themselves and their families. Engagement in caregiving is an important component of the resistance of women with disabilities, and this extends into Malawi's DRM. While the experiences of the Malawian disability activists who participated in this study reflect these forms of social exclusion and violence, these women also transgress the boundaries of social restraints on their perceived "womanhood," or lack thereof.

Societal norms around gendered divisions in Malawian society today reflect a hybridisation of pre-colonial, colonial, and modern-day (neo-colonial) structures. In pre-colonial times, the area now known as "Malawi" contained a variety of different types of societies, including matrilineal societies whose social structures do not fit into a binaristic view of gender roles and power. In many societies, women held prominent roles, engaged in trade and agricultural production, and participated in village politics (Mandala, 1984). Some matrilineal tribes had complex power relationships in which most men would marry into a woman's family, move to her village, and work her family's land, rather than wives moving to their husbands' natal villages (Peters, 2010). Men were heads of households, but through kinship ties with women—fathers, uncles, and brothers, as opposed to husbands (Kachapila, 2006; Segal, 2008).

Christian missionaries and British colonialism introduced Western conceptualisations of patriarchy and gendered divisions to Malawi as a mechanism of social control (Barry & Grady, 2019). Colonisers' focus on economic exploitation and commoditisation attempted to enforce such divisions; labour such as tobacco crop production was open only to men, though they were often in practice aided by their wives. Towards the end of the colonial period, some women engaged in waged labour independently of their husbands (Kachapila, 2006). 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. These examples disrupt tidy Western paradigms of traditional cultures as oppressive and of capitalism as liberating.

Following the end of colonial rule, Dr. Hastings Banda's authoritarian government blurred the lines between an imagined united "Malawian" traditionalism and colonial institutions, drawing on the power of men in matrilineal societies to cement his rule while paying lip service to the role of women in these traditions (Segal, 2008). This included establishing women as keepers of the home and supporters of men—things women had always engaged in, but to which they were now (meant to be) limited (Segal, 2008). This limited women's inclusion in waged formal work in Malawi's evolving capitalist system, enforcing women as solely "domestic providers, doing what they were *said* to have always done" (Segal, 2008, p. 16, emphasis added). However, women did continue to resist within these patriarchal ideals, often becoming de facto heads of households while men sought work away from the family home (Segal, 2008; Sturges, 1998). Today, neo-colonial global capitalism has brought a goal of "economic empowerment" to Malawian women through NGO-led programmes intended to develop women's waged labour skills. If viewed ahistorically, a focus on this more recent turn toward "empowerment" misses that women often already have these skills, but lack the capital to invest in them; it also conceals the resistance of women through their acts of care and provision for kinship groups. Within low-resource settings, resistance operates as a key means of survival. Mkandawire-Valhmu et al. (2013) reflect that representing African women as victims of their countries' cultural structures without agency reflects "Eurocentric and hegemonic discourse" (p. 333). They highlight that this viewpoint ignores African women's history of organising and responding to "severe hardships…often while occupying spaces on the margins of society" (Mkandawire-Valhmu et al.,

2013, p. 334). Mkandawire-Valhmu et al.'s (2013) own study findings "hardly suggest that [Malawian] women consider themselves victims…women [were] actively involved in shaping and determining their own destiny" (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.

The post/neo-colonial work of NGOs promoting economic empowerment of women as a means to reduce minority-world perceptions of oppression in colonially exploited countries such as Malawi has also contributed to a renewed and more visible resistance to prescribed gender roles. "Women speak of *gender* as something we can be made aware of and understand. They point out how 'doing *gender*' makes them less vulnerable and more independent" (Adolfsson & Madsen, 2020, p. 64). Adolfsson and Madsen (2020) found that in Malawi, gender was a new concept, something one "does," altering the division of labour from more recent history: "Daily practices that used to be only for women/only for men have, with the onset of *gender*, become shared work that both men and women can do" (p. 63). Thus, while there remains a gendered division in Malawi, the "practice" of gender can be one that reduces gendered thinking about the practicalities of daily life. At the same time, the concept of gender highlights a men/women binary that does not consider non-binary and gender non-conforming individuals in its theoretical approaches. It remains to be seen what the practical implications of gender as an inclusive practice might bring about for non-binary and gender non-conforming people in Malawi.

Day (2008) 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). 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 that can constitute resistance to oppression. This means that even in "traditional" spaces and roles, women can exercise agency and engage in resistance against their subjugation. 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 principles 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" (Asaki & Hayes, 2011, p. 248), opening up new spaces for resistance that transgressed private home–public boundaries.

Reflecting and drawing on feminist studies calls for more contextually-based, majority-world-focused work. UK-and-USA-led social models of disability, widely held to be the standard for disability movements and studies, have recently been challenged as limited. Place-specific (Haang'andu, 2020; Hamel & Falola, 2021) and new materialist (Feely, 2016) approaches to disability studies have emerged, challenging the universal application of minority-world disability paradigms (though calls for this are not new within majority-world social movements). Price and Goyal (2016) highlight the "pressure to generalize, universalize, and exclude" (p. 304) in disability studies. Haang'andu (2020) suggests "Afro-centric" disability studies as a way to move beyond Euro-and-USA-centric approaches to disability. Araneda-Urrutia and Infante's (2020) work goes a step further and suggests we need a "de-modelling" in disability studies, focusing on local specificity in activism, drawing instead on assemblage theories to connect aspects of divergent DRMs. A de-modelling approach enables considerations of space, place, time, and intersectionality within a particular context. This can help us to engage more deeply with and learn from the specifics of individual DRMs, highlighting ways of working within differently resourced and situated contexts. These calls echo feminist scholars' work on diversifying feminist approaches to research. Day (2008) connects the problem with Western feminist interpretations of African spaces not just to a disregard for intersectionality but also to a misunderstanding of culture and society through the imposition of a Western perspective, similar to recent critiques of mainstream disability studies. 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). Using an Afro-, Malawi-, and individual organisation-centric approach that resists the draw to generalise enables focus on specificity, alternative forms of resistance, and the intersectional forces individual groups work with/against. In calling for "Africanizing disability," Hamel and Falola (2021) note that "an African approach…combines the insights of disability studies with the actual contexts of African experiences and acknowledges both how Africa creates problems for traditional disability studies approaches, even as it offers exciting new potentialities" (pp. 1–2). In this article, I draw on these calls for place-specific models of disability and contextually aware feminist work, focusing specifically on the women of Malawi's DRM and the circumstances they experience and use to build their movement. At the same time, it is necessary to keep in mind the complex history of colonialism, racism, exploitation, and poverty discussed in this introduction, as well as the shifting and nuanced view of "gender" as an introduced concept in Malawi. To do this, I integrate a critical feminist approach to exploring the work of FEDOMA's women activists in a few key ways: (a) through a focus on the agency of women with disabilities, rather than treating the latter as merely oppressed "subjects," and (b) through use of a situated approach,

focusing on activists' life experiences. This approach uses a de-modelling disability studies lens to imagine resistance as specific and situated, within particular spaces and places—in this case, focusing on the ways of working of Malawian DRM activists, within their contexts.

2. Methods

The stories of women disability activists in this article are drawn from a larger interview and participant observation-based project, co-designed with FEDOMA, to explore the experiences of grassroots advocates. FEDOMA staff, managers, and grassroots members helped conceptualise, plan, and implement the study, which received ethical approval from both the University of St Andrews and the Malawi government's National Committee on Research in the Social Sciences and Humanities.

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.

"Full" participatory co-researching in this case proved to be beyond time, funding, and other legal and resource constraints. Van der Meulen (2011) highlights that the "ideology" of participatory research is more often a focal point of discussions on its use than actual methodology. A participatory design process is a practical endeavour, which acknowledges that we cannot always achieve "full" participation. Designing a project collaboratively can help incorporate a participatory ethos into different aspects of "doing" research and help translate the ideal into the practical. In this case, the participatory design period enabled me to learn about the movement and its structures, and collaboratively develop research questions and methods in line with the stated needs and wants of FEDOMA's membership.

I conducted fieldwork from November 2018 to January 2019, after the participatory project design period (September–November 2017). During the project design, FEDOMA representatives and I worked together to determine which grassroots groups I would visit during data collection; we chose one district from each of Malawi's three regions plus a fourth from an urban centre (identified in this article as D1, D2, D3, D4). Due to challenges in communication infrastructure, I arranged to meet grassroots activists in each district after my arrival, and recruited participants from within FEDOMA's grassroots membership in that district, aided by key contacts, especially DDF/ADF board members. I undertook participant observation within FEDOMA's headquarters and grassroots outposts. I interviewed 22 FEDOMA grassroots members: 20 people with disabilities, two mothers of children with disabilities, and eight FEDOMA headquarters staff/managers, three of whom also had disabilities. Sixteen interviewees were women, 14 men. Gender identity was self-reported by participants during the interviews using their own words; none of the participants identified as gender non-conforming, non-binary, or transgender. Additionally, all of the romantic relationships/partnerships discussed were heterosexual-passing. This may be because LGBTQ+ identities and gender non-conformity are in many ways stigmatised in Malawi, and I was a relative stranger to the people I interviewed, despite spending time with the participants during the ethnographic portions of the project (for an in-depth discussion of the forms of repression experienced by LGBTQ+ and gender non-conforming people in Malawi, its connection to colonialism and Christian missionaries, as well as the dangers of focusing only on repression without considering the work being done in favour of LGBTQ+ rights in Malawi see Currier, 2019). Interviewees chose whether a pseudonym or their real name would be used in outputs; in this article, names with an asterisk (*) after their initial use are pseudonyms. Furthermore, person-first language (e.g., persons with disabilities), is the preferred terminology of the Malawian activists who helped develop and participated in the project reported in this article; as such, this is the terminology I use in works based on this project, unless directly quoting from another source.

Interviews were semi-structured and in-depth, focusing on the life stories of each participant, including their life, advocacy work, key issues of focus, hopes for the future, and their experiences and voices within FEDOMA and the DRM. Participants were asked to introduce themselves however they saw fit at the start of the interviews, then were asked some broad additional background questions at the end of the interview, including information about their families, hobbies, religions, disabilities, and other groups and activities they participate in. The interview guide did not contain specific questions about gender and activism, but gender, and particularly the experiences of women, emerged as a key theme from the interview analysis as part of the interviewees' stories about their advocacy work.

Ethical concerns for this study included the usefulness of the research to the disability activists who contributed their time and knowledge, and accessibility. The participatory research design process was an attempt to ensure that the study reflected FEDOMA and its members' priorities. Interviews were conducted in English, Chichewa, and/or sign language, depending on the needs of the participant. I travelled to conduct interviews with J. E., who acted as a local guide and English–Chichewa translator; we contracted a sign language interpreter of the interviewee's choice for interviews as required. Interviews were conducted in a variety of places based on the convenience of the interviewee—including group meeting spaces, work sites, and private homes. Interviews were recorded, and I transcribed the

English language version of the interviews (which were translated in situ). We were able to provide transport (or funds for transport) in many cases. We adjusted our approach throughout data collection to ensure accessibility and safety as far as possible. Not only did engaging with each individual personally regarding their accessibility needs contribute to conducting the research as ethically as possible, but it also provided us opportunities to gain rich insight into participants' daily lives and engage with them in their work, family, and activist activities.

Two rounds of initial coding in NVivo were conducted on the interview transcripts and participant observation fieldnotes, resulting in a set of 50 codes covering a range of thematic material discussed in interviews. An extensive third round of coding was conducted by hand diagrammatically, connecting and identifying synergies and conflicts between the themes. I completed data collection prior to the Covid-19 pandemic, with the intention that I would return to validate the study results with the participants. However, lockdowns forced the cancellation of the return visit to Malawi, which limited the participatory nature of the study (the first output from this study was a report written for FEDOMA to use in developing their five-year plan and share amongst grassroots groups; I had not received feedback on the contents of this report at the time of writing this article).

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 & Muhit, 2003, p. 105). Part of my approach to mitigating my researcher's voice overshadowing that of 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 and be led by individual activists' (and the movement's) stories and language.

One of the key themes that emerged from the data was that of the role of women's advocacy work, the complexities of which I explore (in part) in this article. As mentioned above, specific questions about gender roles in advocacy were not initially asked during interviews, but if participants raised this topic themselves, they were encouraged to discuss them and elaborate. Of critical importance was the tension between women's performance of valued social roles in conjunction with their advocacy roles, and the stigma and expectations of society that they should not be "able" to successfully perform these roles. Key thematic intersections included the particular challenges faced by women with disabilities, women as agents of empowerment processes, familial roles—particularly mothering in grassroots activism—and intergenerational solidarity.

3. Results

Many of the experiences of women disability activists within FEDOMA focused on both the struggles and solidarity of women. Both men and women highlighted similar challenges faced by women with disabilities to those discussed in the previously highlighted research, including sexual violence, exclusion, and abandonment by partners. The perception of women with disabilities as having lower status was particularly emphasised in issues around relationships. Several women told stories of abandonment by lovers, boyfriends, or husbands, especially after becoming pregnant:

> 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)

Men will engage in sexual relationships with women with disabilities but refuse to "legitimise" relationships through marriage—leaving women with disabilities to care for their children on their own—despite the perception that they are not "capable" of family care-work.

Emma* (D2) was abandoned by two men by the time of her interview. She had hope, though, of forming a nuclear family, saying she would like to form a relationship with a man with a disability:

> I got married in those days, and my…husband denied me because of my nature….Some people, they were saying: "No—she will bring a big problem on your life. Maybe she can fall on the fire, or in 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….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's story highlights the trauma of abandonment by her partners. Her ex-husband divorced her as a result of societal pressure. Emma believed that marriage to a man who shared her disability identity could be a solution. However, men with disabilities in Malawi often do not face the same level of difficulty in finding a non-disabled partner as women (Addlakha et al., 2017; 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.

Beyond issues of relationships and abandonment, pregnancy and motherhood can compound financial struggles for women with disabilities. Malawian women with disabilities struggle to gain waged employment, and unmarried mothers may be seen as undesirable employees. Many of the women I spoke to discussed economic issues as a major constraint within their lives. 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. Doreen (D3) was fired from her job as a

waitress due to her deafness, despite having successfully performed the required tasks. These stories demonstrate how women with disabilities were excluded from socially valued roles—however, these same women engaged in advocacy work that challenged this exclusion.

Emma, Doreen, Grace, Ester, and Lyness were all grassroots members of FEDOMA, as were the other women whose stories are drawn upon in this article. Many of these women held leadership positions within their local DDF chapters or their communities as activists. Advocacy work gave FEDOMA women a platform to centre themselves and their own embodied experiences. Women described their "advocate" identities as empowering, counteracting negative and dehumanising life experiences and stigma.

Saba* (D1) highlighted FEDOMA's focus on the 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. FEDOMA's role in caring for the needs of persons with disabilities was portrayed by its grassroots membership as explicitly "womanly" and "motherly." This characterisation highlights a "feminisation" of the activism of a national advocacy organisation, crossing public—private boundaries and emphasising kindness, caring, and nurturing for building a successful movement. FEDOMA as a high-profile, public-facing representative of its membership, is anthropomorphised as a mother.

This emphasis on nurturing within the organisation was also found in the ways women expressed solidarity with one another. Relationship building was discussed seriously within FEDOMA's movement spaces as a way to expand empowerment and provide opportunities for women with disabilities. Women shared knowledge with other women as they attempted to grow the movement. Emma (D2) described the change she witnessed as her DDF's work took hold amongst women in the community:

> There has been a change. Because now we are seeing women standing and raise up their voices. Because we have advocated for them.

They created revolutionary spaces of mutual support in which women with disabilities educated one another on both the traditional roles they could "take back" *and* the new ones they created for themselves.

Mallory* D1's DDF chair, spoke about the impact of a mentor who had founded her DPO:

> She was a founder [of a DPO in D1]….She got transferred to MACOHA [Malawi Council for the Handicapped], where she was going to work, and when she was going…she told me: "I'm leaving to go to MACOHA—Are you interested [in taking] 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, a woman who was herself moving up through the ranks of disability organisations in taking a job at MACOHA, handpicked her district-level successor. She ensured that the work she had begun in the district continued, in this case led by another woman with whom she worked. Now, Mallory is a leader within that DPO, chair of her DDF, and a sought-after expert representative for the disability community in Malawi.

In discussing her role as a leader, however, Mallory initially distanced these achievements from womanhood:

> 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.

At the same time, Mallory "achieved" many of the traditional ideals of womanhood—she is married, a mother, and a teacher, an "acceptable" (and high-status) job for women. By engaging in these roles, she embodied women's success and resistance. Additionally, Mallory's approach to disability advocacy also emphasised positive traits associated with Malawian women. For example, in the quote above, Mallory presented her home as a place for persons with disabilities to seek counsel. In this way, Mallory extended her public advocacy work into her home—the space traditionally associated with women and their care work. Mallory extended the spaces of resistance and community care in her context, challenging public/private dichotomies. Using the home as an extension of their activist space was something only raised by women in interviews. Men focused on economic achievements outside of the house, as a public demonstration of the "ability" of people with disabilities, as well as emphasising their work within the DDF/ADFs out in the community, as did women. When men spoke of their home life, they were more likely to highlight challenges and/or feelings of shame:

> As a man of family…I do nothing. Everything, I depend on someone to support me. Because of my disability, I am failing to support my family. (Leo*, D1)

For some men, home as representative of a lack of opportunity to engage in expected waged labour roles, may have contributed to their being less likely to conceive of

the home as a space of resistance and power in the same way some of the women did.

Despite emphasising her "hardworking spirit," Mallory discussed women's roles, which she believes make women well-suited to advocacy work:

> 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 a visible disability—he claimed that her mother must have slept with an English man, a common myth. This experience affected Mallory to the extent that it informed her priorities as an adult activist. Mallory de-emphasised her womanhood when discussing her position as a leader and public figure. However, she emphasised womanhood when discussing ideas like care work and its impact on persons with disabilities. Mallory's story demonstrates the personal nature of intersecting societal roles in influencing women activists, even those who do not intentionally perform intersectionality (i.e., not intentionally focusing on their own womanhood), in their activist storytelling.

Many participants raised the idea of belief in mothers' "[caregiving] spirit," introduced by Mallory above. 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 consider myself. But I…see others' problems. So that they can be taken into consideration.

Saba pointed to women as selfless caregivers, using it to describe her own motivations for advocacy work. Connecting with and helping others was considered by many advocates to be "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 defied said constraints, engaged in everyday resistance, and transformed the traditional into the radical. In Saba's 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 saw their advocacy work as a responsibility. They believed in their (women's) responsibility to care for others and spread empowerment as an extension of that. Women advocates applied notions of familial caregiv-ing to the DRM, substituting and/or extending their "mothering" into movement spaces. For some women, their focus was specifically on empowering 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 spoke with the authority of embodied experience and, in their speech and actions, they enhanced not only other women's sense of empowerment but also their own.

At the same time, women extended their participation in developing the movement through economic activities and applying women's work to the practicalities of creating better spaces. Elena* (D2) pointed out that the women of her DDF had been the ones to raise the funds for their building to have electricity through sewing and selling handbags:

> We do the work, and we deposit the money, and we use that same money to structure this building….So that's why you see the electricity facility there. Because of that money.

The building they support, a rare luxury for these grass-roots groups, acts as a stable meeting point, enabling them to come together as a group and strengthen their work and relationships more easily.

Women disability activists also used community outreach to connect with women outside of the movement, particularly mothers of children with disabilities who were not already part of the DRM. For example, Ester (D3) connected with mothers she met through her job as a health worker. As a woman health worker and disability activist, Ester had a measure of social capital with women seeking that knowledge:

> I do go to the community, and chat with the pregnant women and give them guidance….On the date of delivery, if the child was born, with some difficulties…I went quite often to help, to take care of the children.

Ester's job allowed her access to women in the community and enabled her to care for children with disabilities (as well as their mothers) from birth.

Rhodah (D3) also took her experiences and learning within FEDOMA and used them to forge new relationships with others outside the movement, providing services and information, and inviting them in:

> In a local area, I brought together the teenagers. So that I can mentor them. About the sexual reproductive health….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.

Women with disabilities like Rhodah, who embraced their empowered role as rights advocates, offered themselves as role models. Rhodah took it upon herself to teach young women about sexuality. She prepared them for the traditional women's roles of wife and mother. In these talks, Rhodah incorporated her own learning from participation in the DRM, emphasising women's rights against abuse:

> They teach us that everyone has his or her own rights...we must not get married because someone has a passionate for us...our rights are...protected. Honoured.

She meaningfully engaged her audience of younger women growing up in an increasingly hybridised, neo-colonial world—where tradition, human rights, and the intermingling of the two present a complex picture. Rhodah intends to pursue her work beyond local disability organising, with plans to run for political office and write a book about women with disabilities.

4. Discussion and Conclusions

In focusing on the experiences of women with disabilities in Malawi, we can gain a more complex understanding of mechanisms of marginalisation, resistance, and empowerment. Following calls to "de-model" (Araneda-Urrutia & Infante, 2020), "Africanize" (Hamel & Falola, 2021), and create "Afro-centric" (Haang'andu, 2020) disability studies, exploring movements within specific spaces, places, and times, with an intersectional lens, can help broaden the inclusivity and knowledge-base for disability organising worldwide. It also enables us to consider key social structures beyond the individual that contribute to the movement—in this case the familial, kinship-style networks that underpin organising for disability rights in Malawi, and the ways in which majority-world activists in this case both utilise and subvert traditional values, developing approaches to organising that reflect hybrid worlds with complex (neo)colonial histories.

Women with disabilities in Malawi experience abuse because of their embodied womanhood, but at the same time are perceived as "incapable" of engaging in traditional, valued social roles. As Tefera et al. (2018) point out, "society does not identify women with disabilities as capable of playing a valuable role....Adopting valued social roles...promotes self-esteem and confidence....Ultimately, participation in valued social roles can lead to the adoption of other valued social roles" (p. 82). In this article, I have explored examples of the way this plays out within Malawi's DRM. As part of their desire for inclusion, many Malawian disability rights advocates sought to engage in traditional women's roles

and emphasised their ability as caregivers in their disability work. At the same time, their engagement in these roles led to them undertaking other types of social roles, including those that reflect the historical roles and resistance of women to limitations on their participation in society. Examples of this include taking on roles as chairs and vice chairs of DDFs and other community groups, Rhodah's plans to run for office and write a book, and using economic successes to improve movement infrastructure. At the same time, this engagement contributes to altering what it means to be a Malawian woman, by including women with disabilities in the definitional spaces of womanhood, and catalysing processes of empowerment that extend beyond the achievement of pivotal social roles of wife and mother.

Seeking valued social roles can be part of what motivates women with disabilities to engage with the DRM. Tefera et al. (2018) note that these are not the desired roles of all women with disabilities, but that these traditional roles are ones from which they are socially excluded if they do desire them, ultimately constraining their agency and self-determination. It is important to note that the participation of women with disabilities in these neo-traditional schemas may serve to reproduce gender inequalities. By engaging in valued social roles, there is a risk that the divisions between genders remain unchallenged. However, this also requires consideration of the intersectionality and practices of women with disabilities. Schriempf (2001) argues for "the recognition that women with disabilities...embody a complex of interwoven situations" (p. 67). Often having to fend for themselves, women with disabilities in Malawi seek to engage in waged labour work, blurring divisive gendered lines in practice. Additionally, as Adolfsson and Madsen (2020) found, the minority-world language of "gender," as a newer concept in Malawi's history, and tied to "women's empowerment" through NGO investment, may mean moving towards new ways of sharing different types of roles and responsibilities. In this, we see the term "gender" as impacted and moulded by Malawi's current and historical social structures into something with a new, more complex, and context-specific definition.

Women in Malawi have always engaged in roles that transgress minority-world conceptualisations of gender divisions and patriarchy, whether in central positions and key kinship roles in pre-colonial societies, or as a means of survival during colonialism, authoritarianism, and in the present day. While none of the activists interviewed for this study mentioned engagement with other emancipatory movements, including women's movements, their experiences, activism, and lives are contributing to a shift in Malawian womanhood, challenging women with disabilities' exclusion from this imaginary. By engaging in highly visible activist roles in the community, they also challenge the notion of women's domain as ending at the boundaries of the home, while simultaneously creating home and care work as spaces of activism. By constituting the personal and traditional as political, women

contributed to longer-term social change, notwithstanding the tensions and contradictions that remain whilst doing so.

Across the stories of the women in this article, aspects of care became profound spaces of empowerment and engagement in social movements. The conceptualisation of FEDOMA as "mother" underscored the politicisation of home-based roles and the utilisation of home-spaces as sites of resistance and activism, and the transformation of this politicisation into a "feminine" politics of care that emphasises the "traditional" (community, caring, nurturing) and the "modern" (individual rights, women's empowerment, hybridity). In this way, the "feminised" public performances of the DRM counter mainstream Malawian political discourse's association of women with an apolitical view of the "traditional." Caring is connected to a "modern" Malawi, which incorporates individualised human rights into an ethics of community caring, expanding collective inclusion to the oppressed and marginalised. In particular, economic engagement and security, and related autonomy, are emphasised because they enable women to care for themselves and their families, reinvesting their economic successes into their communities—which in this case extend to activist networks and the kinship communities created in these networks.

The relationships between women within the organisation, combined with FEDOMA's personification as woman, emphasised the importance of nurturing and caregiving for empowerment within the DRM. However, this is also a heavy burden to place on the most marginalised people within a society, complicating the notion of caring for others as empowering. FEDOMA's women have developed collective structures as part of their 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 subgroups 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 activists to seek and provide collective support.

While this study contains many valuable stories, it focused on members of four of FEDOMA's district groups, and thus referenced only a fraction of the experiences of its membership and Malawi's DRM more broadly. In this article, I have not been able to engage with the full complexity of focusing on women's traditional roles in a positive way and the potential for reproduction of patriarchy; this study also lacks the experiences of LGBTQ+, non-binary, and gender non-conforming people, and the impacts of embracing societally prescribed gendered roles on related social movements. Finally, this study was conducted prior to the Covid-19 pandemic, which has changed so much about our world and about the spaces and circumstances in which disability activists,

including those in Malawi, engage in their work, meaning that there may have been more recent changes to FEDOMA and its grassroots groups' systems of working and networks.

The disability rights work conducted by FEDOMA, and in particular the women activists within it, highlights the need for evolving approaches to disability activism and studies. Drawing on calls to Africanize, de-model, and contextualise disability studies, this work focused on the specific circumstances and forms of resistance engaged in by women activists in Malawi's DRM. Place-specific, localised, and de-modelled approaches can take us beyond hegemonic, Euro-and-USA-centric ways of knowing, exploring, and engaging with disability. This work is already being undertaken in the majority world, and minority world activists and scholars alike can learn from contextual, hybridised, and inclusive ways of creating and maintaining social movements.

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Conflict of Interests

The author declares no conflict of interests.

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