



Disability policy and practice in Malawian employment and education

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Abstract

Malawi is a landlocked country in Southern Africa with a population of 17.5 million. It has taken great strides in addressing disability inequality in recent years. Despite this, Malawian trade unions, educators and disability activists report wide-reaching disability discrimination at an infrastructural and individual level. Situated at the intersections between disability studies and medical sociology, alongside work of postcolonial and Global South scholars, this article highlights how neo-colonial and Anglocentric dominant framings of disability do not necessarily fit the Malawian workforce, as they ignore cultural and structural differences in the causes and maintenance of ill health and disability. Building on interviews with workers with disabilities, trade unionists, educators, government representatives and disability activists in Malawi's two biggest cities, the article emphasises the need to address specific local contexts; while policy asserts a model of social oppression, in practice, disability inclusion requires recognition of the social determinants of disability and inequality, and the economic, political and cultural context within which disability resides. Sharing co-designed approaches to engaging with disability definitions, stigma, language,

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infrastructure and resources, this article highlights the necessity of grounding disability and medical sociological theory in localised framings and lived experiences.

KEYWORDS

disability, inclusion, Malawi, policy, postcolonial, trade unions

INTRODUCTION

Malawi, a landlocked country in Southern Africa with a population of 17.5 million (National Statistical Office, 2019), has taken great strides in addressing disability inequality in recent years. This is seen in the Malawi Government's adoption of international policies and legal frameworks focussing on non-discriminatory practices and the rights of people with disabilities¹ (see [Appendix](#)). Despite policy work at the governmental level, however, Malawian trade unions, educators and disability activists report ongoing, wide-reaching disability discrimination, on both an infrastructural and individual level.

Building on interviews with workers with disabilities, trade unionists, educators, government representatives and disability activists in Malawi's two biggest cities, this article emphasises the need for a consideration of specific economic, cultural and political contexts; not only do definitions of disability differ between contexts but so do the available frameworks to address discrimination. Situated at the intersections between disability studies and medical sociology, and informed by the work of postcolonial, African and disability studies scholars and activists (Barker & Murray, 2010; Meekosha, 2010; Mohanty, 2003; Sherry, 2010), this article highlights how the neo-colonial and Anglocentric nature of much medical sociology and disability studies, and the ways in which these fields explain disability, can be reframed to better suit the issues of the Malawian workforce, and incorporate cultural and structural differences in the causes and maintenance of ill health and disability.

How do trade unionists, educators and activists work for disability inclusion in a way that considers social barriers without dismissing how impairment shapes people's lives in specific contexts or the social determinants of disability and ill health? The interviews, carried out in Lilongwe and Blantyre, demonstrate a distinct gap between policy and practice in disability inclusion. While policy asserts a model of social oppression, in practice, disability inclusion requires recognition of the social determinants of disability and inequality in Malawi, including the implications of disability-related stigma.

Data presented joins other ventures in attempting to extend beyond the dominant Global North remit of disciplinary theorising by co-designing, co-researching and co-writing with an international team of mixed expertise. It builds on a co-designed project attempting to work in solidarity with trade unions, disability activists and researchers in a more decolonial way. To address the gap between policy and practice, and between the social model of disability and medical sociological models of ill health, we gain much by seeing how these intertwine in lived experiences and the environment through a localised framing of disability inclusion.

BACKGROUND

Colonial bias in dominant frameworks

Despite disability being a lived experience and political issue across the globe, academic theorising has been dominated within disability studies and medical sociology by the Global North.² Though the authorship team recognises the significant contributions of medical sociology and disability studies, in this article, we acknowledge the limited remit of such dominant theories and frameworks, mainly in English, which may not work in all economic, cultural and social settings. Equally, the UK-based authors acknowledge the limits of their own work, which perpetuates and sustains these norms. Ghai (2017) has argued that it is essential to contextualise disability and ill health in their local context as a social, cultural and political phenomenon. Scholarship regarding disability must thus reflect on whether people with disabilities in 'Southern' countries share the same issues and challenges, and significantly, if colonialism has shaped those issues.

Global North disability studies have been criticised for taking a universalising approach, at the risk of marginalising the experiences of those living in the Global South (Meekosha, 2011). The devastating harm of colonialism goes unacknowledged, while writers and activists from Southern countries rarely appear in Northern works (Meekosha, 2011). According to Meekosha (2011), contemporary disability studies in this way constitute a form of 'scholarly colonialism' and need to be re-thought, taking account of Southern theories and practices.³

Medical sociological research has similarly been limited to a Global North or Anglocentric outlook, as the analyses of medical sociologies have broadly been confined to Western democracies' health and welfare systems (Bradby, 2016). There has been a disciplinary slowness to engage with health and illness beyond the Global North, to places where medicine is configured and regulated in diverse ways, with disciplines such as anthropology, development studies and international public health doing such work.

Scholars and activists have challenged the colonial/Global North paradigm in frameworks around disability, medicine and health, with Global South voices gaining ground (Connell, 2011; Ghai, 2017; Grech, 2015; Meekosha, 2011; Opini, 2016) and a growing African disability rights scholarship (Chataika et al., 2015; Mji et al., 2011). The *African Journal of Disability* was launched in 2012, and the *African Disability Rights Yearbook* in 2013, while African scholars have proposed local understandings of disability that include indigenous knowledge in the design and implementation of research (Berghs, 2017; Chataika et al., 2015; Owusu-Ansah & Mji, 2013). Scholars have theorised disability in and from an African context (Eide & Ingstad, 2013; Leshota & Sefotho, 2020; McKenzie et al., 2014; Ojok & Musenze, 2019; Owusu-Ansah & Mji, 2013; Shakespeare et al., 2019), with calls for genuine and committed collaboration between the North and South, making use of indigenous knowledge and ensuring mutual learning from each other (Chataika, 2012).

Our collaborative qualitative research project draws on the expertise of an international authorship and research team from mixed disciplinary backgrounds, including trade unionism, the humanities, education, disability studies, medical sociology, management and geography from both the Global South and Global North. The purpose of the paper is twofold: to address the opportunity for disability studies and medical sociology to explore illness and disability in the Global South outside of Global North-centric dominance by drawing on the lived experiences of those with disability in Malawi; and to explore working through research co-design and practical collaboration between international trade unionists and researchers.

Malawi disability legislation and policy

According to Malawi's 2018 census, 11.6% of the population (aged 5 or older) has a disability; approximately 54% of people with disabilities in Malawi are women (Chikasamba, *n.d.*). However, it is difficult to determine precise figures (Chikasamba, *n.d.*). Historically, people with disabilities in Malawi have faced stigmatisation, abuse and violence (Chilemba, 2014), especially those with albinism (Amnesty International, 2018). To address such discrimination, Malawi has produced national legislation and policies advocating for the education, employment and well-being of people with disabilities. Many African countries took the UN Convention on the Rights of Persons with Disabilities (UNCRPD) (2006) as the main instrument for advancing the human rights of people with disabilities. The Convention hailed as a landmark in this struggle (Dziva et al., 2018). Following the UNCRPD, Malawi replaced its 1971 Handicapped Persons Act with updated legislation acknowledging the role of the environment in disabling citizens. The Malawi Disability Act 2012 defines disability as a 'long-term physical, mental, intellectual or sensory impairment, which in interaction with various barriers may hinder the full and effective participation of a person on an equal basis with other persons' (Malawi Government, 2012, p. 3), and makes provisions for implementation of this law.

Work in Malawi

Globally, disability is (re)produced, particularly in relation to the exclusion of people with disabilities from formal employment in the workplace. Research suggests that people with long-term conditions are forced, due to ableist normative workplaces, to maintain business as usual, that is, not disrupting work (Pinder, 1995; Sang et al., 2016, 2021). In many countries, the labour market for people with disabilities is largely informal, with many self-employed workers (Mitra, 2006); people with disabilities are more likely to be employed in unskilled occupations and less likely to hold management positions (Schriner, 2001). This holds true for Malawi.

In 2020, the labour participation rate among the population aged 15–65 in Malawi amounted to around 77.79%, equating to 3.5 million people in the workforce, with the vast majority being subsistence farmers in rural areas. Most work in Malawi is undertaken in the 'informal sector' (9 out of 10 workers are in the informal economy [National Statistical Office, 2014]), which includes small unlicensed businesses, making it difficult to estimate national unemployment and under-employment rates. Informal employment in Malawi is understood as small-scale micro enterprises drawing on household labour, while formal employment typically refers to a job with a formalised arrangement with an employer, including payroll and payment of taxes (Baulch et al., 2019). As will be noted in the analysis, education and employment are linked: the lack of access to inclusive formal education in Malawi is connected to an underrepresentation of people with disabilities in the formalised workforce, due to limited access to schooling and training.

To understand the employment context in Malawi and the initiatives regarding disability, we recognise the long-term effects of colonialism in the country. A diverse country containing numerous languages, ethnicities, regions and cultures since the tenth century, Malawi was colonised by the British in 1891 under the names of British Central Africa and later Nyasaland. The country achieved full independence, as Malawi, in 1964, but remains part of the British Commonwealth, and its political and educational landscape is thus influenced by the UK. Literature on colonialism, science, technology, development and education in Malawi suggests that colonial legacies may be significant contributors to 'underdevelopment' in countries such as Malawi

(Dzama, 2003; Rodney, 2018). Not only does international aid and scholarship note Global South countries mostly in terms of ‘development’ agendas, but such ‘development’ work can be considered to represent a form of ‘neo-colonialism’ (Langan, 2018) that continues to inhibit various African countries.

METHODS

Presenting interview data from Malawian government representatives, trade unionists, employers, educators and workers with disabilities in Malawi’s largest cities, Lilongwe and Blantyre, this study shares local approaches to engaging with disability definitions, stigma, language, infrastructure and resources. The study design for the research was an interview and focus group-based design and employed an abductive analytical approach. Below, we outline recruitment, data collection, participant characteristics and analytical approach.

Research teams that aim to disrupt patterns of colonisation have pointed to the importance of co-design approaches to the design, conduct, analysis and evaluation of academic research to ensure that indigenous epistemologies are embedded in the work (Parsons et al., 2016). Drawing on efforts to decolonise and decentre Northern epistemologies and practices, we accordingly adopted a co-design, disability-led approach to the study. Partnering between researchers, union representatives and formal union structures in both Scotland and Malawi was key in the attempt to carry out the project in the spirit of international solidarity and cooperation, rather than as a neo-colonial project of ‘development’. The project that this article builds on aimed to provide trade unions in Malawi with data and framings, so as to improve their capacity to represent people with disabilities.

Authors acknowledge that despite this approach and our decolonial aspirations, the material and financial basis of this research follows the neo-colonial structures inherent in UK higher education funding. Firstly, the project was funded by the Global Challenges Research Fund (GCRF), which ‘supports cutting-edge research to address challenges faced by developing countries’ and ‘is part of the UK’s official development assistance (ODA)’ (UKRI.org 2022). Indeed, the inherent tension and short-termism of certain international NGOs and their colonial legacies are possibly replicated in this funding led by universities in the Global North.

Prior to commencing data collection, the research team (including UK academic and Malawian trade union researchers and union leaders and activists from the UK and Malawi) met over several days to determine the priorities and the most appropriate research approach for understanding the lived experience of people with disabilities in Malawi. Through these intensive workshops, the team co-designed the research questions, sampling and data collection strategies (including identifying participants and the data collection instruments) and the analysis of the data. This ensured research with, rather than on, end-users. It is important to note that the research is also disability-led with several members of the research team, including those leading the data collection, identifying as disabled or living with long-term conditions that affect their employment experiences. The research team collecting data during the fieldwork also collaborated with a team of Malawian academics and union representatives; these academics joined the UK-based part of the team a month after the data collection to exchange research and perspectives on disability inclusion.

Participant recruitment

Participants were recruited by the Malawi Congress of Trade Unions (MCTU), which was a partner organisation for the project. The organisation of the Malawian workforce is subject to

tripartite management from the government, the Malawian employer association and MCTU. Partnering with MCTU ensured access to relevant participants and a local perspective on disability, work and employment issues, co-designed research instruments and shared authorship and an MCTU national officer was a key member of the data collection team. Adopting a purposive sampling approach, participants were targeted for recruitment specifically because of their job roles and responsibilities. The recruitment strategy resulted in a sample consisting of 12 informal market workers with disabilities, two senior civil servants, one politician, three trade union officials, six trade union representatives, three disability organisation leaders, one education representative and one employers' association representative ($n = 29$). Participants with disabilities were recruited from a central market in Lilongwe and were branch members of a local market-based branch of the trade union for informal workers affiliated to MCTU.

The focus on urban workers in trade unions, and our practice of working alongside local union representatives to identify problems and solutions, was part of the project's attempt to avoid a neo-colonial framing. To avoid unethical situations where white Northern urban researchers 'do fieldwork' in rural areas without speaking the language or having links with the people approached, we collaborated with MCTU, localising and meeting with participants.

Participants were disproportionately male, reflecting men's greater involvement in paid employment compared to women (Soler-Hamperjsek et al., 2021). This requires further exploration to identify gendered elements of paid work and/or disability in Malawi. Previous research notes the importance of understanding disability and gender together, particularly in employment (Sang et al., 2016). Our sample self-identified their gender using gender binaries, the use of which in many African countries is a product of Western colonisation (Hudson, 2016). Future research could consider moving away from such binaries to recognise how diverse gender identities intersect with disability and health.

Our study focussed primarily on visible impairments such as mobility impairments. This was partly due to the implicit association of disability with physical impairments (as set out by respondents) but also due to self-selection of participants. While some discussions of mental health conditions and dyslexia took place in interviews, in all but one case, such a discussion was prompted by the interviewer. Future research work may explore the so-called hidden impairments and health conditions.

This project met the ethical requirements of both the University of St Andrews and Heriot-Watt University. Participants were made aware of the purpose of the research and their freedom to withdraw at any point. Consent was gathered verbally and recorded for Chichewa speakers and via paper consent forms for English speakers.

Research design

Data collection was undertaken by the lead author and authors 2 and 4. One focus group ($n = 12$) was conducted with market workers in their first language, Chichewa, with translation offered by the research partner (and member of the authorship team) from MCTU. The focus group was conducted in a meeting room at the market and lasted approximately 120 min; this meeting was digitally recorded but not transcribed, with author 4 taking notes on what was said in English.

The remaining 17 participants attended either group or one-to-one interviews carried out over a period of two weeks in August 2019, by three members of the team; interviews lasted 30–90 min. Interviewees met with the research team face-to-face in their place of work, MCTU offices or in hotel restaurants where researchers were staying. Interviews were conducted in English and digitally recorded.

Interviews were semi-structured with questions generated both from the extant literature and co-designed through early workshops. Given our intention to decenter Northern epistemologies and practices, primacy was given to topics developed during the co-design workshops. Interviewees were asked how long they had held their role and what it entailed, what they considered disability and long-term ill health to mean, what policies and legislation they drew on to support/manage workplace disability, what obstacles workers with disabilities faced in Malawi and their goals in supporting workers with disabilities. These open-ended questions allowed interviewees to share perceptions and experiences in ways appropriate to them.

Participant characteristics

Tables 1 and 2 provide summary information about focus group and interview participants.

Analysis

Interviews were digitally recorded, anonymised and professionally transcribed (verbatim), while thorough notes were taken at the project focus group. Transcripts were uploaded to NVivo 10 for data management (Leech & Onwuegbuzie, 2011). Repeated ideas and concepts became apparent already during the investigation and solidified when made evident in the data by comparing transcripts and focus group notes in the context of disability focussed literature and activism, medical sociology and social policy literature. Exploring these phenomena from multiple perspectives allowed for further depth, but also provided additional validity as a qualitative form of triangulation (Flick, 2004).

The analytical process used can be considered abductive in approach: the development of codes was informed by a ‘practical compromise of induction and deduction’, capturing the process by which subsequent theorising occurred (Shepherd & Suddaby, 2017, p. 79). The development of codes was informed by specific theoretical and political framings and concerns regarding ‘scholarly colonialism’ (Meekosha, 2011).

It is important to recognise that the empirical data for this article was collected in a cultural, social and political context that the visiting researchers were not familiar with and where the repercussions of colonialism persist. The research team were familiar with ethical debates relating to white, Northern researchers conducting research with Black African communities, and maintained dialog with Malawian research partners to inhibit unintentional manifestations of colonialist or racist practices. Retrospectively, we have discussed the appropriateness of white researchers conducting the fieldwork for the project, the complications of Global North researchers having access to funding our colleagues in Malawi did not and whether the standardised UKHE metrics for success (publications) benefited the authorship team equitably; the current UK Research Excellence Framework (REF) is based on colonial Anglocentric structures in which a high-ranking (4*) publication means one written in English. The authorship team recognises the need to democratise and decolonise research to promote multi-epistemological research partnerships (Chilisa et al., 2017), to which we hope this article contributes. The team advocates for collaborative research, both in relation to the above, and regarding the shared understanding in disability studies to ‘not (do research) about us without us’ (Zhang, 2017).

TABLE 1 Focus group participants

Market workers with disabilities (<i>n</i> = 12)	All male group experiencing visible physical impairments, most resulting from accidents	Recruited by a union official in collaboration with informal workers’ union representatives
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TABLE 2 Interview participants

Participant group	Details—M/F = Male/Female and number for identification in text
Civil servants and politicians ($n = 3$)	Roles in education, employment and disability 1(M) 2(M) 3(M)
Government disability organisation representatives ($n = 2$)	Representatives from MACOHA, government funded organisation 4(M) 5(M)
Independent disability-led organisation representative ($n = 1$)	Representative from FEDOMA, independently funded organisation 6(M)
Trade union officials ($n = 3$)	From MCTU 7(M) 8(F) 9(M)
Trade union representatives ($n = 6$)	Mixed union representation including teaching, university lecturers, hospitality, textiles, food, transport and construction; both formal and informal sectors 10(M) 11(M) 12(F) 13(M) 14(M) 15(F)
Higher education representative ($n = 1$)	Course leader at Malawian University 16(F)
Employers' association representative ($n = 1$)	17(M)

We have striven to maintain principles of collaboration, engaging in co-production of the research questions, research design and analysis. However, while critical of the short-termism of certain NGO work in Malawi, we are simultaneously aware of our own project's short-term stakes. We are, as Heney and Poleykett (2021) argue, constrained by the structures and funding models of the UK higher education system in that while we are committed to eradicating the inequalities experienced by people with disabilities in Malawi, our continued collaboration is dependent upon fragmented funding models and precarious contracts.

The key analytical categories derived from the data centred on (1) social barriers to doing intersecting with social determinants of being, (2) the gap between social model policy and medical model practice, (3) the opportunity for localised theory and practice.

Findings

The findings from this project show a complex landscape for managing long-term ill health and disability in the urban Malawian workforce. Reflecting findings of organisational research

globally, it was apparent that there was some discord between governmental level rhetoric regarding supporting people with disabilities and ground level practice (Kachaje et al., 2014); there were also clear divides between the formal and informal economy.

The UK-based researchers who co-conducted the fieldwork with MTCU researchers were required to reflect on and challenge their understandings of disability and learn from Malawian colleagues, and vice versa. For example, in Malawi, long-term ill health conditions are largely not considered to overlap with disability unless the illness results in a permanent or visible injury. This is apparent in relation to HIV/AIDS with Malawi having one of the highest HIV prevalence rates (Watkins et al., 2011) at an estimated 9% of the adult population (UNAIDS, 2020). Participants reflected on how HIV positive people can anticipate varied educational and employment trajectories dependent on when in their lives they received their diagnosis and whether they disclosed their diagnosis to their employers, if employed in the formal economy. HIV/AIDS is conceptualised in a cultural and historical way, specific to Malawi and linked to education, medical programmes and international intervention.

It is necessary to acknowledge the impact of the presence of two white female researchers on the nature of data collection. Despite the partnership with MCTU, a trusted organisation among the participants, it was apparent throughout data collection that participants were used to meeting representatives from the Global North often in a 'development' capacity, and those in positions of authority showed extraordinary hospitality and generosity to the research team and were keen to talk about further funding opportunities for research.

The focus group participants were similarly familiar with the presence of 'mzungus'. Given the colonial history and relative wealth of some of the research team, they asked how the research would benefit them, and made it clear that what they actually needed was a cash injection to support their businesses and families. That they stayed to speak with the team for over 2 h, knowing they would not be recompensed for their time, possibly speaks to the complicated dynamic created by having Global North researchers present, linked to the trust in local union representatives and MCTU. The research team, inclusive of union representatives, explained that local unions and MCTU hoped to use the data to lobby politicians for improved working conditions within the market, and within the research partnership, we were hoping to apply for further grants to engage in further co-produced research.

Social determinants of disability intersect with social barriers to employment

In Malawi, disability is not conceptualised in relation to exclusion from work in the project interviews unless discussing formalised workplaces. Though representing a minority of the labour force, formalised economy work became the focus of many of our interviews because of participant selection, the urban environments in which we conducted fieldwork, and the visible connections between legislation and policy related to employment in formal work.

Both disability studies and medical sociology have explanatory potential in our findings. The social model of disability recognises the environmental barriers to accessing work. These disabling barriers were identified by participants as a significant issue for workers:

In the different places in Malawi ... when you go into the markets, they are not friendly to people with a disability. Although the law is there, the Act is there, a lot of our issues are just on paper.

(P10)

To be honest, the working environment, in terms of the facilities, the offices, they are not accessible.

(P1)

They identified how formal economy workplaces are not designed with workers with disabilities in mind, and as a result, work environments, even for white-collar, urban workers, were ableist, inaccessible and exclusive. There is also a long-standing issue with stigma and notions that people with disabilities would not be 'productive' at work. To some extent, it can be argued that disability is constructed in these formalised working environments due to the application of legislation and purpose-built but inaccessible working environments.

The inaccessibility of work environments was echoed in informal economy settings: the disabled market workers spoke almost exclusively about the inaccessible environment within which they worked. Mentioning the difficulties of obtaining bank loans for their businesses due to discrimination, they also mentioned inaccessible routes and public toilet facilities at the market. In such informal work environments, the Disability Act and other legislation are harder to enforce when infrastructure rather than a specific employer stands accountable.

Participants reflected on their limited access to schooling and appropriate training. As with many countries, exclusion from paid employment in Malawi is preceded within the life course by a (sometimes formally) limited education (van der Wel, 2011), particularly in areas where there is scope for prestigious careers such as the sciences:

For persons with disabilities [in Malawi]... some of them have never even had access to education... in the areas of Sciences it's even worse... persons with visual impairment at secondary school level, they don't do Mathematics. Which means when we even go to university we can't do Mathematics! So we are already limited from that lower level.

(P6)

Persons with disabilities have a lot of challenges, and as far as employment is concerned ... for one to be employed, you need education, you need training, and then you can talk about employment. So programmes start from education. Many students with disabilities have challenges attending education.

(P4)

One union representative participant, echoing the disability advocacy organisation representative quoted above, posed questions about why students with disabilities disappear from science careers between primary schools and secondary schools as they are not allowed to progress.

In the UK and Global North more generally, sociological understandings of ill health and disability have been conceptualised in opposition to being able to participate in activities including paid work or the exclusion of workers with disabilities from the labour force. It was clear from our participants that the labour market in Malawi undermines such notions of disability and ill health because the primarily informal economy and subsistence work in Malawi require paid labour irrespective of health status, compounded by people's limited recourse to forms of social security. Understandings of ill health and impairment in Malawi do not preclude working, nor automatically exclude people with disabilities from the labour market. When asked what he thought disability was, the below participant answered:

I would also relate it not 100% to incapacitated, incapacity as such, but the kind of disability that would make you not be able to do certain functions normally like

other people do... But that does not mean that you cannot do something. You can be economically active.

(P2)

The labour market in Malawi does not inform definitions and conceptualisations of disability based on economic engagement, paying taxes and the citizenship this might entail, because, as this participant outlines, it would situate the majority of working-aged Malawians as disabled:

The economy is not well, to create jobs, let alone decent jobs. The number of people that are in decent jobs are just few... So, what that means [is that] 1 million people are the ones that are feeding the 16 million, because of the taxes. 9 million are working age and economically active, but only 11% of them formal sector so pay taxes.

(P7)

Trade unions in Malawi organise in both the informal and formal sectors, with the MCTU-affiliated Malawi Union for the Informal Sector (MUFIS) set up in 2000. As the participant below highlights, informal workers—including those with disabilities—in Malawi occupy a liminal space where they are neither considered workers nor economically inactive:

It wasn't easy for people to accept that the informal workers are also employees. I'm sure that is also the mind-set that people have over people with disabilities.

(P8)

There is a space left by disability frameworks that define disability according to the effect on day-to-day activities, including employment (e.g., the UK Equality Act), ill health and work, to incorporate an informalised workforce, subsistence work and access to education.

A further complication to understandings of disability in Malawi relates to the causes of ill health and disability. Inadequate access to health care can result in avoidable, preventable and/or treatable conditions sustaining or worsening over time, with workers having to adapt their practices to manage their condition. Similarly, due to the informal nature of much work and limited legislative input, the workplace is a place where workers are at risk of acquiring disability. Participants then often situated ill health and disability as health and safety issues, advocating *'for safe working conditions that may not lead to people acquiring disabilities at work'* (P1). Both union representatives and the employer association representative gave examples of workers who had been injured or disabled at work and then discriminated against due to their disability.

From participant interviews, it was apparent that the social determinants of disability and ill health were geographically and economically specific and were not constructed explicitly in relation to exclusion from paid work or an inability to work. Disability was something individuals managed and constructed locally, dependent on their employment status, familial networks, the application of government policy and the gap between policy and practice.

The gap between social model policy and medical model (development) practice

Like the social model of disability, Malawian policy places people with disabilities in a political category and seeks to address the disadvantages they experience. Despite this, there were several examples of how legislation is ignored, not upheld adequately or misinterpreted:

They talk a lot! ... If you ask people about the policies here, they tell you a lot: “We have a lot of policies, we have heaps of them in our offices, they are gathering dust”. But, one, awareness of people of those policies is not there on the ground. You go out there, people know nothing. We have a Disability Act, but when you go out there, people know nothing about it! And I hear that those people there in the Ministry department, they are even considering an idea of reviewing it. How do you review an Act which in reality has not been implemented?

(P16)

The above participant highlighted a central concern of many of the interviewees, that while the content of the legislation was positive, its implementation was piecemeal. This can be viewed as a somewhat universal issue: the UK members of the research team during interviews echoed similar experiences of frequent gaps between policy and practice in UK workplaces. However, a number of participants drew specific connections between the confused constructions of ill health and disability and the legacy of international ‘development’ strategies.

Some participants described how condition-specific organisations (particularly in relation to albinism, HIV/AIDS, visual impairments and epilepsy) develop support services and educational opportunities, such as education programmes in rural areas designed to undermine particular health beliefs and programmes of stigmatisation and vaccination. A feature of these interventions, beyond the potential to create a condition-specific hierarchy in participant data, was that the delivery and management of many international agencies was paternal in style, something that also carried into state-provided education:

Currently, issues of special and inclusive education are considered as charity issues. Probably because previously, the missionaries were ... supporting this.

(P2)

A member of the country’s main advocacy organisation identified certain international NGOs as well as some Malawi state initiatives as being *for* people with disabilities, not necessarily *with* or *led* by them—as opposed to the participants’ own organisation:

We can hire all other people, even those without disabilities, for other offices. But leadership has to be by persons with disabilities.

(P6)

The same participant outlined a clear gap between policy and practice as NGOs struggled with inclusive practices as employing organisations in Malawi:

Most of these even international NGOs come with their agenda of inclusion. But you’d find that for them to accommodate persons with disabilities, it would not

be easy for them. You'd find they've signed commitments, whatever, out there, but [when] they come to Malawi – nothing like that is happening. ... Maybe from the government, who still at one point or other get a person with a disability as an employee. But within the private sector, in the international NGOs fraternity or the NGO fraternity, it's not that easy for them to take up persons with disabilities.

(P6)

While cultural ideas about disability remain in Malawi since pre-colonial times, it was implied in interview data that the 'soft colonialism' of certain international NGOs (Englund, 2006) have also shaped understandings of disability and illness in Malawi, possibly especially in urban centres and formal work, as the policy language of the nation is English, though Chichewa is also an official language. The language of development politics is largely English, though other Global North/wealthy nations engage in such projects. Many Malawians speak their local language as their first language, with English as a second or third language (and many not speaking English), a fact that further highlights the gap between policy and practice.

Opportunity for localised theory and practice

In localised contexts in Malawi, the experiences of people with disabilities and long-term health conditions are not adequately addressed by dominant theories in disability studies or medical sociology. Specifically, we see that disability as a concept is fluid, shifting across contexts where those with responsibility for supporting people with disabilities rely on their own or externally defined (e.g., by government initiatives or NGOs) understandings, which position disability as linked to needs. The quote below exemplifies the tension between applying externally defined concepts of disability to actual experiences of disability, which transcend the definitions of models developed in Global North disability studies. Instead of an expanded notion of 'disability' that includes other experiences, definitions are mismatched from experience:

You know, also, issues of understanding what a disability is, it's a huge problem here ... People really don't know what disability is. [Interviewer asks how the participant defines disability.] ... 'It's difficult to define. In Malawi we don't have localised, contextualised definition of disability. So we usually borrow the same textbook disability definitions to refer to a person who in one way or another has either an impairment or who is deprived in a certain area of some basic needs. So we are not only focussing on those who have impairments, but also those who have extra needs that require extra support.

(P16)

One respondent noted the interaction of impairment and environment as defining disability:

I will define it [disability] from the working experience. ... Disability is a social concept. It's something that does not reside in a person; it's a result of an interaction between a person that has impairment, whether that is physical, sensory, mental, intellectual. So with that impairment, interacting with the environment, if there are barriers that are preventing this person to actually function and also take part in

whatever is happening in the society; so the result of this interaction it's a disability. So, in short, disability comes when the environment is not conducive.

(P1)

As the quote below shows, within official (English-language) Malawian disability discourse there is a move away from stigmatising language, as 'disabled' is considered a stigmatised word. However, there is no holistic alternative in English and therefore the focus is on 'impairment', which covers a vast array of conditions from mobility and sensory impairments to so-called learning disabilities.

Actually, the word disabled already brings elements of stigma, outright. But because we don't have another alternative word... maybe that's why sometimes we talk of a person with an impairment. But that alone if we critically report it we also see that it is also not friendly.

(P2)

The statement above begins by drawing on what Global North disability scholars recognise as the language of the social model of disability, namely referring to impairments. However, we see a divergence from the dominant social model of disability by the rejection of the term 'disabled' as it is considered stigmatising by participants; this duality sits in contrast to the social model of disability which considers disability as social oppression, or identity first language which celebrates disability (Dunn & Andrews, 2015).

These fluid understandings of disability can affect who is able to access interventions designed to improve health and wellbeing. Stakeholders often rely on those with positions of power within communities (in this case, the chief) to identify people with disabilities rather than using legally defined parameters when locating members of the community to participate in initiatives:

We just go to the community, we ask the chief: "Can you bring for us people? And amongst them must be persons with disability". And we're speaking to these people, we address these people: "This is the initiative we are coming up with, and from this day it's your[s]. You will tell us when you mobilise yourselves – when you set the groups, you will tell us you do that. We'll be waiting to hear from you."

(P6)

The above strategy depends on self-identification of disability, or potentially community identification, in familial networks.

Participants reflected on difficulties when engaging with the Malawian government when new national-level initiatives are designed to support people with disabilities. As one participant argued, top-down government policies may be more palatable to government entities:

I'm assuming because policies and guidelines that have to do with disabilities usually emanate from government and go down, and therefore it is much, much easier for government entities to embrace them and put them into practice.

(P17)

As seen above, the social model—despite informing policy—may not work on the ground. This is especially the case in the informal sector, where a lack of infrastructure makes social model-based

policy difficult to enforce. Trade union officials from MCTU noted in interviews that one key way of improving workers' conditions in Malawi, including for workers with disabilities, is by formalising more parts of the economy, so that workers can more easily learn their rights and legislation is followed.

DISCUSSION

Through a series of interviews with key stakeholders and a focus group with market workers with disabilities, this data has revealed that disability itself in Malawi is defined or framed in localised and contextual ways, not always fitting into dominant models emanating from the Global North, although definitions are often rooted in medicalised, impairment-specific understandings, for example, mobility or sensory impairments. Indeed, in contrast to dominant models of disability, which increasingly aim to move away from individualised notions of disability towards understanding disability as social oppression or a difference to be celebrated (Dunn & Andrews, 2015), the data reveals a renewed motivation to stigmatise disability while drawing on alternative discourses. As participants described, disability discourse within Malawi often draws on an individual's needs and addressing those, and the rights of a person with disabilities, framed—as in the country's constitution—as a human rights issue.

There is a disparity between Northern or dominant capitalist formulations of work and Malawian ones in terms of formal versus informal work and how notions of disability are (or are not) framed around this. In many national contexts, disability is understood through the lens of participation in paid employment (economic activity); indeed, the degree of participation in employment is often used as a proxy for the severity of the degree of functionality linked to disability (Andrade et al., 2015). However, as our data demonstrates, such an approach is not useful in economic contexts where formalised employment is the exception rather than the norm. In Malawi, most people, including workers with disabilities, occupy a liminal space where they are neither in formalised employment nor economically inactive. Formalised employment is relatively rare in Malawi, and those engaged in the informal economy are often not considered workers or employees. Where disability research and legislative frameworks define disability in relation to engagement in paid employment, they neglect contexts where formal employment is not commonplace.

Research has pointed to the importance of understanding disability and employment across the life course, taking into account exclusions from education which restrict subsequent employment opportunities (van der Wel, 2011). If people with disabilities or long-term health conditions cannot access formal education, we will see continued exclusion from formal employment. The data presented here shows that these patterns are reflected in Malawi. Banks and Zuurmond (2015) describe the affirmative action policies designed to support Malawian children with disabilities to stay in formal education. However, we see again a recurring theme in the data: the gap between policy and practice. Participants in the current study recounted the exclusion of children with disabilities from the study of mathematics, the key discipline that underpins much of formal education, particularly in scientific careers.

This article has highlighted the damaging legacy of colonialism, through universalising definitions of disability and the short-termism of both UK research funding and certain NGOs for workers with disabilities and long-term health conditions in Malawi. Our data echoes the findings of Zhou (2019), who argues that within Malawi, formal health care is usually impairment or disease-focussed, for example, focussing on pregnant women with HIV. This individualised,

condition-specific biomedical approach, while benefitting some people, is often informed by neoliberal ideologies that fund the work of NGOs delivering such care, and risks ignoring community health care and familial structures of society (Kalinga, 2018).

Presenting new data on disability inclusion in the Malawian workforce, we posit that trade unions and workplace inclusion can be a key way to improve disability rights. One respondent (P1) noted that while the public sector is largely regulated and reached by policy due to its close ties with the government, trade unions can advocate specifically in the private sector to ensure good working conditions that make sure that people do not become disabled at work, that people with disabilities do not face discrimination and that they have access to reasonable accommodation at work. However, he highlights that it is not only the employer organisation who needs to work on recruitment and training policies, and to what extent they present barriers for employment of disabled people, but the trade unions themselves need to improve on disability inclusion:

[Work is needed on] the involvement of disabled people in the work of the trade union. They shouldn't just be the end beneficiaries. They are part and parcel, they should be part and parcel, of the whole process.

(P1)

MCTU officials noted that while, in their experience, many workers with disabilities do not join a union, a visually impaired people's trade union has recently formed and contacted MCTU to affiliate. While disability is still to be mainstreamed into the organisation, several MCTU officials and other union representatives mention specific individual union representatives with disabilities.

Disability needs to be understood in the local context to avoid a universalist framing that ignores the lived experiences of people with disabilities and the social-economic-political-cultural-environmental contexts in which they live (Ghai, 2017; Mohanty, 2003; Parekh, 2007; Shuttleworth & Kasnitz, 2005). The universalising approach of disability studies potentially neglects local, regional and inter/national economies and the labour market when it comes to policy assumptions and application. Conversely, medical sociology has largely neglected experiences of illness in the Global South, despite the potential for international solidarity and learning.

We endorse the argument made by Chataika (2012) that critical disability studies engage in genuine collaboration across the globe. Alongside the theory building and experiential focus of medical sociology, scholars from both disciplines can learn from indigenous knowledge, which in Malawi, as with other nations, has been neglected, misrepresented and ignored. With their longstanding traditions of international solidarity and grounding in workplace struggles around the world, trade unions can be key partners in this collaboration.

CONCLUSIONS

This article sought to understand the lived experience of disability and of supporting people with disabilities into employment in Malawi and potential links with education through a co-designed project run in collaboration with trade unions. Through interviews and a focus group, the data revealed complex patterns of how disability is defined, its tenuous relationship with paid (particularly formal) employment and the liminal status of people with disabilities in informal work. Interviews demonstrated a distinct gap between policy and practice in disability inclusion.

The findings of this study trouble the waters of both disability studies and medical sociology theorising, highlighting how neo-colonial and Anglocentric frameworks are not necessarily

appropriate for the Malawian workforce or education system. The dominance of the Global North and the English language has favoured universalist tendencies and certain implicit cultural values, resulting in the marginalisation of people with disabilities in the Global South. A large part of the theoretical models in these fields assume a relationship between work and ill health (either exclusion, or non-participation). This model does not work in the context outlined above. We argue that disability and ill health must be understood in their geographical and historical contexts if efforts to eliminate health and disability inequalities are to be successful.

There is still a need for more participatory research and genuine partnerships in research and action (Phiri, 2014; Swartz, 2014). Working from and with Malawian trade unions to improve disability inclusivity in the workplace, allowing unions as agents in civil society to work for change, is one way to foster contextually specific and grassroots research. Collaborative and sustained long-term research led by scholars, people with disabilities and activists outside of the Global North will enable not only the advancement of scholarly thinking but also the development of successful interventions that move us towards social justice.

AUTHOR CONTRIBUTIONS

Lena Wånggren: Conceptualization (Equal); Data curation (Equal); Formal analysis (Equal); Investigation (Equal); Methodology (Equal); Writing—original draft; Lead, Writing—review & editing (Equal). **Jennifer Remnant:** Conceptualization (Equal); Data curation (Equal); Formal analysis (Equal); Funding acquisition (Equal); Investigation (Equal); Methodology (Lead); Writing—original draft (Equal); Writing—review & editing (Equal). **Sarah Huque:** Formal analysis (Equal); Writing—original draft (Supporting); Writing—review & editing (Supporting). **Limhani Kachali:** Conceptualization (Equal); Investigation (Equal). **Katherine J. C. Sang:** Formal analysis (Equal); Funding acquisition (Equal); Writing—original draft (Supporting), Writing—review & editing (Equal). **Jenipher Ngwira:** Conceptualization (Supporting); Writing—original draft (Supporting), Writing—review & editing (Equal).

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DATA AVAILABILITY STATEMENT

This data is not available, since it contains sensitive information.

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ENDNOTES

¹ The authors use ‘person-first’ language in this article to reflect the language used in Malawi and the UN Convention on the Rights of Persons with Disabilities (UNCRPD) rather than language advocated by the Social Model of Disability scholars who use ‘disabled persons’ to recognise that people with impairments are disabled by an inaccessible environment and society. Notably, the UNCRPD was initiated by Mexico, and mobilised for by Global South disability activists.

- ² “North/South” terminology came into use in the 1960s as shorthand for a complex of inequalities and dependencies: industrialised versus raw material producing countries, rich versus poor, those with military power versus those without, high technology versus low technology, and so on. “Southern” countries are, broadly, those historically conquered or controlled by modern imperial powers, leaving a continuing legacy of poverty, economic exploitation and dependence’ (Meekosha, 2011, p. 669). Global North countries are usually characterised as ‘developed, high in-come, thriving, or first world countries’, while Global South countries (in Africa, Central and Latin America, and most of Asia) are usually referred to as ‘developing, low-income, failing, majority world, or third world countries’ (Stubbs, 1999).
- ³ For a consideration of colonialism’s long term and current economic implications on labour structures, politics, economic participation and national policy, see McCracken (1983); Chipeta (1986); Ross (2009); Banda and Kayira (2020).

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APPENDIX: MALAWI DISABILITY LEGISLATION

Inclusion of people with disabilities in all social activities, including education and employment, is a major feature in international legal frameworks, such as the United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (UN 1993), United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN 2006), International Labour Organisation Convention on Anti-Discrimination in Employment and Occupation (ILO, 1958) and 2030 Agenda for Sustainable Development Goal 8, which emphasise decent work and economic growth (UN 2015). In response to such international disability policies, standards

and frameworks, Malawi has developed national legislation and policies that advocate for the education and wellbeing of people with disabilities using a social model of disability.

Relevant policy and legislation for this article include the Constitution of Malawi (1994), National Policy on Equalisation of Opportunities for Persons with Disabilities (2006), National Policy on Special Needs Education (2007), the Disability Act (2012) and the Malawi Growth and Development Strategy III (2017–2022). The government of Malawi is now considering new legislation that would update and combine the 2012 Disability Act and the 1971 Handicapped Persons Act.

- Constitution of the Republic of Malawi

Malawi's Constitution (Government of Malawi, 1994) recognises the rights of persons with disabilities in line with international instruments. Section 20 guarantees the protection of people with disabilities from discrimination. Equality and non-discrimination as fundamental principles of human rights policy are reflected in the constitution, as it states that all individuals are equal as human beings by virtue of the inherent dignity of each human being. No one, therefore, should suffer discrimination on the basis of race, colour, ethnicity, gender, age, language, sexual orientation, religion, political or other opinion, national, social or geographical origin, disability, property, birth or other status as established by human rights standards. The Constitution (Section 26) further guarantees all people the right to education, with women, children and people with disabilities in particular given special consideration in the application of this right in Section 30.

- National Policy on Equalisation of Opportunities for Persons with Disabilities

The Cabinet of Malawi approved this policy in July 2006, with the then Ministry of Disability and Elderly Affairs (MoDEA) overseeing its implementation. Promoting the rights of persons with disabilities to enable them to play a full role in society, it aims to ensure that concrete steps are taken with disability issues to be integrated into all government development strategies, plans and programmes. This extends to the development of coordinated management systems of planning, implementation and monitoring at all levels, building the capacity of all disability actors and mounting nationwide public education and awareness campaigns about disability.

- National Policy on Special Needs Education

This policy, developed by the Ministry of Education, Science and Technology and stakeholders in 2007, aims to develop the personal, social and academic competencies of learners with special needs. The policy identifies barriers to the implementation of special needs education (such as inadequate funding, teaching and learning materials, inaccessible infrastructure and shortages of specialist teachers) and outlines strategies to overcome these (e.g., advocacy, early identification, assessment and interventions for learners, appropriate education and a supportive institutional framework). However, although the policy itself contains positive positions, most of the contents have not been fully implemented.

- The Disability Act

The Disability Act (2012) guarantees the right of access for persons with disabilities, including children with disabilities, to at least 22 services. The major services cover health and rehabilitation; premises and services or amenities; education and training; social protection; social services;

cultural, sporting and recreational activities; and information and communication technologies, among others. Section 12 of the Act states that the Government shall recognise the rights of people with disabilities to work and employment. Furthermore, Section 13 prohibits any form of discrimination in work and employment based on disability. The Act is in line with international instruments such as the UNCRPD and the Convention on the Rights of the Child (CRC).

- Malawi Growth and Development Strategy III (2017–2022)

The Malawi Growth and Development Strategy III (MGDS) is the national development plan for the period 2017–2022. The strategy states that people with disabilities are vulnerable and therefore need interventions that can empower them by improving access to education, vocational training, employment opportunities and health services and other productive resources.

In many countries, the policy proposed in the CRPD and following national Acts are not easy to implement in practice. Despite many efforts, many have yet to close the gap on the ideals of the Convention, mainly because of limited resources amongst state-funded institutions for advancing disability issues (Dziva et al., 2018). Previous studies on disability inclusion and policy implementation in sub-Saharan Africa demonstrate that when disability policy is taken from a non-local model, there is a gap between inclusion policy and practice (Dziva et al., 2018; Marsay, 2013; Pal et al., 2016). As Abimanyi-Ochom and Mannan (2014) note, despite governments excelling in commitment to disability rights by producing legislation, policies and socio-economic programmes, the evidence highlights a continuing ‘implementation gap’ between laws, policies and practice, due to negative cultural attitudes towards disability, poor funding, inadequate training in inclusive education and limited access to accessible information and assistive devices. Despite world-class policies and ratification of the CRPD, implementation is sometimes inadequate: ‘rights do not automatically enable people to live better lives’ (Marsay, 2013). Monitoring implementation remains difficult.

The present study confirms previous evidence of the distinct gap between disability policy and practice in Malawi. The national legal frameworks must be reinforced so that interventions concerning people with disabilities are carried out with an inclusive and rights-based approach to ensure that no one is left behind. These instruments put people with disabilities at the centre, as rights holders who must be involved in all stages of measures adopted by Malawi, from planning and implementation to accountability in employment.

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