

## Fragmented yet together: the disability movement in Sierra Leone

Amélie van den Brink<sup>a</sup>, Willem Elbers<sup>b</sup>  and Aisha Fofana Ibrahim<sup>c</sup>

<sup>a</sup>African Studies Centre Leiden, Leiden University, Netherlands; <sup>b</sup>Gender & Diversity Studies, Radboud University, Nijmegen, The Netherlands; <sup>c</sup>Institute for Gender Research and Documentation (INGRADO), Fourah Bay College, University of Sierra Leone, Freetown, Sierra Leone

### ABSTRACT

The on-going struggles of disability movements worldwide have been examined from multiple perspectives. As of yet, however, research into this topic has largely overlooked experiences on the African continent. This article seeks to address this gap by presenting a case study of the disability movement in Sierra Leone, West Africa. The study finds that on the one hand the Sierra Leonean disability movement is fragmented (referring to the tendency of groups to work individually as opposed to operating in a collective manner), thus limiting synergy. Three main 'centrifugal' forces underlying fragmentation are identified: resource scarcity, impairment specific interests and capacity differences between impairment types. On the other hand, the movement somehow manages to survive and even achieve modest successes. The research shows that interdependence, shared experiences of marginalization, and a clear identification of the 'other' have a unifying effect.

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### Points of interest

- The disability movement in Sierra Leone is fragmented, meaning it struggles to formulate a unified position and act collectively, yet somehow survives and even manages to achieve some successes;
- The fragmentation is fueled by competition between groups, a hierarchy between impairment types and interests that are impairment specific.
- The movement is kept together by mutual dependence to achieve key goals and raise funds, shared experiences of marginalization and negative experiences with 'outsiders'.

**CONTACT** Willem Elbers  [w.elbers@maw.ru.nl](mailto:w.elbers@maw.ru.nl)

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- The research offers recommendations to disability groups and donors to mitigate fragmenting forces while strengthening unifying forces.

## Introduction

Disability movements around the world typically experience constraints and challenges which impede their ability to achieve their goals. Critical questions have been raised about the inclusiveness of movements and their ability to represent different intersecting identities and mobilize constituencies (Priestly 1995; Vernon 1999; Hugemark and Roman 2007). Furthermore, movements that accept governmental funding are known to run the risk of becoming 'co-opted' by the government. Besides mission drift and reduced organizational autonomy, this can result in reduced credibility and a weakening of constituency ties (Oliver and Barnes 2006; Chang 2017; Mladenov 2009; Acheson and Williamson 2001; Bezmez and Yardımcı 2010). Similarly, financial dependence on international aid has been identified as having a range of undesirable and disempowering consequences for disability movements in the global South due to unequal power relations (Meyers 2014; Wehbi 2011; Nuth 2018; Chataika et al. 2015).

As of now, however, there has been little in-depth analysis of the constraints and challenges faced by disability movements in Sub-Saharan Africa. Drawing upon qualitative research conducted in Freetown, Sierra Leone in 2017 and 2018, this article asks two interrelated questions: (1) What are the constraints and challenges faced by the disability movement in Sierra Leone? (2) Why does the disability movement continue to survive and achieve successes despite being fragmented? For reasons of demarcation, our analysis focuses on the *internal* dynamics of the movement. In our analysis we draw in particular on the experiences and history of the Sierra Leone Union on Disability Issues (SLUDI), which is the disability umbrella organization in Sierra Leone.

We start by framing our research agenda within the existing literature of the constraints and challenges faced by disability movement. After a discussion of methodology, we address our research questions in three steps: first, we provide a brief historical overview of the disability movement in Sierra Leone, highlighting the role of SLUDI and some of the successes that have been achieved. Second, we examine the dynamics that have a fragmenting effect on the movement. Third, we explore why the disability movement, despite these constraints, continues to survive. The article ends with a set of conclusions and practical lessons for the disability movement and the donor community.

## Disability movements: a literature review on constraints and challenges

This paper positions itself in the literature dealing with the constraints and challenges faced by disability movements. This section provides a brief overview of the main debates in this literature, highlighting key studies and findings.

There are several important ongoing themes of study and debate in the literature on disability movements. Notable themes include movement emergence and history (see, e.g. Gebrekidan 2012; Fontes 2014; Jayasooria and Ooi 1994; Chander 2016; Hayashi and Okuhira 2001; Sabatello 2013), strategies and outcomes (see e.g. Anesi 2018; Pearson and Trevisan 2015; Waltza et al. 2015; Zhang 2017; van Houten and Jacobs 2005; Kim 2010; Miles et al. 2012; Chua 2014; Hann et al. 2015), goals and priorities (see, e.g. Oliver and Barnes 2006, 2012; Shakespeare 2013; Sheldon 2005; Hughes 2009) and movement constraints and challenges. Our research seeks to contribute to the last theme.

It is our understanding that there are at least three recurring themes in the literature on the challenges and constraints faced by disability movements: (1) issues related to diversity, inclusiveness and mobilization, (2) co-optation, institutionalization and marketization, and (3) the adverse effects of international aid.

The first sub-strand concerns the various causes and consequences related to commonality and difference in disability movements. The starting point here is that disability movements are often profoundly heterogeneous; group identities are determined by the type of disability and the degree of impairment, as are varying levels of access to financial resources and political power. The wide spectrum of determinants in group identity formation raises critical questions about the inclusiveness of the movements and their ability to represent and mobilize its constituencies due to internal power dynamics (Conejo 2011).

For example, Priestly (1995) found that blind Asian people in Leeds (UK) perceived issues of 'difference' as more important in mobilizing disabled people at a local level than the issues of 'commonality'. In this case, respondents identified more strongly with their experience of specific impairment (i.e. blindness) and cultural identity (i.e. Asian) than with their shared experience of disability. A different point is made by Vernon (1999) who argues that just because a social group (people with disabilities) is oppressed, one cannot assume that these very people are not also capable of practicing oppression towards other minority groups (in this case, within the disability movement). Hugemark and Roman (2007) examine the diversity and divisions within the Swedish disability movement. Their research focuses on the

power dynamics that occur within disability organizations and shows how these are related to various (intersecting) identities.

The second sub-strand, which deals with issues of co-optation, de-politization and marketization, highlights the risk of relying on government funding (Oliver and Barnes 2006). An overall finding here is that financial dependence contributes to movements losing sight of their original goals and autonomy, which ultimately undermines their credibility and increases the distance from their constituencies.

Based on research in Taiwan, Chang (2017) demonstrates that disability advocates in Taiwan have become increasingly depoliticized by accepting governmental funding, shifting from advocacy work to service delivery. Similarly, Mladenov (2009) examines the participation of Bulgarian disabled people's organizations in policymaking. His study describes how the 'representatives' of Bulgarian disability movement became depoliticized when their participation became institutionalized through the National Council on Integration of People with Disabilities. In another study, carried out in Northern Ireland, Acheson and Williamson (2001) found that the state welfare structure provides both opportunities and constraints for disability activists. While disability groups benefit from governmental resources for the implementation of their programs, the processes of co-optation and institutionalization that accompany funding can also weaken their voices. In a different cultural environment, the work of Bezmez and Yardımcı (2010) examines the relation between disability organizations and the state in Turkey. They found that due to the institutional, political, cultural and historical specificities of Turkey, most non-governmental organizations maintain relations of patronage with state actors. Such relations provide very little room for organizations to adopt a rights-based discourse.

A third sub-strand theme in the literature concerns the adverse effects of international aid on disability movements in the global South. A common thread in this strand is that donor-recipient relations are characterized by unequal power relations that produce various undesirable effects. These power relations are often positioned within broader neo-colonial critiques.

Based on fieldwork in Nicaragua, Meyers (2014) found that international NGOs tend to work in a top-down manner which hinders the ability of local disability groups to set the agenda. In a similar vein, Wehbi (2011) finds that international donor funding plays a problematic role in disability advocacy in Lebanon because donors impose strategies and approaches. Overall, she concludes that the conditionality used by international aid agencies can hinder disability rights activism and contribute to the marginalization and exclusion of disabled people. Nuth (2018) found a similar pattern in Cambodia. Her study demonstrates that DPOs, due to resource dependence, align their policies and strategies with those of international donors. Such alignment

has several negative effects, including programmes that do not address local priorities and DPOs losing touch with their constituencies. Chataika et al. (2015) argue that disability rights within international development are framed within charitable and neo-colonial approaches which impede activism and disregard 'sites of resistance'. As such, Chataika argues that international aid can have a disempowering effect and runs the risk of reproducing and even reinforcing existing stereotypes and discourses.

Overall, in-depth empirical academic work on movement constraints and challenges in Sub-Sahara Africa has remained rather limited. To our understanding, the literature either discusses the constraints and challenges of disability movements in Sub-Saharan Africa at a general level (e.g. Chataika et al. 2015) or focuses mainly on the South African experience (e.g. Howell, Chalklen, and Alberts 2006) which may be less representative for other countries on the continent. In this paper, we address this gap and provide a sustained analysis based on fieldwork in Sierra Leone.

## Methodology

Ethical Clearance was obtained through Sierra Leone Ethics and Scientific Review Committee via the Institute of Gender Research and Documentation (Fourah Bay College, University of Sierra Leone) and from SLUDI. Also, prior consent forms and verbal statements were made available to every participant.

We collected qualitative data in the capital of Sierra Leone, Freetown, during 2017–18. We examined the disability movement by focusing on the Sierra Leone Union on Disability Issues (SLUDI), the nation's disability movement's umbrella organization. This was based on the idea that the history and experiences of SLUDI, due to being a nexus in the disability movement, would offer a 'window' to observe the broader dynamics of the disability movement.

We employed grounded theory and historical methodologies to unravel the various dynamics of the disability movement landscape. Grounded Theory, especially, was useful for theory building and discerning social actors' "perceptions, meaning, and emotions," with regard to both similarities and differences in opinion (Mattoni 2014, 38; Ritchie et al. 2003) through participant observations and semi-structured interviews.

Our participatory observations were made during SLUDI's formal and informal meetings and activities, such as meetings, press conferences and rallies, providing 'initial sampling' for subsequent semi-structured interviews (Charmaz 2006, as quoted in Mattoni 2014). Semi-structured interviews were chosen because they allow for flexibility to be open, and focused (Jamshed 2014). A total of 45 interviews were conducted which included both SLUDI

staff and members of the broader disability movement. The latter included interviews with founders/key members, organizers and activists, aged 19-60, and sometimes possibly older, with some second-round interviews for clarification and more in-depth information.

A historical approach using interviews and analyzing archival material helped situate the movement's history, starting with its formation and its growth trajectory over time. We were especially interested in SLUDI's operating structure, its relations with members and its lobbying and advocacy activities to better establish its event analysis and to gain further insights into its broader mobilization dynamics and history (Oliver, Cadena-Roa, and Strawn 2003; Diani 2002).

During data collection, grounded theory's 'transparent' approach to "addressing ethical concerns" and reflexivity (Mattoni 2014: 38-39) became important to consider. For instance, it was discovered early during data collection that the movement is struggling with many internal issues. Writing about them would touch upon sensitivities which might put the movement in a negative light and potentially bring harm to its members and future donor funding. Thus, we had to continuously reflect on our approach in order to try and present a 'balanced' perspective and protect members.

Interviews provided rich data for the initial step of analysis. A general data analysis framework was developed using an open coding process whereby data was broken down into smaller categories. Connections between the categories and subcategories were created to make primary categories, providing a descriptive narrative. Data that were coded differently were seen as disagreements. From this process, *meanings* produced by social actors and particular "perceptions, identities, emotions and cultural dimensions" were uncovered (Della Porta and Diani 2006, 11). To make sure the framework was working, results of the grounded theory analysis were verified with archival data and observations for purposes of triangulation and for enhanced validity and reliability of the results. Results were further verified with participants during interviews, transcriptions and during a preliminary "learning event" symposium. Due to the sensitivity of our data, we have removed participants' identities, and some of their organizational names.

### **The movement and SLUDI: a brief history**

While disability activism has a long history in Sierra Leone, it is generally agreed that the brutal eleven-year Civil War (1991–2001) had a catalyzing effect on the disability movement. During the war, thousands of injured civilians received care in makeshift refugee camps (Berghs and Dos Santos-

Zingale 2011). Persons with disabilities seized the opportunity to come together by clustering into smaller groups of people with similar afflictions. Together, they took stock of their shared interests and wrote to international NGOs to secure their own resources, including food rations, clothing and medical supplies. A former SLUDI president and a polio survivor remembers: "DPOs (Disabled Peoples Organizations) formed when 5-10 people with disabilities were around ... [and] appointed someone as chairperson who will be writing to World Food Program, Red Cross etc., for oil, bulgur, and other foods" (interview 9/11/2017).

The ease of forming new organizations led to the 'mushrooming' of disability organizations. For instance, the number of polio groups increased from one to twenty-five during the war. Some of these groups further organized themselves into unions such as the Polio Victims Association (now Polio Challenged Association) (1992) and the Amputee & War Wounded Welfare Association of Sierra Leone (2000). At the same time, the proliferation of disability groups inspired further discussions to form a union with palpable powers that could represent them all, and for them to speak to the government in an unified manner. In 1994, Professor Emeritus Eldred Jones (a non-disabled member who had an interest in pushing the disability agenda and who later became visually impaired) and DPOs organized around blindness and polio affliction held several meetings to discuss their unionization. In 1995, SLUDI, the Sierra Leone Union on Disability Issues (SLUDI), was founded.

At the time of writing (2019), SLUDI is the main disability umbrella organization in the country. Given its umbrella status, SLUDI is a membership-based organization whose members consist of national civil society organizations working on disability issues, including DPOs, from all over the country. SLUDI aims to connect, unite, represent and amplify the voices of its members towards other key stakeholders, particularly the government.

SLUDI has some 120 registered member organizations scattered in the Northern, Southern and Eastern provinces. Of these, fifteen members form the National Executive Board. They are elected to positions every four years at bi-annual general meetings, held in January and June. Board members meet once a month, sometimes more during emergencies. Crucial for the functioning of SLUDI are its relations with its constituencies. Its board-members pay visits to organizations and individuals on a regular basis. They help to conduct organizations' elections, reconcile conflicts between members and between members and non-disabled persons, and provide moral support.

As a 'watch dog', SLUDI tries to make sure that local and international NGOs, the state and other institutions working on disability issues adhere to standardized treatment protocols for people with disabilities. Also, it

attempts to advance the position of its members by implementing developmental and cultural activities, such as micro-credit schemes, agro-food processing and marketing projects, skills training and physical rehabilitation (interviews and archival data). SLUDI has close linkages with the Ministry of Social Welfare Gender and Children's Affairs and largely depends on national and Western aid agencies for funding.

Since its formation in 1995, SLUDI has achieved some successes in its lobby and advocacy work. It has mobilized its members through several cycles of protest, held various media interventions and other public initiatives. An example encountered during the fieldwork period was the commemoration of the December 3<sup>rd</sup> (2017) International Day for Persons with Disabilities. Part of the festivities and activities included skits, friendly football matches amongst members and non-disabled persons, sensitivity-enhancing media and protest campaigns for the wider public on the plight of people with disabilities. Overall, informants widely agree that SLUDI's work has at least contributed to the establishment of several key policies and institutions, including the drafting and later implementation of the 2009 Disability Act for the inclusion, promotion and protection of the rights of persons with disabilities. Other achievements include securing scholarships for people with disabilities in tertiary education and establishing the National Commission for Persons with Disabilities in 2012.

### **Fragmentation: centrifugal forces**

A recurring concern expressed during interviews is the fragmentation of the disability movement in Sierra Leone. Nearly all informants stressed the struggles of the movement to formulate a unified position and to act collectively. Their underlying concern is that there is a tendency within the movement of organizations pursuing their own interests, rather than operating in a collective manner to achieve joint outcomes. This study found that this fragmentation manifests itself in a variety of ways:

- Organizations compete with one another for funding, members and visibility, even at the expense of other organizations within the disability movement.
- Organizations undertake projects and programs in isolation, rather than work with others to complement each other and achieve joint goals.
- Groups of a certain impairment type stick to their own, and do not engage with other disability organizations.
- Organizations often distrust each other and do not openly communicate strategic opportunities for influencing important disability policies.



Our research identifies three main ‘centrifugal’ forces that underlie the fragmentation: (1) resource scarcity, (2) differentiated interests of different impairment types, and (3) capacity differences of different impairment types. The next sub-sections explain these forces and their effects.

### *Resource scarcity*

Disability groups in Sierra Leone are typically pre-occupied with securing funds in which organizations spend considerable time and energy on acquiring resources. In Sierra Leone, a country rich in resources but with a disproportionate high number of poor people, the opportunities to raise funds locally are severely constrained. While most associations ask for membership fees, these are generally low, limiting the scope of the activities that can be undertaken. Many Disabled Persons Organizations (DPOs) find themselves in a situation where ‘chasing’ funds is not only a time-consuming activity but also one that has become a goal in itself. This runs the risk of crowding out activities that contribute to the goals of the movement.

The pre-occupation with fund raising became particularly apparent during the civil war when disability groups proliferated. These groups became aware of the financial possibilities from incoming development aid which resulted in a frenzied scramble for funding. One disability activist remembers the period when “everyone was competing for the same aid. It was really difficult to stop everyone from competing with each other” (interview 9/11/2017).

To ensure their own financial survival, DPOs compete with each other for funds. Consequently, there is a tendency amongst groups to see each other first and foremost as competitors, rather than as potential partners for change. This can be clearly illustrated by the history of SLUDI which, despite being an umbrella organization whose official mission is to advance the interests of members, competes with its members for funding. Since its inception in 1995, the organization has spent substantial time and resources engaging international donors for financial support to implement projects. This has contributed to a widespread view that SLUDI, at times, puts its own interests above its members.

For instance, a prominent SLUDI member recalls during the umbrella’s early days that “there were [sic] a lot of feelings that SLUDI was going to take over the work of [...] other DPOs. We saw SLUDI as an enemy because we were [...] writing to the same donors for support” (interview 8/9/2017). For many donor agencies, SLUDI became the preferred disability group to fund given its umbrella status, capacity, reach and network. With SLUDI as the primary recipient of scarce donor funds, other DPOs became frustrated and aggrieved. The sentiment is still felt today and DPOs tend to be

skeptical of SLUDI's 'open arms' to help them find funds for their own various initiatives.

Besides competition for funds, informants shared numerous examples of disability groups in Sierra Leone competing with each other for members. Although small, membership fees are nevertheless important to cover administrative and activity costs. Without these funds, groups can hardly survive, especially in the long-term. Moreover, the more membership a group gains, the more legitimacy it has and the stronger its position and status in the movement. This is particularly helpful in an environment where many DPOs have similar objectives. While most groups allow members to cross over to other groups, some groups seek membership loyalty in order to secure their membership and funding base. According to informants, the 'snatching' of members has become a widespread practice within the movement. This behavior has strengthened the tendency of DPOs in Sierra Leone to see each other as competitors rather than as potential partners.

The issue of competition for members and the damaging effects it produces can also be observed in the history of SLUDI. While SLUDI's membership base consists of organizations rather than individuals, the dynamics are very much similar. In 2002, for example, SLUDI engaged in a dispute with another disability group called the 'National Disability Congress'. Soon after its formation, the National Disability Congress began to attract SLUDI's members with its promise of providing economic opportunities such as tailoring, tie-dying and manufacturing of assistive devices. The group ballooned overnight and threatened the membership base and position of SLUDI. When it sought membership registration with SLUDI, the latter refused and demanded its dismantling. The result was a two-year dispute between the two groups which had disastrous effects. Besides dividing the disability community, the fighting undermined SLUDI's ability to mobilize its constituents, effectively rendering its advocacy work ineffective. During the two years of fighting, much of SLUDI's attention was focused on its own survival rather than strengthening disability rights and uniting its members.

Finally, resource scarcity contributes to DPOs aligning themselves with political parties. Many examples were shared of how key leaders within the movement openly align themselves with political parties to gain political favors in the form of funds and political positions. Such alignment happens especially during election periods when politicians try to secure support. Political alignment has contributed to distrust and divisions among movement members because it creates different camps and damages the feeling of togetherness. Numerous examples were cited by informants of politicians playing 'divide and conquer' by strategically supporting certain disability groups whilst undermining other groups. According to informants, resource scarcity makes disability movement vulnerable to such political 'games.'

Political alignment and its effects on the movement can also be clearly observed in the history of SLUDI. In the 2012 national elections for example, the president of SLUDI sided with the All People's Congress (APC), one of the two major political parties in Sierra Leone, thereby alienating SLUDI members who supported the opposition party, the Sierra Leone People's Party. A group of visually impaired persons contested SLUDI's position but was immediately prohibited from participating in SLUDI's general elections that same year. A member of a visually impaired group remembers, "the majority of [SLUDI] members ... come from APC, which has a stronghold in the North. [These members] aligned themselves with the party and government officials. For those who are not APC [like me], they ... were not looked upon kindly because of [our] association ... they singled me out and others" (interview #2 of 2, 9/11/2017). Informants explained that SLUDI's political alignment is an important reason why some disability groups choose to not cooperate with SLUDI today.

### *Diverging interests*

A second centrifugal force within the disability movement in Sierra Leone concerns the different interests that different impairment types have. DPOs in Sierra Leone tend to have members of the same impairment type. Interviewees said that it was more convenient for persons with the same impairment to get together since they face similar challenges and stigma, understand each other and can share common solutions. A polio disability activist for example explains that "the physically challenged need different things than the blind. We all need different treatments, supplies, etc." (interview 21/8/2017).

As persons with disabilities in Sierra Leone associate mostly with others of the same impairment type, it is not surprising that DPOs mainly cooperate with other groups of a similar impairment type. One informant explained that "because of the different categories of disability, we see ourselves as different people" (interview 9/11/2017). These findings suggest that persons with a disability in Sierra Leone experience their collective identity<sup>1</sup> first and foremost at the level of their specific impairment as opposed to the overall group of disabled persons. The segregated cooperation per impairment type becomes problematic when there is a need to advocate for issues that affect all impairments.

From the onset, the differentiated interests of different impairment types have provided a major challenge for SLUDI to unite its members. "Sometimes we think that the needs of [the different disabilities] are too diverse to share a common goal [in SLUDI]" (interview 21/8/2017), explained an informant. Throughout SLUDI's history this has affected the organization's

ability to mobilize its members and persuade them to undertake joint action. One recurring joint action issue, for example, has been the accessibility of learning materials to support the reading and writing of people with disabilities nationwide. However, each time SLUDI tries to rally its constituents on this issue only a handful of organizations come out and lend their support; therefore, undermining the movement's collective force and lobbying and advocacy prowess.

### ***Capacity differences***

According to informants, organizations made up of polio survival and visually impaired persons tend to be strongest in Sierra Leone. The hearing impaired and groups that are still fighting to be recognized as a disability group, such as the albinos and people with mental health problems or cognitive impairments, tend to be weaker capacity-wise. These groups tend to have more difficulties organizing themselves, managing their organizations effectively and mobilizing support.

These differences are clearly related to the (divergent) history of educational opportunities for different impairment types in the country. Historically, polio survivors have had the least problems in accessing education and their group consists of a core of articulate and educated leaders and entrepreneurs. This is followed by the blind/visually impaired group who, unlike the other impairment types, have had access to special education for over 30 years. It is no coincidence that the first DPOs in the country were established (in 1976) by visually impaired persons. Other impairment types still face great(er) difficulties in accessing education. For example, there are only two schools for hearing impaired in the whole of the country (in Freetown and Makeni), which are not a realistic schooling option for those living in others parts of the country. Mainstream schools are not a feasible alternative due to the lack of sign language teachers and/or hearing aides.

In light of the above differences between different impairment types, it is not surprising that key positions within the National Commission for Persons with Disabilities (NCPD) and SLUDI have historically been held by polio survivors and visually impaired persons. This, however, has contributed to a widespread view amongst other disability types that their people are benefiting less from these prominent disability organizations. About the NCDP, for example, a member of an amputee group said: "...they [the Commission] are not inclusive with us ... they don't care about us. They have isolated us" (interview 21/11/2017). Similarly, another respondent explains that "everyone knows that SLUDI likes to work with the blind and physically challenged [i.e. the polio group]. They like to stick together like bread and butter. It has

been like that for a very long time now” (interview 09/12/2017). According to respondents, the feeling that key organizations in the disability movement work primarily to serve polio survivors and visually impaired persons have impeded the overall sense of unity in the movement. Moreover, the capacity differences between impairment types contribute to a sense of hierarchy within the movement.

### **Keeping it together**

We have argued in this paper that resource scarcity, diverging interests and capacity differences have contributed greatly to the fragmentation of the disability movement in Sierra Leone. However, and somewhat surprisingly, instead of simply disintegrating, we see a movement that is still somehow together and trudging-on despite the fissures. Our research identifies three main reasons that keep the movement from falling apart: (1) interdependence, (2) shared experiences of marginalization, and (3) a clear identification of the ‘other’.

First, there is a realization between different groups and impairments types that they need each other if they are to achieve their goals. Despite impairment-specific interests, important joint interests remain. Many of the sought-after changes at the policy and awareness raising levels are relevant for all impairment types. It is very difficult or nearly impossible for individual groups and single impairment types to achieve these changes. Achieving results requires sufficient critical mass whilst demands for change are less easy to ignore by a movement speaking with one voice. Historically, in Sierra Leone, persons with disabilities have been more successful in drawing attention to their demands and in advocating for inclusion in all aspect of social, political and economic life than they would have if they worked in silos. As a member of a disabled persons organization (DPO) noted “perhaps it is the need to respond [collectively] to the challenges faced by the PWD [persons with disabilities] community that has kept the movement alive, despite its fragmentation” (Interview 30/10/2018).

In recent years, the international donor community also provides incentives to work together. The rise of the Sustainable Development Goals (SDGs) and the ‘Leave No One Behind’ agenda resulted in more attention for disability issues whilst bringing greater emphasis on multi-stakeholder cooperation. Globally, the SDGs have resulted in more attention and funding opportunities for inclusion. As noted by a chief executive of an NGO “donor interests in the area of disability is increasing and the demand for ensuring inclusion in programmes has taken a new positive trend. So we are seeing organizations going after disability organizations to justify the relevance of their interventions. Inclusion as an aspect of development is now the norm

as seen in the SDGs and national programmes. So, this global hype is a blessing for the PWD movement” (interview 30/10/2018).

At the same time, the rise in funding opportunities for disability is accompanied by a greater demand for multi-stakeholder cooperation. Increasingly, donors are interested in achieving results at the sectoral level, which typically cannot be achieved by single organizations alone. The community of persons with disabilities increasingly recognizes this and informants cited several examples of organizations working together and presenting themselves as a unified movement to capitalize on this interest.

Second, the shared experiences of marginalization across all impairment types contribute to the unity of the movement. One informant noted that “even though we [have] different disabilities, we [have] a broader problem—that is we are disabled” (interview 11/9/2017). Even as DPOs compete for primacy and recognition, there is a common understanding among people with disabilities that they should stick together despite the challenges, because they are the most marginalized in society. In Sierra Leone, all impairment types face discrimination and stigmatization related to a widespread lack of access to resources, such as proper housing, education and employment opportunities. Informants explained how negative societal attitudes and behavior in general towards people with disabilities contribute to a feeling of ‘us versus them’ mentality. Moreover, they explained that shared experiences of hardship and marginalization create a moral and emotional connection with ‘fellow disabled’.

There exists an inert form of solidarity through which disabled persons look out for and protect each other. This is often couched in one of their slogans “you touch one, you touch all.” This is summed up well by a key leader in the movement: “We may fight each other but we will not allow an outsider to mess with one of our kind. [...] Now it’s about finding a solution to our general problem of exclusion” (Interview 2/10/2018). These findings illustrate that collective identity not only exists at the impairment level as illustrated in the previous section, but also at the overall movement level.

Third, within the community there is a clear sense of ‘the other’: outsiders who are perceived as often not having the community’s best interest at heart. There is a long history in Sierra Leone of people with disabilities being treated as needy recipients of charity, both by the government and (international) organizations. During the civil war, a lot of funds were raised for people with disabilities by NGOs. More often than not, people with disabilities had very little to no say over what was done with the funds and some funding never reached the intended recipients. It was during this time that a consciousness emerged regarding the idea of people with disabilities determining their own destiny. This implied resisting those persons or organization who talk on their behalf or over their head. “Our experiences of

discrimination and marginalization, our experiences of the desire for people to speak on our behalf made us realize that we cannot continue like this. We wanted to come out and speak for ourselves and represent ourselves,” said a key leader of the movement (interview #1, 9/10/2017). The resulting foundation of SLUDI should not only be seen as a manifestation of the felt need for self-determination, but also as part of a process of collective identity formation fueled by the identification of the ‘other’.

The feeling that ‘outsiders’ do not necessarily have the best interest of people with disabilities at heart persists till this very day. This has manifested itself in a hypersensitivity to being exploited by ‘outsiders.’ Informants cited examples of NGOs pitting one group against the other in the pursuit of funds. One informant explained that “NGOs used the division within the movement, especially SLUDI, and the disability community to solicit for funds for their own benefit while pitting one group against another” (interview 2/10/2018). Overall, many people with disabilities interviewed for this study believed that both NGOs and INGOs are partly responsible for the fragmentation of the disability movement. Paradoxically, this simultaneously strengthens the movement’s collective identity and as such contributes to its unity.

## **Conclusion, discussion and recommendations**

This study seeks to contribute to our understanding of the challenges and constraints experienced by disability movements in Sub-Saharan Africa. Based on a case study of the movement in Sierra Leone it seeks to better understand the forces that contribute to its fragmentation and to keeping it from falling apart. The study identifies three main ‘centrifugal’ forces underlying fragmentation: resource scarcity, impairment specific interests and capacity differences between impairment types. Furthermore, it finds that interdependence, shared experiences of marginalization, and a clear identification of the ‘other’ have a unifying effect on the movement.

The study illustrates that the three ‘centrifugal forces’ lie at the basis of a complex set of interrelated dynamics. These include the tendency to go for one’s own organizational interests at the expense of others (creating distrust), unequal educational opportunities and an unequal representation of different impairment types (contributing to a movement hierarchy), political alignment (creating tensions and camps) and impairment specific interests (limiting interaction across impairment types). A similar set of dynamics underlie the three ‘unifying’ forces. Of particular importance are funding condition and interdependence to achieve overarching goals (providing incentives for cooperation), shared experiences of marginalization (creating an emotional connection and feelings of solidarity) and negative experiences

with ‘outsiders’ (fueling distrust in ‘outsiders’ and a desire for self-representation).

The study yields a number of practical recommendations for disability groups and donors. Leaders in the movement have a responsibility to promote broader awareness that key goals can only be achieved by working together. Additionally, relevant disability groups should ensure an equal representation of different impairment types whilst refraining from political alignment. Donor agencies should stimulate cooperation between DPOs, including those of different impairment types. Moreover, they should fund strategically, taking sensitivities with regard to competition into account whilst being very critical towards political alignment and the (un)equal representation of different impairment types. Finally, they should invest in the education of persons with a disability, particularly impairment types with a historical educational disadvantage.

## Note

1. The term has been used in different ways across time. See for example Melucci (1995), Poletta and Jasper (2001), Acheson and Williamson (2001), and Flesher-Fominaya (2010).

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## ORCID

Willem Elbers  <http://orcid.org/0000-0002-0485-368X>

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