

Breaking down Barriers

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The Disability Movement in Sierra Leone

Fragmented Yet Together

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Executive summary

This paper examines the dynamics affecting the cohesion of the disability movement in Sierra Leone, focusing on the willingness and ability of Disabled Persons Organizations (DPOs) to work collectively. The study finds that the disability movement is fragmented (referring to the tendency of DPOs to work in isolation) yet somehow manages to achieve collective successes at key moments. The study identifies three forces that contribute to the movement's fragmentation: resource scarcity, impairment specific interests and capacity differences between impairment types (the physically and visually impaired generally being better educated and having stronger organizations than other impairment types). Furthermore, three 'unifying' forces are identified: interdependence, shared experiences of marginalization, and a clear identification of the 'other'. The findings imply a change agenda for both movement leaders and donor agencies.

Introduction

Disability movements around the world play a crucial role in uniting persons with disabilities, promoting their rights and providing services. But how united are these movements, particularly in the global South? This question is crucial since a degree of unity and cooperation is needed for movements to survive, thrive and achieve results. Working collectively creates a myriad of potential synergy including speaking with one voice to the government, combining different skillsets, sharing crucial information, increasing campaign visibility, mobilizing larger groups and increasing the scope of activities. As a collective, disability groups can achieve results they could never achieve if they would work alone.

Based on empirical research, this paper examines the dynamics affecting the unity of the disability movement in Sierra Leone. The starting premise is that the movement is fragmented, yet somehow manages to refrain from falling apart, even realizing several collective successes. This paper asks the question: What are the forces that (simultaneously) drive fragmentation

and cohesion within the disability movement in Sierra Leone?

The analysis is based on qualitative data collected in the capital of Sierra Leone, Freetown, during a six-month period in 2017-2018. The research employed a range of methods including participatory observation, focused group discussion, archival research and interviews with 45 members of the disability movement. The study aimed to capture the perspectives and experiences of a wide range of impairment types and organizations, including the national umbrella organization SLUDI. During the research practical support was provided by One Family People which is the strategic partner organization of Liliane Foundation in Sierra Leone.

Fragmentation

A recurring concern expressed by informants is the fragmentation of the disability movement in Sierra Leone. They spoke about the inability of groups within the movement to act collectively and formulate a unified position. Specifically, there is a tendency within

the movement for organizations to pursue their own interests, rather than operating in a collective manner to achieve joint outcomes. As explained above, this directly undermines the viability of the movement and its ability to achieve results. This study found that this fragmentation manifests itself in a variety of ways:

- Groups compete with one another for funding, members and visibility, sometimes at the expense of other organizations within the movement.
- Groups often 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.
- Groups do not always openly communicate strategic opportunities for influencing important disability policies.

Three main centrifugal forces perpetuate the cycle of the fragmentation: (1) resource scarcity, (2) impairment specific interests and (3) capacity differences between impairment types.

Resource scarcity

Disabled Persons Organizations (DPOs) in Sierra Leone are typically pre-occupied with securing funds. They spend considerable time and energy on acquiring resources. Sierra Leone is a country rich in resources, but with a disproportionate high number of poor people. Thus, opportunities to raise funds locally are severely constrained. Also, while most associations ask for membership fees, these fees are generally low, limiting the scope of activities that can be undertaken. Organizations as a result find themselves in situations where 'chasing' funds is not only a time-consuming activity but also one that has become a goal in itself. 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 has undermined cooperation and trust between groups.

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 run. Moreover, the more members a group gains, the more legitimacy it has and the stronger its position and status in the movement. According to informants, the 'snatching' of members has become a widespread practice within the movement. This behavior has further strengthened the tendency of DPOs to see each other primarily as competitors.

Resource scarcity has also contributed 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 especially happens 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 others.

Diverging interests

Different impairment types have different interests. DPOs in Sierra Leone tend to have members of the same impairment type. Often it is more convenient for persons with the same impairment to get together since they face similar challenges and stigma, understand each other and can share solutions. A polio disability activist for example explains that 'the physically challenged need different things than the blind. We all need different treatments and supplies.'



A person with a physical disability and a person with visual impairment put on a skit about increasing Persons with Disabilities political representation in the 2018 Elections.



A giant sized protest poster made by another movement-like group of PWDs asking for the National Commission for Persons with a Disability to release its 2015-2016 financial reports.

As persons with disabilities in Sierra Leone associate mostly with others of the same impairment type, it is not surprising that DPOs tend to cooperate mostly with other groups of a similar impairment type. These findings suggest that persons with a disability in Sierra Leone experience their collective identity (sense of belonging to a group) first and foremost at the level of their specific impairment as opposed to the overall group of persons with disabilities. The segregated cooperation per impairment type becomes problematic when there is a need to advocate for issues that affect all impairments.

Capacity differences

Disability groups whose members consist of polio victims 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, people with mental health problems or cognitive impairments, tend to be weaker capacity-wise.² These groups often have more difficulties organizing themselves, managing their organizations effectively and mobilizing support.

These differences seem to be related to the (divergent) history of educational opportunities for different impairment types in the country. Historically, polio victims have had the least problems in accessing education and their group consists of a core of articulate and well-educated leaders. This is followed by the visually impaired group which, 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.

In light of the above capacity differences between different impairment types, it is not unexpected that key positions within the National Commission for Persons with Disabilities (NCPD) and the umbrella organization SLUDI have historically been held by polio victims and visually impaired persons. This, however, has contributed to a widespread view amongst other impairments types that they are benefiting less from these prominent disability organizations. This impedes the overall sense of unity while contributing to a sense of hierarchy within the movement.

Cohesion

Resource scarcity, diverging interests and capacity differences have contributed greatly to the fragmentation of the disability movement in Sierra Leone. However, instead of simply disintegrating, we see a movement that nevertheless refrains from falling apart, and which, at key moments, manages to act collectively. This manifests itself in a variety of ways:

- For realizing key legislative and legal changes, groups of different

impairment types have worked together and mobilized their constituencies.

- There are numerous examples of groups working together in joint projects and programs.
- There is a feeling of togetherness in the movement that transcends impairment types.

The study finds three main forces that drive movement cohesion: (1) interdependence, (2) shared experiences of marginalization, and (3) a clear identification of the 'other'.

Interdependence

Regarding the 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 together requires sufficient critical mass whilst demands for change are less easy to ignore by the government if the movement speaks with a unified voice.

In recent years, the international donor community has also provided incentives to work together. The rise of Sustainable Development Goals (SDGs) has resulted in more attention for disability issues whilst bringing greater emphasis on multi-stakeholder cooperation. Globally, the SDGs have resulted in giving persons with disabilities more direct attention through various rehabilitative initiatives and funding opportunities for inclusion. At the same time, the rise in funding opportunities for disability is accompanied by a greater demand for multi-stakeholder partnerships. Increasingly, donors are interested in achieving results at the sectoral level which typically cannot be achieved by single organizations alone. The disability community recognizes this, and informants cited several examples of organizations working together and presenting themselves as a unified movement to capitalize on this interest.

Shared experiences of marginalization

The shared experiences of marginalization across all impairment types further contribute to the unity of the movement. Even as DPOs compete for primacy and recognition, there is a common understanding among persons 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 that their shared experiences of hardship and marginalization has created a moral and emotional connection with 'fellow disabled'.

There exists a sense of solidarity through which disabled persons look out for and protect each other that transcends impairment types. This is 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'. These findings illustrate that a collective identity not only exists at the impairment level as illustrated above, but also at the overall movement level.

Clear sense of the 'other'

Within the community there is also a clear sense of 'the other': outsiders who are perceived as not necessarily having the community's best interest at heart. There is a long history in Sierra Leone of persons with disabilities being treated as needy recipients of charity, both by the government and (international) organizations. During the eleven-year civil war (from 1991 to 2002), a lot of funds were raised by NGOs for war victims; although some funding initiatives also focused on some disability groups such as the blind and polio victims. More often than not, persons with disabilities had little to no say over what was done with the funds and some funding never reached them. It was during this time that a consciousness emerged regarding the idea of disabled persons determining their own destiny. This implied resisting those persons or organization who talk on their behalf or over their head.

The feeling that 'outsiders' do not necessarily have persons with disabilities' best interest at heart persists till this very day. This has manifested itself in a hypersensitivity to being exploited by 'outsiders.' Informants cited examples of NGOs (and government officials) pitting one group against the other in the pursuit of funds. Overall, many informants believed that both local and international NGOs 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 and recommendations

The study sheds light on the complex set of interrelated dynamics that fragment the disability movement in Sierra Leone. These include the tendency to go for one's own organizational interests at the expense of others (creating distrust), impairment specific interests (limiting interaction across impairment types) and capacity differences between impairment types (contributing to a movement hierarchy). A similar set of dynamics underlie the three 'unifying' forces. Of particular importance are mutual dependence in achieving overarching goals and acquiring funds (providing incentives for cooperation), shared experiences of marginalization (creating an emotional connection and feelings of solidarity) and negative experiences with 'outsiders' (fueling

distrust in these '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 foster cooperation and promote broader awareness that key goals can only be achieved by working together. Additionally, when applicable, disability groups should ensure an equal representation of different impairment types whilst refraining from political alignment. Donors have the responsibility to take broader movement dynamics into account when funding individual groups. This means being aware of how funding affects cooperation/competition and being critical towards political alignment and the (un)equal representation of different impairment types. Also, with regard to capacity strengthening, donors might consider taking the broader movement into account. This means providing additional capacity strengthening to organizations of impairment types whose capacity is weakest and/or investing in the education of persons with impairment types that historically have had an educational disadvantage.



photo: Amélie van den Brink

A person with a physical disability in a wheelchair wheeling up one of Freetown's main roads during afternoon traffic.

Further reading

Brink van den A. (2018). *Together Yet Fragmented: A Comparative Case Study of the Women and Disability Movements' Collective Identity Formation and Maintenance in Sierra Leone*. RESMA-thesis. Leiden: Leiden university.

Notes

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² Amputees, who are an important group in Sierra Leone due to the civil war, often do not consider themselves to be disabled. They are generally seen as being more educated than other groups and have had more financial aide to access education.