

**Pushing boundaries in disability advocacy**

# **Breaking down Barriers to inclusion**

**Edited by Willem Elbers**

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**January 2020**

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*Anneke Donker and Willem Elbers, January 2020*



# Foreword

Proud and satisfied, I wrote the introduction to this publication about the experiences with, and the outcomes, of the research conducted in the *Breaking down Barriers* project. Proud because *Breaking down Barriers* placed the Liliane Foundation at the core of a learning trajectory with vigorous and inspiring partners at home and in the global South. Satisfied, because *Breaking down Barriers* has met its objectives and has enabled us to learn from a diversity of projects on disability advocacy while building and disseminating a body of knowledge to a (potentially) worldwide audience.

The fact that *Breaking down Barriers* has met its objectives was underscored by the honorable conferment last March of the 'Impact Challenge Award'. It was for the first time this prize was awarded for 'the most inspiring learning experience in the field of impact-oriented work' in the Dutch non-profit sector. The jury stated that the *Breaking down Barriers* team showed the biggest development throughout the project period and gave praise that the knowledge produced and experience gained have been shared in accessible formats, both on paper and digitally.

The Liliane Foundation, founded in 1980, has a history of 40 years supporting children with disabilities and their families in low- and low-middle-income countries in Africa, Asia and Latin America. Initially focusing on support of individual children, the awareness grew that the sustainability of the support-structures and real social inclusion of children with disabilities can only be reached by securing equal opportunities and equal rights for all people with disabilities. The rules and regulations of the international UN Convention on the Rights of Persons with Disabilities, a convention ratified by 163<sup>2</sup> countries, forms an internationally recognized starting point here.

In the same 'era' in the history of the Liliane Foundation, it became more important for the international development sector to verify its assumptions on the efficacy of methods and strategies. With its strong international network and already long history of supporting children with disabilities, the Liliane Foundation felt a responsibility to contribute to knowledge development in this field. Cooperation with scientific partners was an obvious path to meet the need for evidence.

Here is where the African Studies Center came in. Embedded in Leiden University, with a track record on knowledge development in African countries, and - on a personal level - close ties with the Liliane Foundation, the African Studies Center was a natural partner to investigate the

possibilities of research on disability advocacy, with key roles for local partner organizations and academics. The rest is history: *Breaking down Barriers* started in 2015, and One Family People in Sierra Leone, the Cameroon Baptist Convention and Cheshire Homes Society in Zambia became project-partners in their respective countries. The results of this learning trajectory can be read in this publication which delivers a wealth of information and insights.

With the project *Voices for Inclusion*, a spin-off from *Breaking down Barriers*, the Liliane Foundation further builds and expands upon the knowledge and insights gained. Together with 'Voice'<sup>3</sup> and the Dutch Coalition on Disability and Development (DCDD), we have initiated a project in which face-to-face-learning between different types of marginalized groups, from different countries in Africa and Asia, served to identify influential and effective methods for lobby and advocacy while exploring options for new collaborations.

The joint final conference of the *Breaking down Barriers* and *Voices for Inclusion* projects on the 29<sup>th</sup> of January 2020 is a natural moment for the launch of this publication. This conference brings together a large number of stakeholders from practice and academia, all interested in increasing the power of advocacy, influencing governments for policymaking on behalf of, with or by vulnerable people. It is my hope that the conference will offer a platform for exchange and inspiration for breaking down barriers to inclusion.

Steven Berdenis van Berlekom  
Executive Director, Liliane Foundation



photo: Rommie DankeIman

<sup>1</sup> The Impact Challenge is a sector-wide initiative with the aim of further increasing the social impact of the non-profit sector and making it more visible. <http://www.impact-challenge.nl/>

<sup>2</sup> As of 01/01/2020

<sup>3</sup> Voice is a grant facility of the Netherlands Ministry of Foreign Affairs, managed by a consortium between Oxfam Novib and Hivos.

# 1 Introduction

Willem Elbers

The publication examines the conditions under which advocacy can produce meaningful change for persons, children and youth in particular, with disabilities. In pursuing this goal, this book introduces eight original empirical case studies based on research conducted in Sierra Leone, Cameroon and Zambia which explore the factors and dynamics that determine the results of disability advocacy. A ninth paper presents an analytical framework for organizational advocacy capacity based on an extensive literature review. Overall, the publication offers insights and lessons for disabled people's organizations, local and international NGOs and donor agencies.

In a way, this publication is a product of its time. In the past decade, the rights and interests of people with disabilities gained prominence on the international development agenda. This has been further solidified with the Sustainable Development Goals and the *Leave No One Behind* agenda. Encouraged by the growing interest in disability issues, civil society organizations are becoming increasingly active in trying to raise awareness and making governmental policies and practices more disability inclusive. It is widely recognized that civil society plays an important role in promoting the rights of marginalized groups, including people with disabilities, through advocacy.

Effective civil society engagement in advocacy requires a clear understanding of the factors and dynamics that determine its success. As of yet, however, the success factors of disability advocacy in the global South remain poorly understood. The learning trajectory *Breaking down Barriers* (see box 1), of which this publication is an integral part, is rooted in the observation that little publicly available evidence exists on disability advocacy. In the (Critical) Disability Studies literature, for example, there has been relatively little attention for the organizational and managerial aspects of disability rights and advocacy. Furthermore, very few (international) disability organizations have publicly shared their evaluation studies of advocacy campaigns. *Breaking down Barriers* addresses this gap while seeking to advance the debate on disability advocacy in the global South.

## Box 1. Breaking down Barriers to inclusion

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The *Breaking down Barriers* learning trajectory was initiated by the Liliane Foundation and the African Studies Centre (Leiden University) in 2015. The trajectory aimed at generating robust evidence on the success factors of advocacy for children with disabilities and strengthen the advocacy capacity of Liliane Foundation and its strategic partners. The research in the trajectory was conducted by talented postgraduate students as part of the fulfillment for a (Research) Master's degree. The students were carefully selected from five different Dutch universities for their talent and motivation. The case studies presented in this publication are based on the theses written by the respective students.

Key partners in the trajectory have been One Family People (OFP) in Sierra Leone, The Cameroon Baptist Convention Health Services (CBCHS) and Cheshire Homes Society of Zambia. In each of the three countries, a local academic offered field supervision while ensuring that the research undertaken was context sensitive and met quality and ethical standards. Besides generating academic knowledge on disability advocacy, learning events were organised in the three countries which targeted a wide range of stakeholders and revolved around the real-world implications of research findings. The project's management consisted of Anneke Donker (Liliane Foundation) and Willem Elbers (African Studies Centre).

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The findings from *Breaking down Barriers* allow us to critically reflect upon the existing practices of disability groups, (I)NGOs and donors. This reflection challenges existing practices and yields three key priorities with regard to the future of disability advocacy. These priorities relate to the central importance of (1) movement building, (2) intersectionality and (3) the personal change of persons with disabilities, which enables them to challenge prevailing views and norms on disability.

### Movement building

Structural change can only be realized if persons with disabilities play a leading role in their own emancipation. This gives the disability movement, which consists of disability activists and groups seeking to secure equal opportunities and equal rights for all people with disabilities, a central role in the struggle for disability inclusion. Generally, persons with disabilities have the best understanding of their own needs, interests and barriers. Disabled people's organizations have greater credibility and legitimacy than organizations without a clear constituency. Also, we need to recognize that the time frame of social and political change, which often takes decades, goes beyond the funding cycles or policy priorities of (I)NGO or donor agencies. The alternative, advocacy on behalf of persons with disabilities,

is justifiable only in exceptional situations, for example when persons with disabilities are not in a position to speak for themselves. In fact, advocacy for disabled people can actually be counterproductive as it confirms and reproduces the negative stereotypical view that they cannot take care of themselves.

The disability movements in Sierra Leone, Cameroon and Zambia are all fragmented and have great difficulties to function as a collective, high-lighting the need for movement building. While strong and united disability movements are the key towards social and political change, the common pattern is that they are fragmented along impairment types (e.g. physically, visually, hearing impaired). Different impairments face different types of stigma and societal barriers. Consequently, it is often more convenient for persons with the same impairment to get together as they face similar challenges. The research found that persons with disabilities experience their collective identity, their feelings of belonging to a group, first at the level of their specific impairment. Their 'general disability identity' comes second. As a consequence, disability associations tend to have members of the same impairment type and cooperate mostly with others of the same impairment type. The fragmentation within the movement is further strengthened by capacity differences between impairment types. Generally, the physically and visually impaired tend to be better organized and educated than other impairment groups. These differences are clearly related to differences in the educational opportunities that different impairment types have historically enjoyed in countries like Sierra Leone, Cameroon and Zambia.

Despite the crucial role of the disability movement in achieving change, social movement building has not been a priority for INGOs and donors. In fact, in several ways, the practices of INGOs and donors actually go against the notion of building a strong and united movement. Persons with disabilities can only be agents of their own emancipation if they can set their own priorities. It has been widely documented in the literature, however, that donors and INGOs often work in a pre-determined and top-down manner which negates the ability of local disability groups to set the agenda. Few donors and INGOs are directly accountable to persons with disabilities. This is paradoxical, as advocacy, and rights-based approaches in general, imply that aid recipients are transformed from 'passive beneficiaries' to 'rights-holders' and persons with agency. Furthermore, most donors and INGOs prefer to work with 'professional' NGOs with the capacity to design projects and write accountability reports, as opposed to more informal expressions of citizen action, such as disabled people's organizations, which have a constituency but may lack capacity. Capacity building often does not prioritize the ability of groups to be 'actors in their own right' but instead tends to focus on their capacity to implement donor-funded projects and fulfil accountability requirements.

### Intersectionality

The findings of *Breaking down Barriers* also imply is that intersectionality should be a key principle of disability advocacy. Disability advocacy which only considers the disability part of people's identity runs the risk of being less effective. Advocacy strategies are rooted in an understanding of what drives exclusion. Persons with disabilities have multiple, overlapping and interrelated identities. They are not only marginalized because they have a disability, but also because of other identities like their gender, age, sexual orientation or ethnicity. For example, girls with disabilities may not only be marginalized because of their disability, but also because of their gender and age. This is called intersectionality. Addressing the root causes of these girls' marginalization therefore requires accounting for their overlapping multiple marginalized identities. This makes intersectionality a crucial lens for designing more effective and inclusive advocacy strategies.

Adopting intersectionality as a key principle also creates opportunities for new alliances that increase the likelihood of achieving and amplifying results. Where multiple identities are associated with interrelated and overlapping mechanisms of marginalization, intersectionality enables advocates to forge new relations with non-disability groups (e.g. youth, women) depending on the issue at hand. By joining forces with these other groups, it becomes possible to combine human and managerial resources and search for solutions that go beyond each group's limited vision of what is possible. More concretely, such new relations can provide access to crucial new knowledge and expertise, increase critical mass, access to new networks, increase campaign visibility, mobilise larger groups and generally increase the scope of advocacy work.

Intersectionality is equally important for making the disability movement itself more inclusive. While this movement plays a key role in advocating for equal opportunities and equal rights for people with disabilities, *Breaking down Barriers* found the movements in Sierra Leone, Cameroon and Zambia to be far from inclusive. Age, gender and impairment type in particular have a major impact on people's ability to make their voice heard. The level of involvement of youth and women typically remains limited due to socio-cultural norms regarding age and gender which are not only (re)produced by (older) men, but also by women and young persons themselves. This raises critical questions about whose needs and interests are considered within the advocacy undertaken by these movements. If the disability movement's advocacy work is to genuinely represent its constituency, it cannot avoid taking diversity into account.

### Personal change

Finally, the findings of *Breaking down Barriers* imply that the personal change of persons with disabilities, which enables them to challenge prevailing societal views and norms, should be a key goal within disability advocacy.

There is a great need to work towards personal change as many persons with disabilities have internalized negative social views on disability, keeping them from undertaking action to improve their situation. In Sierra Leone, Zambia and Cameroon, there is a huge stigma attached to disability and persons with disabilities are persistently excluded and constrained from active participation in society. There is a widespread view that persons with disabilities are helpless, unable, and are a burden upon society. Many persons with disabilities have internalized these negative attitudes and views about their disability, suffer from shame and a low sense of self-worth and blame themselves for their predicament. This prevents them from questioning their situation, envisioning any possibilities for a better future while limiting their assertiveness and aspirations. Such inaction then, in effect, further confirms and reproduces the existing negative social views on disability. Consequently, there is a great need for advocacy that enables persons with disability to envision a different life, providing a sense of being in control over their one's life and thus greater sense of responsibility of one's actions.

The current advocacy discourse runs the risk of prioritizing political and structural change at the expense of personal change. Existing definitions and approaches of advocacy, including those used by the Dutch government in its current civil society policy, stress the centrality of political change and influencing the decisions of those of positions in power. Advocacy in this line of thinking is mainly about setting the political agenda, shaping societal and political debates and influencing procedures, policies and laws. While the research conducting in *Breaking down Barriers* certainly validates the importance of political change, the downside of this 'political' focus is that it obscures the importance of the much-needed personal change of persons with disabilities.

Realizing personal change is a precondition for building a strong and successful disability movement. Advocacy that is based on the belief that people with disabilities should be agents of their own change, as opposed to needy recipients of support, has to embrace the importance of personal change. To be successful, the disability movement needs persons who are willing and capable of challenging dominant views and norms on disability. Once people with disabilities start working towards a better future, they simultaneously show society that disability does not equal inability. The research has shown that there is a great need for role models with disabilities who act as champions of the disability movement. These role models can show others with a disability that success is possible. They can offer the inspiration needed to enable others to overcome a state of passiveness, look differently at themselves and start taking life in their own hands.



## 2

### Advocating inclusive education in Cameroon

# Which organizational resources matter?<sup>1</sup>

Sebastian Potthof and Willem Elbers



## Executive summary

In many countries, children with disabilities are excluded from equal opportunities in society. Through lobby and advocacy civil society organizations can play an important role in convincing governments to make their policies and practices more inclusive. As of yet, the success-factors of lobby and advocacy remain poorly understood. Based on evidence from Cameroon, this study identifies three types of organizational resources that are decisive for achieving advocacy outcomes. First, to be taken seriously by power holders, credibility is key. Credibility is about being recognized for one's track record, performance and integrity. Second, strong social ties are crucial for gaining access to specialised expertise and power holders. Third, successful engagement with power holders requires charismatic representation. Much depends on the rhetorical skills of the person doing the actual face-to-face contact with power holders and his/her (perceived) commitment and sincerity. Overall, the findings demonstrate that a strong presence where power holders reside is an important precondition for being seen as a relevant player and building up and maintaining relations with power holders.

## Introduction

According to estimates from the World Health Organization, roughly 15% of the world's population lives with a disability, of which 150-200 million are children under the age of 18<sup>2</sup>. These Children With Disabilities (CWDs) are particularly vulnerable given their dependence on their family and care-takers. Often CWDs face severe forms of discrimination and stereotyping, typically based on prejudices, a lack of knowledge and prevailing cultural beliefs. Difficulties in accessing services in the areas of education, employment, healthcare and social and legal support further contribute to their marginalization.

Creating equal opportunities for CWDs and enabling them to participate in society to the fullest of their potential is crucial. Civil society organizations can play an

important role in promoting inclusive policies and practices through lobby and advocacy. Effective advocacy requires a clear understanding of the factors that determine its success. Despite the growing interest in lobby and advocacy to improve the position of marginalized groups, these success factors remain poorly understood.

Drawing on evidence in Cameroon, this paper seeks to improve our understanding of the success-factors of advocacy. In particular, it seeks to clarify which organizational resources are most crucial for local civil society organizations in achieving advocacy successes for CWDs.

## The study

This paper is based on research which examined the SEEPD-programme in Cameroon. SEEPD stands for Socio



photo: Liliane Fondis

Inclusive women's group active on Sexual and Reproductive Health and Rights (SRHR).

Economic Empowerment of People with Disabilities and is implemented by the Cameroon Baptist Convention Health Services (CBCHS), a local civil society organization based in Bamenda. At the same time CBCHS is partner of the Liliane Foundation in Cameroon. The SEEPD-programme is funded by CBM, an international NGO seeking to improve the quality of life of people with disabilities in the poorest communities of the world. SEEPD

started in 2009 following the observation that there were almost no children with impairments in mainstream schools in Cameroon. Moreover, those few CWDs that managed to go to mainstream schools faced the additional problem that the existing examination policy did not take their special needs into account.

SEEPD was developed in response to these constraints among others. The program aims to empower CWDs in the North



Joining forces. The SEEPD-programme creates a Regional Network for evidence on Inclusive Education.

West region by increasing their participation in government schools and convincing the government to make inclusive education standard-practice in Cameroon. Education is inclusive when children with and without impairments learn together and participate in the same classes. Advocacy has been an important element of SEEPD and the program has targeted a range of governmental power holders at different levels. These include the Ministry of Education, Regional delegates (responsible for education policy at the regional level), the General Certificate of Education Board (or GCE Board, responsible for examination policy) and municipal councils (responsible for budget allocation for community development) and parent-teacher associations. To convince power holders regarding the importance of inclusive education, CBCHS used a variety of advocacy tactics. These include mass sensitization through the media (television, radio and newspapers), formal and informal meetings with power holders, workshops, piloting inclusive education in government schools and providing specialized advisory support to strengthen the government's capacity in the field of inclusive education.

#### Advocacy achievements

Since SEEPD started in 2009, it has realized a number of important advocacy successes. At the time of research, the most prominent outcomes include:

1 *Sensitisation of the general public on matters of disability rights and inclusive education.* The program reached the general public through its Community Based Rehabilitation (CBR) teams, radio and television programmes and the mobilization of religious and traditional authorities. SEEPD encouraged parents and caretakers to send children with impairments to school, thereby creating a 'demand' for inclusive education.

- 2 *Sensitisation of key power holders regarding the need for inclusive education.* Formerly, disability rights and inclusive education used to be 'hidden' topics in North-West Cameroon. SEEPD had done much to make these issues visible and put them on the political agenda.
- 3 *Implementation of inclusive education in 17 pilot schools.* SEEPD succeeded in convincing the government to pilot inclusive education in 17 government schools. Besides providing education opportunities to individual CWDs, the pilot schools served to demonstrate feasibility of inclusive education to the government.
- 4 *Improved Examination Conditions for CWDs.* SEEPD managed to convince the government to adopt a new examination policy for the Anglophone part of Cameroon that takes the special needs of CWDs into account. Amongst other things, SEEPD provided an embosser to the GCE Board for improved braille translation of exams.
- 5 *Signing of action plans for disability mainstreaming by 18 Municipal Councils.* SEEPD entered into partnerships with a number of Councils to make their policies disability inclusive. In each Council, a focal person was installed acting as an intermediary between the Councils and SEEPD.

The study identified a wide range of resources that played a role in achieving these outcomes. Three resources, however, clearly stood out. This brings us to the next section.

#### Credibility

The first organizational resource that stood out as playing a key role in contributing to power holders' receptiveness to CBCHS's advocacy message is credibility. To be perceived as credible people have to know you in the first place. CBCHS clearly bene-



fitted from having a strong brand recognition, particularly in the Anglophone region of Cameroon. This can be traced to the organization's long history. Building on the prior work of German missionaries and American Baptists, the CBCHS was founded in 1953. Since its early years the organization has offered health services and amongst other things paid attention to disability (leprosy). Over the years, the organization became an established healthcare provider in the North-West region. Many people in the region, including individuals working for the government, know CBCHS from personal experiences with its health services.

So what made CBCHS credible in the eyes of power holders? Three elements stood out. The first one is the organization's track record. Given the fact that CBCHS's track record dates back to the 1950s, there is no doubt amongst power holders about the organization's knowledge and expertise on health and disability issues. Power holders made it clear that CBCHS can talk with real authority about these issues. The organization's credibility is further boosted by its reputation of being a strong performer. Most people, including power holders, know from personal experiences that the health services offered by CBCHS are amongst the best in the North-West Region. Finally, power holders emphasized the importance of the organization's integrity. In particular, they pointed out that the Christian (Baptist) identity of the organization contributed to CBCHS being seen as honest whilst being genuinely concerned for the well-being of Cameroonian people.

**Strong social ties**

The second organizational resource that played a major enabling role in the achievement of advocacy outcomes concerns CBCHS's strong social ties. First of all, these ties proved to be crucial in gaining

access to the required expertise in the field of inclusive education. While CBCHS has an extensive track record on disability issues, this has been mainly in the medical field. SEEPD, however, required expertise in the field of (inclusive) education. To gain access to such expertise, CBCHS from the start made good use of its existing connections with special schools in Kumbo and Mbingo. The expertise present in these schools in teaching children with impairments proved to be pivotal in the training of 'regular' teachers for the 17 pilot schools.

SEEPD also benefited immensely from its existing connections with power holders, in particular regional delegates. Here the network of its education advisor, who acts as the program's main 'ambassador' or lobbyist towards power holders, proved to be crucial. Of importance here is that the husband of the education advisor is a traditional leader, which makes the advisor a Queen and therefore a respected figure in Cameroonian society, especially in the North-West Region. Moreover the fact that her husband used to be a regional delegate for education proved to be helpful in gaining access to (current) regional delegates and convincing them to participate in the sensitization workshops. Once these delegates as the highest education authorities in the region were 'on board', the schools and the teachers could not decline the invitation to participate in the workshops organized by SEEPD.

**Charismatic representation**

While credibility is crucial for being taken seriously by power holders and social ties are key for gaining access to them, power holders themselves cited the charisma of the education advisor as an important reason as to why they had been receptive to SEEPD's advocacy message. Within the program the education advisor has been responsible for most face-to-face contact

with key power holders. Power holders made it very clear that they were impressed by her sincerity, motivation and commitment. Moreover, the interviewees highlighted that she also has the rhetorical skills needed for persuasion. Both the personality and skills of the education advisor proved to be pivotal to convince power holders.

**Local presence**

The above findings also shed light as to why SEEPD has been quite successful in the North-West of Cameroon while it (as

of yet) has not yet achieved the same level of success at the Ministry of Education in Yaoundé. The study shows that CBCHS's circle of influence is concentrated in the Anglophone part of Cameroon. While CBCHS is clearly established as a 'brand' in the North-West and South-West part of Cameroon, power holders at the Ministry of Education were not familiar with the organization as a relevant player in the disability and education fields. Similarly, while CBCHS has strong ties with power holders in the Anglophone part of Came-



photo: SEEPD

We Ring the Bell campaign referring to the SDGs motto Leave No One Behind. We Ring the Bell is an worldwide initiative of the Liliane Foundation aiming at raising awareness for the right to education of children with disabilities.

roon, it mostly lacks such ties at the Ministry of Education in Yaoundé. It is illustrative that one of the main persons at the Ministry-level who did make an effort to 'champion' SEEPD (the Secretary General of the Ministry of Secondary Education) is somebody who originates from the North-West

Region and is a personal contact of the education advisor. Overall, the findings show the limitations of lobbying power holders from a distance and, therefore, the importance of having a strong presence where power holders reside.



photo: Johannes Odié

### 3

#### Effective advocacy for children with disabilities

# Why the political system matters<sup>1</sup>

Zuleikha Mohammed and Willem Elbers

#### Further reading

Potthof S. (2016). *How Capacity Matters - Understanding Lobby and Advocacy for Inclusive Education in Cameroon*. MA-thesis. Nijmegen: Radboud University.  
See [www.barriersfree.org](http://www.barriersfree.org)

#### Notes

- <sup>1</sup> We would like to acknowledge the support of CBM in conducting this study and sharing the lessons learned from the SEEPD-programme.
- <sup>2</sup> World Health Organization (2011). *World Report on Disability 2011*. Geneva: World Health Organization.

## Executive summary

There is a great need for inclusive policies and practices which give Children with Disabilities (CWDs) equal opportunities to participate in society. Whilst civil society organisations can promote the rights of CWDs through lobby and advocacy, the factors that determine advocacy success remain poorly understood. Based on evidence from Cameroon, this study illustrates how a country's political system can both enable and constrain advocacy for CWDs. It shows that local NGOs have more opportunities to engage in successful advocacy when key power holders are close by, lack resources and can profit electorally from 'partnering' with the NGO concerned. In addition, the study found that in restrictive settings where critical civil society voices are not tolerated, existing governmental policies on disability offer a legitimate base to engage power holders.



Open Door Day of Inclusive Education at Government Bilingual High School in Kumbo, Cameroon. A SEEPD-programme's initiative.

## Introduction

People with disabilities are amongst the most marginalized and impoverished people. Children with Disabilities (CWDs) in particular are vulnerable, considering that they often cannot raise their voice and depend on their family and caretakers. Marginalisation and discrimination faced by people and children with disabilities are typically rooted in prejudices such as the underestimation of the potential of the individual, stereotyping, and the lack of knowledge or simply fear of disability. In many societies, different cultural beliefs can additionally enforce stigmas leading to exclusion and neglect, physical abuse and severely low employment opportunities.

Overall, there is a great need for inclusive policies which provide equal opportunities for people with disabilities, especially children. Civil society organizations can play an important role in promoting the rights of and opportunities for CWDs through lobby and advocacy. Effective engagement in lobby and advocacy requires a clear understanding of the factors that determine its success. As of yet, however, these success factors remain poorly understood.

Drawing on evidence in Cameroon, this paper seeks to improve our understanding of the success factors of advocacy. In particular, it examines how the political system - the way in which politics and governance are organized - affects the ability of local NGOs to engage in advocacy work for CWDs.

## The case study

This study on which this paper is based examined the SEEPD-programme in Cameroon. SEEPD stands for Socio Economic Empowerment of People with Disabilities and is implemented by the Cameroon Baptist Convention Health Services (CBCHS), a local NGO based in Bamenda. At the same time CBCHS is partner of the Liliane Foundation in Cameroon. The SEEPD-programme

is funded by CBM, an international NGO seeking to improve the quality of life of people with disabilities in the poorest communities of the world. In 2009, CBCHS noticed that there were almost no children with impairments in mainstream schools in Cameroon. Moreover, even if CWDs managed to go to school, they faced additional difficulties such as a governmental examination regulations that do not take the special needs of CWDs into account.

In response to these problems the SEEPD-programme was developed. SEEPD aims to empower CWDs in the North West region by increasing their attendance in government schools and convincing the government to make inclusive education the official standard in Cameroon. Inclusive education happens when children with and without disabilities participate and learn together in the same classes. Advocacy has been an important strategy in the programme and SEEPD has targeted a range of governmental power holders at different levels. The most notable power holders are the Ministry of Education, Regional Delegates (responsible for education policy at the regional level), the General Certificate of Education Board (or GCE Board, responsible for examination policy) and municipal Councils (responsible for budget allocation for community development).

To convince power holders about the need for inclusive education, CBCHS has used a variety of advocacy strategies. These include public education through the media (television, radio and newspapers), formal and informal meetings with power holders, piloting inclusive education in government schools and providing specialized advisory support to strengthen the government's capacity in the field of inclusive education.



### Advocacy outcomes

Since its inception in 2009, SEEPD has achieved a number of important advocacy successes. The most notable ones include:

- 1 *Sensitisation of key power holders regarding the need for inclusive education.* Inclusive education, previously a neglected topic in Cameroon, has become a visible issue, both in terms of the existing problems and the solutions it requires. Prior to directly sensitising power-holders, SEEPD first ensured that parents of CWDs expressed a demand for inclusive education. This was achieved through a weekly radio-show and community sensitisation work.
- 2 *Implementation of inclusive education in 17 pilot schools.* SEEPD got the authorization to pilot inclusive education in 17 regular government schools. Besides providing education opportunities to CWDs, the pilot schools served to demonstrate to the government that inclusive education is feasible. Ensuring full implementation of inclusive education to some extent remained a challenge.
- 3 *Improved Examination Conditions for CWDs.* SEEPD managed to convince the government (GCE Board) in the English-speaking North-West and South-West region to adopt a new examination policy



PDNP (Programme National de Développement Participatif) says it is ready to collaborate with the SEEPD-programme in promoting disability-inclusive development.

that takes the special needs of CWDs into account. Amongst other things, SEEPD provided an embosser to the GCE Board for improved braille translation of exams.

- 4 *Signing of action plans for disability mainstreaming by 18 Municipal Councils.* SEEPD convinced a number of Councils to mainstream disability issues, particularly regarding education, in municipal policy and budget allocation. In each Council, a focal person was installed who acts as an intermediary between SEEPD and the Councils.

The key question now is how the political system in Cameroon enabled and constrained CBCHS in achieving these outcomes. This brings us to the next section.

### Opportunities for advocacy

The study found that the political system in Cameroon provided four major opportunities for CBCHS to engage in advocacy.

First, decentralization in Cameroon has created opportunities to access relevant power holders precisely in the part (North-West Region) where CBCHS' network and reputation are strongest. Since 2004 the political system in Cameroon has been decentralized. For the implementation of education policy, the central state authority (Ministry of Education in Yaoundé) relies on a number of other government agencies such as the Regional Delegates, the GCE Board and municipal Councils. These power holders have the authority to create and implement policies, as long as these are in line with national policy. For SEEPD having relevant power holders situated closely at its headquarters had several advantages. First of all, it contributed to power holders' willingness to listen to SEEPD's advocacy message as CBCHS could approach power holders in the area (North-West Region) where its reputation, track record and network is strongest. Moreover, these

power holders' close proximity to the CBCHS headquarters greatly reduced travelling distances which contributed to their willingness to participate in workshops whilst reducing transportation costs.

Second, local level power holders have been receptive to CBCHS because decentralization has given them considerable responsibilities for which they do not have the expertise or resources to fulfill. Since the decentralization of the political system in Cameroon, there has been a devolution of responsibilities and authority to local power holders. The transfer of responsibilities from the central state, however, has not been matched by the transfer of resources. As a consequence, local power holders tend to lack the capacities and resources to fulfill their mandate. Consequently, local power holders are encouraged by central state authorities to raise their own (additional) funding. This makes them receptive to working with reputable NGOs such as CBCHS, which offers them opportunities to gain access to resources.

Third, the electoral concerns of municipal Councils in Cameroon has made them receptive to CBCHS which offered opportunities for favorable publicity. In Cameroon Municipal Councils and Mayors are elected. This makes them sensitive to favorable publicity as their future position depends on positive election outcomes. By being seen as creating and implementing policies that benefit the community, Councils hope to generate such publicity. CBCHS was aware of the Councils' electoral interests and was therefore keen to present its advocacy message as an opportunity for the Councils to better fulfill their responsibilities and generate a positive press. While engaging the Councils, SEEPD could build upon its public education work which had also aimed to make disability an issue that voters would be concerned about. CBCHS

used its media team to generate publicity for any council (in)action related to inclusive education.

Fourth, in a restrictive setting where critical civil society voices are not tolerated, existing governmental policies on disability offered a legitimate base for CBCHS to engage power holders. The political culture in Cameroon is such that civil society organizations that openly challenge the authority of governmental bodies are not tolerated. This means that advocacy organizations must be very careful in how they engage power holders. Within this restrictive setting, advocacy opportunities lie for an important part in existing policies and conventions which the government has ratified. For promoting the rights of CWDs this is not necessarily a problem as many problems related to CWDs in Cameroon are not so much caused by the absence of good laws and policies, but by the fact that they are not properly implemented. While approaching local power holders, CBCHS made sure that it was not perceived as a 'troublemaker' while highlighting that its demands were in line with existing national policies.

### Sustainability of advocacy outcomes

The study also found that the sustainability of the advocacy successes achieved by CBCHS in the long run could potentially be undermined by precisely those features of the political system which enabled SEEPD to be successful in the first place.

First, whilst decentralization offers opportunities to access the government at the local level, advocacy successes achieved at this level may be undermined by power holders higher up in the line of authority. Due to decentralization, CBCHS could gain access to relevant local-level power holders located in the area where its sphere of influence was strongest. While these local power holders have the authority

to create and implement policies as long as these fit national policies, they can be overruled by power holders higher up in the chain of authority. In the case of SEEPD, a number of teachers who had been trained under the programme to teach inclusively were transferred by the Ministry of Education to other schools. This contributed to several of the schools struggling to implement inclusive education.

Second, whilst local power holders' lack of resources offers opportunities to engage in advocacy, it also may undermine the sustainability of results obtained. Part of the achievements of SEEPD in the field of inclusive education can be attributed to local power holders' lack of funds and capacity and subsequent willingness to work with CBCHS. The lack of funds, however, means that the continued implementation of inclusive education in the pilot schools to a certain degree depends on the resources brought in by the SEEPD-programme. This raises doubts as to whether the achieve-

ments can be sustained and up-scaled in the long term. CBCHS has recognized this and is currently reaching out to the Ministry of Education which is responsible for making national education policy and controls the national education budget.

Third, whilst electoral dynamics at the level of municipal Councils offer opportunities to engage in advocacy, they also have the potential to undermine the sustainability of achievements. Councilors and Mayors are preoccupied by electoral concerns and they want to be viewed as creating and implementing policies that benefit the community. While SEEPD made use of these electoral concerns, the question is whether the agreements with the Councils will survive the next elections, particularly if new Mayors and Council-members are elected. This is particularly important because SEEPD's successes at the local level for an important part depend on the personal relations that were developed with individual Councilors and Mayors.



*We Ring the Bell* campaign in Benin. In front of the Parliament 600 children advocated Inclusive Education. On their behalf Ines (18) in sign language made a passionate plea to the Parliament's President. Hearing fellow student Jonita (12) translated her appeal. *We Ring the Bell* is an worldwide initiative of the Liliene Foundation aiming at raising awareness for the right to education of children with disabilities.

#### Further reading

Mohammed Z. (2016). *Easy Access, Easy Wins? Advocating for Inclusive Education in Cameroon. MA-thesis*. Amsterdam: University of Amsterdam. See [www.barriersfree.org](http://www.barriersfree.org)

#### Notes

<sup>1</sup> We would like to acknowledge the support of CBM in conducting this study and sharing the lessons learned from the SEEPD-programme.



photo: Ronnie Dankeiman

## 4

### Advocating for inclusive education in North-West Cameroon

# Realising behavioural change in a resource scarce environment<sup>1</sup>

Toke Custers and Willem Elbers

## Executive summary

In Cameroon, most children with disabilities do not attend (mainstream) schools. Prevailing social views are unfavourable with respect to investing in these children. This study examines the persuasion strategy of a local civil society organisation, the Cameroon Baptist Convention Health Services, in a campaign to promote inclusive education in the North-Western part of the country. Although it is too soon to establish whether inclusive education will become the new norm in the North-West, it is clear that key stakeholders are now sure of its importance. Three elements in the persuasion strategy appeared key for winning over stakeholders. The persuasion strategy (1) challenged the broader negative social views on disability as opposed to solely focusing on educational issues; (2) offered tailored rationales regarding investing in schooling for children with disabilities, which resonated with the specific values, beliefs and feelings of different stakeholders; (3) presented inclusive education as the most appropriate solution to the problem of low school enrolment rates among children with disabilities. The study also shows that in the resource-scarce environment of North-West Cameroon, winning over stakeholders is insufficient for behavioural change to occur. Stakeholders may be 'won over' but may still lack the resources to act. Cameroon Baptist Convention Health Services addressed this issue by supplementing its persuasion strategy with the strategic provision of key resources.

## Introduction

While reliable statistics are absent, it is clear that children with disabilities in the global South are at a considerable disadvantage in terms of school enrolment, educational attainment, and learning. The consequences of non-attendance are enormous. Besides limiting these children in their ability to decide who to be, what to do and how to live, the lack of schooling also has an adverse economic impact on the family, community and even the country. Fortunately, global awareness of the need for Inclusive Education (IE) is increasing. The United Nations Convention on the Rights of Persons with Disabilities calls for full inclusion of persons with disabilities in society. Several targets in the Sustainable Development

Goals are related to disability and IE. However, in many countries, including those in Sub-Saharan Africa, the political will and resources for implementation are often lacking.

This paper examines the advocacy programme of Liliane Foundation's strategic partner organisation in Cameroon: the Cameroon Baptist Convention Health Services (CBCHS), a local civil society organisation from the North-West of Cameroon. CBCHS has achieved a considerable degree of success in convincing key stakeholders to champion IE. More specifically, the study zooms in on the organisation's persuasion strategy and teases out those elements that were key to 'winning over' target audiences.



photo: CBCHS

Voliet a role model shares her educational experience as a woman with disability to encourage her peers with disability.





Strategic meeting to mainstream IE in the CBC Education system.

**The study**

In 2009, CBCHS started implementing the Socio Economic Empowerment of People with Disabilities (SEEPD) programme in North-West Cameroon.<sup>2</sup>

SEEPD was born out of the observation that few children with disabilities in Cameroon attend mainstream schools. Moreover, those that did attend mainstream schools faced additional constraints, such as an examination policy that did not take the diverse needs of children with disabilities into account. SEEPD aims to address this situation by promoting the participation of children with disabilities in government schools and convincing the government to make IE standard-practice in Cameroon.

Since its inception in 2009, CBCHS has targeted a number of audiences including government officials, local government authorities, religious and community leaders, school authorities and teachers, parents of children with disabilities and the general population. CBCHS used different strategies for different audiences. Government

officials, community leaders and religious authorities were engaged in personal meetings, consultative discussions and workshops. Headmasters and school personnel learned about inclusive education through workshops. Parents of children with disabilities received knowledge through personal and community meetings organised by community-based rehabilitation workers. Finally, the general population was sensitised with regard to the importance of IE for children with disabilities through different media outlets such as television, radio and newspapers.

While it was too early at the time of research to establish whether IE will become standard practice in North-West Cameroon, it is clear that CBCHS has been successful in mobilising key stakeholders to champion the concept. As a result of their effort:

- Regional government officials supported the piloting of IE in the North-West region;
- Seventeen school authorities implemented IE in their respective schools.

At the time of research, preparations were being made to extend the programme to additional schools in the Northwest and West regions;

- Community and church leaders provided support in helping to persuade parents of children with a disability to send their children to school;
- Parents were persuaded to send their disabled children to school;
- The Cameroon General Certificate of Education Board revised its examination policy to take the special needs of disabled children into account;
- Municipal councils signed action plans for making municipal policy disability inclusive.

To clarify how CBCHS managed to win over these stakeholders, research was carried out in the North-West of Cameroon over a period of two months in 2017. The study used a combination of semi-structured interviews (36 in total), two focus group discussions and participatory observation. Interviews targeted a range of respondents and informants, including staff of CBCHS, community and religious leaders, school headmasters, teachers, regional government officials, mayors and parents of children with disabilities.

**Challenging prevailing views**

In Cameroon, persons with disabilities are often stigmatised and discriminated against. Traditional beliefs play an important role in the stigma attached to disability and the discrimination resulting from it. A prevailing notion is that disability is caused by people failing to show due respect to supernatural and spiritual forces, such as ancestors. Such beliefs go hand in hand with a widespread lack of understanding of the medical causes of disability. Furthermore, persons with disabilities are widely viewed as helpless, unable, and as a burden upon society.

There is a strong belief that impaired children cannot fulfil the roles that children are supposed to fulfil, which is taking care of their parents when they are old and supporting the family.

Given the above, the persuasion strategy did not focus specifically on schooling for children with disabilities, but on disability in general. CBCHS realised that before they could convince different audiences to embrace IE, they would first have to challenge the broader negative views on disability in the North-West region. As long as these negative views remained unchallenged, people would not consider the limited (mainstream) school attendance of disabled children as a pressing problem in need of addressing. CBCHS subsequently regarded the sensitisation of the general public with respect to disability as a pre-condition for promoting the 'solution' of IE.

CBCHS used a variety of communication channels to encourage people to rethink their existing views on disability. The information that was provided explained, amongst other things, that disability does not come from witchcraft, but has medical causes instead. It then becomes clear that many forms of disability, like other medical conditions, can be prevented, addressed or even cured.

Furthermore, CBCHS explained that people with impairments are disabled by the society in which they live. In other words, that disability results from barriers and attitudes in the community that limit participation. These constraints result in many persons with disabilities suffering as a result of poor education, poverty, lower social standing, and ending up in a vicious cycle in which poverty and disability reinforce one another. In this context, CBCHS tried to drive home the idea that the responsibility for dealing with disability also lies in the community.

Finally, CBCHS went to great lengths to explain and demonstrate that if persons with disabilities are supported and offered opportunities just like other people, they are capable of achieving great successes. In communicating this point, CBCHS tried to provide concrete evidence by letting role models tell their own stories on radio shows and during meetings. Many respondents cited these concrete 'success stories' as particularly eye-opening.

### Rationales for investing in schooling

Another important element of the persuasion strategy consisted of providing tailored rationales to different target audiences as to why they should invest in the schooling of children with disabilities. These rationales were carefully crafted messages seeking to resonate with the specific values, beliefs and feelings of different stakeholders.

Firstly, CBCHS tried to make things personal by pointing out that disability is something that could affect anyone. Traffic accidents, for example, are very common in the area and people are left disabled by these incidents on a fairly regular basis. The argument raised is then; "if disability affected you or your children, you would want to be included and offered opportunities".

Secondly, CBCHS argued that children with disabilities can also provide social security to parents in their old age, by emphasising that they can be economically productive when given the opportunity. A widely held view in Cameroon is that education for children is crucial because it increases the opportunities for getting a good job, securing an income and becoming the future care providers for their parents. CBCHS built upon these ideas by explaining that children with disabilities, just like other children, can work and earn a living when properly schooled. Consequently, CBCHS argued that it makes

sense to invest in the schooling of children with disabilities as they also have the potential to become future care providers.

Thirdly, CBCHS appealed to religious norms and values and pointed out that investing in the schooling of children with disabilities is the morally right thing to do. They particularly emphasised the notion that everybody is created equal in the eyes of God, and the idea that "we are all brothers and sisters". The argument here is that as good Christians or Muslims, people should treat children with disabilities with love and care, just like they should treat their other brothers and sisters.

Fourthly, CBCHS emphasised the duties of different stakeholders, which relate to their role or formal position in society. To government officials, they pointed out that it is the formal duty of the government to take care of its citizens, and that children with disabilities are part of the population. To school personnel, CBCHS emphasised that the law states that all learners, including children with disabilities, should have access to schooling. Towards parents, CBCHS stressed that it is their parental responsibility to take care of their children, even if they have a disability, and that a failure to do so could attract legal sanctions.

### Presenting IE as the solution

Besides convincing different audiences that the low school enrolment rates of children with disabilities are an urgent problem in need of being addressed, CBCHS went to great lengths to present IE as the most appropriate solution. Here, the organisation built on its earlier explanation that disability results from barriers and attitudes in the community that limit participation. If disabled people are disabled not by their impairments but by society's failure to take their needs into account, society must adapt instead of the other way around. This means that education

must be made inclusive so that children with disabilities can access the full range of educational opportunities, just like everyone else. Moreover, being part of a mixed classroom enables children with disabilities to experience a sense of inclusion, form a wide circle of friends and get support from non-disabled learners. At the same time, non-disabled peers will realise that persons with disabilities also have talents enabling them to revise their views and move beyond prevailing stereotypes.

While presenting IE as the solution, CBCHS also provided concrete knowledge which enabled stakeholders to take action. After all, stakeholders can only embrace IE if they know what to do. By offering knowledge on how to move forward, CBCHS effectively eliminated potential reasons stakeholders might have for not doing anything. In workshops, teachers learned how to teach classes consisting of both disabled and non-disabled learners.

Church and community leaders learned how they could identify children with disabilities and convince their respective parents to send their children to school. Parents learned about the possibilities for inclusive education at public schools while receiving practical advice on how to better take care of their disabled child. Municipal civil servants learned how to incorporate ramps into future building plans so that children with disabilities can access new schools.

### Resource support

In debates on advocacy, the emphasis usually lies on influencing the views of target audiences and creating 'political will'. A key assumption here is that once these audiences have changed their mind, they will change their behaviour. This study challenges this assumption.

CBCHS realised that in the resource-scarce environment of North-West Cameroon, convincing target audiences of the



Training of teachers on brail to enable them include learners with visual impairment in their class lessons.

importance of IE in itself would be insufficient. People may be persuaded but may still lack the capacity or resources to actually do something. Consequently, CBCHS made the strategic provision of resources part of its persuasion strategy. For each type of audience, CBCHS carefully assessed whether specific materials or finances would be needed to get things moving. For example, certain poor families received financial support enabling parents to pay school fees and send their disabled child to school. CBCHS also supported schools with teaching materials and in some cases financial support. Several schools, for example, received computers

and funds to pay the wages of sign language teachers, interpreters and braille transcribers. Finally, CBCH donated an embosser to the Cameroon General Certificate of Education Board and trained its staff in brailing exams.

The strategy of carefully providing key resources to remove bottlenecks is clearly a practical solution to get things done in a resource scarce environment. It does raise questions, however, about whether the results achieved in the SEEPD programme can be sustained and up-scaled in the long term. CBCHS is aware of this issue and is in dialogue with the Ministry of Education to look for a structural solution.

#### Further reading

Custers T. (2017). *Opening up for Inclusive Education in Cameroon. Understanding frame resonance in NGO advocacy*. MA-thesis. Wageningen University & Research. See [www.barriersfree.org](http://www.barriersfree.org)

#### Notes

- <sup>1</sup> We would like to acknowledge the support of CBM in conducting this study and sharing the lessons learned from the SEEPD-programme.
- <sup>2</sup> The programme is funded by CBM, an international NGO seeking to improve the quality of life of people with disabilities in impoverished communities.



photo: Beyond Borders

## 5

### Advocacy for disability

# Can participation enhance outcomes?

Emma Frobisher, Willem Elbers and Aisha Fofona Ibrahim



## Executive summary

In many countries people with disabilities suffer from exclusion. Advocacy can contribute to changes in norms, policies and practices, and thereby help address the root causes of exclusion. As of yet, the success-factors of advocacy remain poorly understood. Using the experiences of the Girl Power Programme in Sierra Leone, this paper examines how participation of those being advocated for in all stages of the advocacy process can enhance the impact of grassroots advocacy. Based on extensive research, it identifies three ways in which participation, in this case of girls with disabilities, can enhance the impact of grassroots advocacy. First, the study shows that by involving girls with disabilities in activities that develop their self-advocacy skills, participation can contribute to an increase in self-esteem and self-confidence. Second, that through sustained interaction between girls with disabilities and 'abled' girls, participation can contribute to inclusion and the formation of new social ties. Third, by giving girls with disabilities a public platform and framing them in a positive light, participation can contribute to community awareness and inspire other girls with disabilities.



photo: Emma Frobisher

One Family People staff doing baseline surveys.

### Introduction

Increasingly, advocacy is seen as a way to address a wide range of developmental issues, for example access to education, access to healthcare and sexual and reproductive rights of women. Particularly in the global South, people and children with disabilities in particular suffer disproportionately: they are frequently excluded

from attending school, they are more likely to need medical treatment but less likely to have the ability to pay for it, and women and girls with disabilities are often at a higher risk of experiencing physical and domestic violence.

Creating equal opportunities for people and children with disabilities and enabling them to participate in society to the fullest

of their potential is crucial. Civil society organizations can play and have played an important role in raising awareness and promoting inclusive policies and practices through advocacy. However, despite the growing interest in advocacy aimed at improving the position of marginalized groups, these success factors remain poorly understood. In essence, effective advocacy requires a clear understanding of the factors that determine its success.

Based on an in-depth case study of a grassroots advocacy programme in Sierra Leone, this paper examines the role of participation in grassroots advocacy. In particular it seeks to clarify whether and how participation can enhance the outcomes of advocacy work.

### The case study

Like most countries in Sub-Saharan Africa, Sierra Leone has patriarchal cultural roots that dominate both the private and public sphere. Significant gender inequalities exist in society due to entrenched discriminatory socio-cultural norms and values. Girls and young women have higher rates of illiteracy and fewer economic and decision-making opportunities. In remote areas, women tend to marry at a very young age and sexual violence is widespread. Girls with disabilities suffer from these problems to a disproportionate extent and face a triple discrimination on the basis of their age, gender and impairment.

The Girl Power Programme (GPP - The Girl Power Programme was implemented by OFP in close collaboration with Dutch based NGO International Child Development Initiatives - [www.icdi.nl](http://www.icdi.nl)) was a grassroots gender advocacy programme that ran between 2011 and 2015 seeking to change societal norms and governmental policies and practices related to sexual violence against girls and their lack of educational opportunities. The programme's core

strategy consisted of mobilizing girls and enabling them to advocate for themselves.

Although the GPP was designed for the rights of girls in general, One Family People (OFP), a local NGO implementing the GPP, and at the same time partner of the Liliane Foundation in Sierra Leone, made a particular effort to ensure that girls with disabilities participated in the programme activities. They encouraged these girls to participate in the community self-help groups alongside other 'abled' girls, to attend the programme's performances and demonstrations, and to speak out as project ambassadors at events in front of power holders and the community and to raise awareness of the problems of sexual abuse against girls, including girls with disabilities. OFP implemented the GPP in a total 13 communities in the Western Area and Moyamba Districts.

The study identified three major ways in which the participation of girls with disabilities in community advocacy activities enhanced the outcomes achieved by the GPP.

### Increased self-esteem and self-confidence

A number of studies have found that people with disabilities in Sierra Leone have internalised negative stereotypes about themselves, causing them to distance themselves from social situations believing they are not worthy of joining in. Such sentiments were echoed by the girls with disabilities participating in the study. A girl explained that "before I knew this organisation (One Family People), I was ashamed. I thought when I talked, people would never even consider me".

In the GPP, the staff of One Family People repeatedly emphasised that all girls are capable of achieving their goals, and that 'disability is not inability', a motto they frequently repeated to boost the girls' morale. By explicitly ensuring the partici-



photo: Beyond Borders

Advocacy by music: in their songs The Walpoleans plead for an inclusive society in which everyone can participate.

pation of girls with disabilities, who are usually left out of social activities, the GPP enabled these girls to learn new skills and strengthen their capacity as vocal and confident young women. Through repeatedly speaking out on issues of sexual violence and early marriage in the GPP, girls with disabilities learned to speak out and articulate their frustrations.

After having internalised negative perceptions about themselves for so long, their experiences in the GPP have helped girls with disabilities to become more confident and dignified. They have come to recognise their potential to contribute to their social world and see themselves in a more positive way. Overall, the girls are now more capaci-

tated to speak up for themselves when people discriminate against them. For example, one girl explained that "before Girl Power, I would just keep my head looking down. But now if someone discriminates against me, I use this as an opportunity to defend myself and educate them".

### Inclusion and new social ties

Inquiries about what the girls found most challenging about living with a disability invariably produced the response that it is other people's attitudes. As with most people, these girls value social interaction, acceptance and a psychological sense of connection to others. Their daily reality, however, is one of discrimination and



exclusion. A girl explained that “the society makes you feel like you are a disabled. There is something like this barrier between us and them. They don’t recognise us, they think we are useless”. Much of the discrimination that surrounds girls with disabilities is borne out of fear and ignorance.

The GPP brought girls with disabilities into a position where they frequently interacted with ‘abled’ girls, something which rarely happened before. As girls with disabilities participated in the activities alongside abled girls, the latter could experience for themselves that girls with disabilities are not all that different. They are in fact just girls who by chance happen to have a disability. By creating recurring events in which ‘abled’ girls and girls with disabilities interacted, the GPP diminished girls with disabilities’ sense of social exclusion and segregation from other young people. Moreover, it contributed to the feeling that they are seen as individuals and less as ‘the disabled’. Finally, friendships have been formed where previously they would not have existed. Having been deprived of these things for so long, the new social relationships have brought improvements to the girls’ psychological wellbeing.

### Community sensitisation and increased recognition

The stigma surrounding disability is deeply entrenched in Sierra Leone, with a widely held belief that it is caused by a parent’s sin or the work of the devil. Having a child with a disability is typically a source of shame. Families of girls with disabilities often hide these girls resulting in their invisibility in the community and in society in general. Consequently, girls with disabilities are frequently voiceless, side-lined and devalued by the majority, and are routinely considered to be ‘not there’. Multiple barriers prevent them from participating in every-

day childhood activities and they are frequently considered not fit for education or future employment. Few children with disabilities in Sierra Leone are sent to school, with girls even less likely to be in school than boys.

In the communities, the GPP consistently framed the girls not as ‘the disabled’, but as ‘girls’, to remove focus from their disability. Girls with disabilities were given a platform to interact in the community from a position of strength and dignity. They could present themselves as eloquent and confident young individuals responsible and capable of standing up for their rights and taking the lead in a community initiative. For many people in the community, witnessing a group of girls with disabilities in this way for the first time was an eye opener. The GPP showed that these girls are not so different from their peers, as they too have academic potential and a capacity to play a role in their social world.

The participation of girls with disabilities in the GPP has helped to sensitise and change the mind-set of people in the community who have seen this group in a completely new light. Framing girls with disabilities as responsible and capable of standing up for their rights demonstrated that their potential to actively contribute to their social world is no different to that of other young people, and this has helped to not only raise their status in their surroundings, but also to break barriers at both gendered and disability levels. One girl explained that “being part of the Girl Power Programme was the first time we got respect in our community”. Many of the girls found it also helped to increase their status within their own family settings. Moreover, the girls with disabilities who were at the foreground of the advocacy activities acted as role models and became a source of inspiration to other girls with disabilities.

### Wider relevance

Besides clarifying how participation can enhance the impact of grassroots advocacy work, the findings of the research also have a wider relevance within the ongoing debate on advocacy for disability.

First, the finding that the participation of girls with disabilities in advocacy activities produces a range of direct benefits for these girls sheds new light on the type of results advocacy work can achieve. In the literature, advocacy is often presented as diametrically opposed to service delivery.

Advocacy is associated with targeting the root causes of exclusion (producing long-term and indirect results) while service delivery is generally seen to be about satisfying immediate needs. The experience of the GPP shows that this contradiction is not necessarily valid. By adopting a participatory approach, grassroots advocacy can address root causes while simultaneously satisfying immediate needs.

Second, while much of the attention in advocacy usually goes out to the message, this study instead underlines the importance



Women in the lead, defending children with disabilities’ right to education.

photo: One Family People

of the messenger. In the practitioner literature, particularly in the many 'how to' guides on advocacy that can be found on the internet, developing an appealing advocacy message is typically identified as a precondition for a successful advocacy campaign. The interest in the message is also reflected in academic literature on activism which emphasises the importance of 'framing' to understand outcomes. In contrast, the experiences of the GPP em-

phasizes the relevance of the messenger. This study demonstrates the importance of providing a platform for people with disabilities where they can present themselves to the public in a positive manner. Besides having beneficial effects on the individuals themselves, this also contributes to raising awareness in the community, including other people with disabilities, that 'disability is not inability'.

#### Further reading

Frobisher, E. (2016) *Disability Mainstreaming or Away-streaming? The Case of One Family People and the Girl Power Programme in Sierra Leone*, MA Research Paper. The Hague: Institute of Social Studies (ISS). See [www.barriersfree.org](http://www.barriersfree.org)



## 6

### Empowerment and the Young Voices Project in Zambia

# Stepping out of the shadows<sup>1</sup>

Lindsay Vogelzang, Willem Elbers and Thomas Mtonga

## Executive summary

Too often the voices of youth with disabilities remain silent. This raises the question how these youth can best be empowered. As of yet, little research has looked at interventions seeking to empower youth with disabilities. Based on research in Zambia, this paper addresses this gap. It examines a one-year project in which two youth groups were formed and trained in advocacy and leadership skills whilst being taught on different models of disability and disability rights. These groups, which came together in monthly meetings, also undertook outreach activities to sensitise communities and companies about disability issues. The research shows that the project activities had a range of positive effects on the youth that participated in the project. Reported effects include reduced feelings of isolation, a more positive self-image, a strengthened self-confidence and increased assertiveness. Overall, the project enabled the project-participants to envision and pursue life goals they previously could not imagine. As a catalyst for enabling the youth to (also) change their environment, in particular raising awareness in communities and companies on disability issues, the project was severely constrained. In particular, the project-period was too short and the issues too deep-rooted whilst insufficient funds were available to overcome the (transport) costs of follow up activities.



photo: Lindsay Vogelzang

Young Voices and students from Twatasha Community School are marching together in their community to show their dedication to inclusive education and celebrate the international day for children with disabilities.

### Introduction

In many developing countries the voices of youth with disabilities are not heard. As persons with disabilities, they face multiple physical and social barriers to participate fully in society. As young people, they are typically confronted with societal norms that value acceptance of the decisions taken for them by elders.

If we believe that young people should be involved in decisions that have a direct impact on their lives, the same holds for youth with disabilities. Furthermore, youth with disabilities can make valuable contributions to society in general. This makes the empowerment of youth with disabilities a crucial goal to pursue. The question is, however, what is needed for such empowerment to occur. While there is an extensive literature on empowerment,

very few studies have examined interventions targeting youth with disabilities. Drawing on evidence in Zambia, this paper seeks to address this gap.

### The Young Voices Project

In 2015-2016 the Cheshire Homes Society of Zambia (CSHZ) implemented the Young Voices (YV) project with one year of funding from the German Embassy. The YV-project focused on young persons with disabilities in Zambia as agents of change. The specific goals were (1) to build the capacity of young people with disabilities as change agents, (2) to enable them to push for the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) in Zambia and (3) in general to improve human rights and living conditions for persons with disabilities. The project built





photo: Lindsay Vogelzang

Young Voices, students, parents, community members and representatives of local politics gather together to join the youth their creative performances of all schools in the Kafue community.

upon the experience gained during the similarly named Young Voices program that was implemented by the Leonard Cheshire Global Disability Alliance in 20 countries in 2009-2012.

To achieve its goals, the YV-project implemented a range of activities. Most importantly, two youth groups of about 30 persons with disabilities in the age range of 16 to 25 years were formed. These groups

were subsequently trained in the areas of disability rights, advocacy skills and leadership. In addition, two types of outreach activities were undertaken using awareness raising materials produced in the project. One group visited several communities to convince parents of children with disabilities to stop hiding their children (which is still a common practice in Zambia). The other group tried to sensitize companies about

the tax benefits they could enjoy if they employed persons with disabilities.

This paper analyses and discusses whether and how the Young Voices project contributed to the empowerment of youth with disabilities. The analysis distinguishes between internal and external empowerment. Starting from the recognition that marginalized people often refrain from taking action because they lack the self-esteem, assertiveness and knowledge to do so, internal empowerment refers to people gaining the capacity to imagine doing things they never thought themselves to be capable of. External empowerment happens when individuals (and groups) then use this capacity to challenge the power structures in their environment (economic, political, social) that sustain their marginalization. The question for the YV-project is therefore whether the youth with disabilities that participated in the project gained the capacity needed to take

action (internal empowerment) and change their environment (external empowerment).

The research was carried out over a period of three months in 2018 in Lusaka, using a combination of semi-structured interviews (29 in total), focus groups (three), Photovoice and participatory observation. Interviews targeted a range of respondents and informants, including members of the Young Voices groups, CSHZ-staff, youth with disabilities that did not participate in the project, and community members and company representatives that were targeted in the outreach activities. Participatory observation was carried out at CSHZ and the two youth groups.

### Stepping out of the shadows

This study found that the YV-project was quite successful in enabling youth with disabilities to 'step out of the shadows' as one participant put it. The youth that participated in the project reported a



photo: Lindsay Vogelzang

Members of Young Voices participating in a focus group to discuss the impact of the program on their notion of empowerment.



Young Voices discussing the impact of the activities they undertook to raise awareness in the society and reduce stigma.

range of positive changes related to their internal empowerment: reduced feelings of isolation, a more positive self-image, a strengthened self-confidence and increased assertiveness. Overall, these qualities gave them a new confidence to pursue life goals they previously could not imagine. Three characteristics of the project proved crucial for achieving these positive outcomes.

Firstly, the project brought youth with disabilities together, some of which were role models to their peers. The youth participating in the project all share the experience of being different from the rest of their family and/or community. Some of them were 'hidden' from the outside world when they were young. Besides experiencing feelings of isolation, many of the project-participants explained that they lacked self-confidence and had low self-esteem prior to participating in the

project. The YV-project brought youth with disabilities together which reduced feelings of isolation whilst having a positive effect on their self-image. Many youth explained that working closely with group members who already had leadership skills and an entrepreneurial mindset had been particularly inspiring. These 'successful' peers challenged their own negative self-image and showed them that persons with disabilities can create their own success.

Secondly, the project taught the youth (also) about the social model of disability, which says that disability is caused by the way society is organized, rather than by someone's impairment, whilst making them aware of disability rights. A recurring topic in the life stories told by the Young Voices is that they are often seen as 'the problem' by their environment. As such, it is not surprising that many of them to some degree have internalized this idea. In the

YV-project trainings, however, they were introduced to different ways of understanding disability, with an emphasis on the social model. For several of the youth, this was a liberating eye opener. By discussing the social model they learned to view their limitations as (also) arising from their environment, not necessarily from within themselves. Furthermore, the youth learned about disability legislation and their rights. For many of the YV-participants the training was their first encounter with the notion of having rights. Rights awareness provided the youth with a new perspective about the opportunities they have for realizing change. In particular, it boosted their confidence to take action.

Thirdly, the project paid explicit attention to public speaking, both in theory and practice. A recurring topic in the interviews was that youth with disabilities often refrain from speaking out due to a negative self-image, shyness and lack of communication skills. Public speaking played an important role in the skills trainings that were offered to participants. The youth could subsequently practice these skills during their monthly group meetings and outreach activities. A number of the YV-participants explained that they overcame (part of) their shyness while becoming more confident to speak out and defend their rights. Furthermore, several of the youth explained how they became inspired by the project and gained a new sense of purpose as disability activists.

### Inbuilt project constraints

Besides internally empowering youth with disabilities, the YV-project also aimed to change the broader environment via disability sensitization work that was undertaken in communities and companies (external empowerment). Unfortunately, the research found little evidence of (lasting) effects of the outreach activities. The

study identified three key characteristics of the project-design that constrained the sensitization work.

First, the outreach activities were one-off, whilst the intended changes of sensitizing communities and companies require a sustained effort over a longer time period. The fact that the research found little evidence of sensitization is not particularly surprising. Creating awareness and changing societal beliefs about disability are difficult to achieve, let alone in activities without follow up. Unfortunately, the YV-project did not have sufficient financial resources for sustained outreach work.

Second, the youth still lacked the capacity needed to undertake sensitization work at communities and companies. The youth who participated in the project learned a lot, but their starting levels in terms of disability (rights) awareness and advocacy skills were also very low. At any rate, changing deeply engrained thinking and practices requires considerable capacity. The trainings offered by the YV-project were insufficient to get the youth to the required level of capacity.

Third, the outreach activities were constrained by limited funds for transport. Transport and mobility constraints have a major impact on the lives of youth with disabilities in Zambia. Besides having to wait longer for mini-busses to pick them up (drivers are not keen to pick up individuals with disabilities as this can be more time consuming), public transport is particularly challenging for wheelchair users who have to pay higher fees as they need more space in the vehicle. In the YV-project a significant share of the resources was spent on covering transport costs for the project-participants. Although the higher costs of transport were foreseen in the original project-proposal, the amount earmarked for transport had to be reduced before the proposal could be funded. The

### Recommendations

From this study the following lessons can be learned for future interventions seeking to empower youth with disabilities:

- 1 Ensure that youth groups are of mixed composition reflecting different levels of capacity and personal growth to enable role effects to occur;
- 2 Helping youth to realize that the constraints they experience (also) arise from society as opposed to (only) their impairment is crucial for overcoming a negative self-image;
- 3 Creating opportunities for youth to learn about, and practice, public speaking is key for gaining self-confidence and enabling them to defend their rights;
- 4 Ensure that empowerment interventions acknowledge that changing deep-rooted beliefs, policies and practices requires considerable capacity and adopting a long term perspective;
- 5 Take into account that youth with disabilities face additional mobility constraints that affect their ability to mobilize and undertake collective action.

### Further reading

Vogelzang L. (2018). *Disability is not Inability. A Case Study of Empowerment of Young Persons with Disabilities in Zambia*. MA-thesis. Amsterdam: University of Amsterdam. See [www.barriersfree.org](http://www.barriersfree.org)

### Notes

- <sup>1</sup> We would like to acknowledge the German Embassy for enabling us to learn lessons from Young Voices programme.



photo: One Family People

## 7

### The introduction of police officers with disabilities in Sierra Leone

# Can exposure reduce prejudice?

Silvia Peirolo, Willem Elbers and Aisha Fofona Ibrahim



## Executive summary

Awareness-raising initiatives are crucial to address discrimination against People With Disabilities (PWDs). But what makes such initiatives successful? Building on evidence from Sierra Leone, this paper clarifies the factors that shape the success of disability awareness interventions. More concretely, it examines an initiative in which police officers with disabilities were employed by the Sierra Leone Police to work alongside 'abled' police officers with the aim of challenging negative stereotypes. The study unfortunately did not find clear evidence that sustained interaction between abled and disabled police officers resulted in the former revising their negative views of PWDs. Four explanatory factors emerged: (1) different selection procedures used for disabled and abled police officers contributed to the belief that unqualified and inadequate PWDs were hired; (2) this belief was further strengthened by the importance attached to bodily strength within police culture; (3) disabled police officers were appointed to positions hidden from the public, and (4) were provided with limited career opportunities, which both reinforced existing negative stereotypes and strengthened the idea that PWDs are incompetent.

## Introduction

With an estimated 10 percent of the world's population living with a disability, it is not surprising that PWDs represent the world's largest minority, with 80% estimated to be living in developing countries. People living in poverty are more vulnerable to impairments and in many developing countries, PWDs face marginalization in all sectors of society, including education, health, employment and justice. Discrimination is often underpinned by the deeply entrenched belief that sin, voodoo or black magic are causes of disability.

Challenging attitudes is typically seen as the first step towards building an inclusive society for PWDs. Awareness-raising initiatives are key to this. The question, however, is under what conditions such initiatives can be effective. Drawing on evidence from Sierra Leone, this paper seeks to improve our understanding of the success factors in disability awareness interventions. It examines an initiative in which police officers with disabilities were employed by the Sierra Leone Police to work alongside 'abled' police officers with the aim of challenging negative stereotypes.

## Case study

In Sierra Leone, many PWDs are rejected by their families and end up living on the streets. It is not uncommon for them to engage in illegal and often degrading activities such as begging or sex work in order to satisfy their basic needs. Police officers are regularly involved in actions against PWDs, and both groups have developed negative views of each other. There is a common perception within the police force that PWDs are troublemakers; people that like to fight and use abusive language: "Na dat mehk God mehk u so" [this is why God made you that way] is an expression frequently used towards them during conflicts.

In 2012, the Sierra Leone Police started out by hiring four PWDs in their Communication department in Freetown with the aim of challenging the stereotypical attitudes of police officers towards PWDs, and improving the relationship between the two groups. Five years later, in 2017, a total of ten police officers with disabilities were working with the Sierra Leone police force in the Communication and Maintenance departments in the Western Area.



Presentation of preliminary research findings in Freetown in December 2017.

All newly hired police officers had a physical disability. The initiative built on the assumption that by having police officers with disabilities as colleagues and creating sustained, positive, intergroup encounters, 'abled' police officers would revise their negative perceptions of PWDs. In other words, that positive experience with individual PWDs would result in police officers revising their negative views of PWDs in general.

This paper analyses and discusses whether and how the initiative contributed to a change in attitudes of police officers towards PWDs. The research was carried out in Freetown over a period of six months in 2017, using a combination of semi-structured interviewing (32 in total) and participatory observation. Interviews targeted a range of respondents and informants, including police officers of various rank, police officers with disabilities, PWDs and staff of disability NGOs. Participatory observation was carried out at various police stations, barracks, detention centers, PWD-communities and a disability NGO.



photo: Silvia Peiró

Police officers with disabilities after graduation from the Police Training School in Hastings in 2012.

### Lack of change

The study first of all found that, given the huge stigma attached to disability in Sierra Leone, the fact that the Sierra Leone Police implemented this initiative was already a major accomplishment in its own right. In addition, the research found that generally, police officers with disabilities maintained cordial relations with most 'abled' colleagues. In a few individual cases, friendships emerged between the disabled and 'abled' police officers. Overall, however, the study did not find clear evidence that sustained interaction between abled and disabled police officers resulted in the former revising their negative views of PWDs. Four factors emerged that explain why the initiative failed.

First, different selection procedures for disabled and abled police officers resulted in the widely shared belief that unqualified and inadequate PWDs had been hired. Unlike 'regular' recruits, police officers with disabilities did not have to pass an entrance examination or motivational interview. Because the selection process for PWDs was less demanding compared to the normal selection procedure for police recruits, many police officers believed that disabled police officers had been hired only because of their disability and had thus received preferential treatment. This created a feeling of resentment towards disabled colleagues, which had significant implications: (1) there was a risk of devaluing disabled police officers' real accomplishments, (2) The idea that disabled police officers cannot stand on their own feet was reinforced, and (3) it may have increased tensions, as police officers were convinced that disabled police officers received the same benefits without deserving them.

Secondly, the research found that the importance attached to bodily strength within police culture contributed to scepticism regarding the potential of PWDs to

be competent police officers. A common belief among 'abled' police officers was that disabled police officers were weak and not physically fit, and that there was 'something wrong with their body'. They were therefore often sceptical about the role of 'physically unfit people' within the police, which was an environment where the body was seen as a crucial asset to 'get the job done'. Because they could not be sent to control riots, to patrol the streets, or arrest the public as front-line officers, disabled police officers were not seen as 'real' police officers.

Third, disabled police officers were appointed to positions hidden from the public, which reinforced existing negative stereotypes and strengthened the idea that PWDs are incompetent. While disabled police officers were hired by the police, they were at the same time asked to remain invisible. Police officers with disabilities were all appointed to positions that did not involve direct contact with civilians. They were also not allowed to wear a police uniform. Both these decisions seem to have been made out of fear that police officers with disabilities appearing in public would negatively affect the reputation of the police, and that the public would ridicule a physically unfit police officer.

Fourth, disabled police officers were provided with limited career opportunities, which again reinforced existing negative stereotypes and strengthened the idea that PWDs are incompetent. The study found that disabled police officers did not have opportunities to climb the professional ladder in the police force. Not only were they prevented from working in different departments, a necessary requirement to be promoted to a higher rank, but there was also a common perception among police officers that disabled police officers would never achieve command positions because of their physical limitations. Overall, it can



photo: Silvia Peiró

Two of the first police officers with disabilities recruited in 2012.

be argued that the professional environment of the disabled police officers reinforced the negative views that existed about people with disabilities, and consequently, the notion that disabled police officers were not full-fledged police officers.

### Local understandings of disability

Whilst examining whether and how the initiative contributed to a change in attitudes among police officers towards PWDs, the study also found that the phrase 'persons with disabilities' is problematic for disability awareness interventions. The initiative aimed at challenging police officers' stereotypical attitudes towards 'people with disabilities'. This terminology is part of the global disability discourse that is widely used by international NGOs and multilateral organizations such as the WHO and World Bank. This study found, however, that 'people with disabilities' as an over-arching

expression reflecting different kinds of disabilities does not reflect local understandings of disability. In fact, police officers in Sierra Leone appear to have a compartmentalized and hierarchical concept of disability. For example, many police officers do not consider people with mental and intellectual impairments, or amputees and war-wounded, to be disabled. Their concept of disability mostly relates to physical and sensory impairment. Furthermore, police officers identify a hierarchy in types of impairments. In this hierarchy, physical impairments are considered somehow 'superior' (less disabling) to sensory impairments, while mental and intellectual impairments, as far as they are seen as disabilities, are placed at the bottom of this hierarchy.



A squad of police officers with and without disabilities in Hastings in 2012.

This analysis has important practical implications for international agencies seeking to promote disability awareness. First, they need to be aware that local understandings of disability may be different from theirs. In Sierra Leone, understandings of disability are heterogeneous and include different value judgments regarding different categories of impairment. The phrase 'PWDs' runs the risk of hiding the local perceptions of police officers and probably of many other citizens in the country. Second, the findings stress the importance of using locally recognized categories of disability in interventions, as opposed to the overarching notion of 'people with disabilities'. Interventions that do not acknowledge local understandings of disability run the risk of failure by design. In Sierra Leone, the 'fragmented' and 'hierarchical' understanding of disability means that exposure to one type of disability is not likely to result in revised views of other types of disability. Third, disability awareness interventions must take into account that for some impairment types, addressing negative stereotypical attitudes may be harder than for others. People with disabilities that are ranked lowest in the hierarchy of impairments (e.g. mental and intellectual disabilities) also tend to be the most marginalized. This implies that change for the most marginalized PWDs is likely to be the most difficult to achieve.

#### Further reading

Peirolo S. (2018). *Cops without uniforms in Sierra Leone: challenging police officers' stereotypes towards people with disabilities*. MA-thesis. Wageningen: Wageningen University. See [www.barriersfree.org](http://www.barriersfree.org)



## 8

### How inclusive is the disability movement?

# The case of North-West Cameroon

Daniel Boyco Orams, Willem Elbers and Auma Okwany



## Executive summary

Disability associations provide services and advocate for the rights of people with disabilities. The question, however, is whether these associations are inclusive in terms of whose needs and interests are taken into account in the associations and whose are excluded and why. Based on empirical research conducted in Cameroon, this paper looks at the dynamics of participation in disability associations. In particular, it examines how characteristics of social identity -age, gender and impairment type-affect the possibilities of association members to express their views and voice their concerns. The study findings reveal that age, gender and impairment type have a major impact on people's ability to make their voice heard. The level of involvement of youth and women remains limited due to socio-cultural norms regarding age and gender which are not only (re)produced by (older) men, but also by women and young persons themselves. Furthermore, the study finds differences by disability type. The physically and visually impaired are better able to promote their interests than those with hearing and intellectual impairments, who face several constraints. These constraints are directly related to a historical development of disability support in the context studied, which has granted more opportunities to those with physical and visual impairments and reflects a hierarchical societal understanding of disability.

## Introduction

In many contexts in the global South, disability associations play a key role in providing services and promoting the rights of people with disabilities. But how inclusive are disability associations themselves? This is an important question because the degree of inclusiveness determines the extent to which the voices of different people they serve are heard. Moreover, it points to the underlying issue at stake here, which is whether the activities of disability associations are cognizant of and reflect the different needs and concerns of their members.

Based on empirical research with eight disability organizations, this paper explores the extent of inclusiveness of the disability movement in North-West Cameroon. In doing so, the paper is guided by an intersectional perspective in which members of disability associations are viewed as having multiple social identities, each of which can have an enabling or constraining effect in terms of their participation. The question at stake is whether and how these intersectional factors, in particular the social identity characteristics of age, gender, impairment type, affect the ability of association members to express their views and concerns.

The research was carried out over a period of six weeks in 2018 using a combination of 29 semi-structured interviews, six focus group discussions and participatory observations. Interviews targeted officials and members of eight grassroots associations of persons with disability, officials of the Coordinating Unit of the Associations of Persons with Disability (CUAPWD), government representatives, and officials of the Cameroon Baptist Convention Health Services (a prominent local NGO). Participatory observation was carried out at the eight above mentioned disability associations, mainly by attending their meetings.

## Disability associations in North-West Cameroon

The network of disability associations in North-West Cameroon consists of 64 registered associations linked together through the umbrella organisation, CUAPWD. Since its inception, the CUAPWD has been providing an institutional space for interaction and exchange whilst offering technical support and undertaking advocacy activities. The 64 disability associations vary in membership size, age, impairment focus and their active status. The diversity characterizing the broader disability movement is reflected in the eight associations that participated in the study (see Table 1 further on). Similar to the broader movement, most of these associations are formally open to people with different impairments. Two of the participating associations have a specific impairment focus.

Given the politically restrictive environment in Cameroon, the associations involved in the study did not have an explicitly stated goal of promoting disability rights. Instead, their objectives are framed as promoting social and economic inclusion. This is reflected in membership motives that include opportunities for socialization (making friends, meeting people), opportunities for self-improvement (learning skills that can lead to income generation) and benefitting from possible charity.

In principle, the associations aim for monthly membership meetings although the actual frequency is often lower due to obstacles including the on-going political violence in the area and accessibility impediments including inadequate infrastructure compounded by heavy rainfall (during the rainy season). Issues discussed during meetings include upcoming association events such as training opportunities and gatherings, individual members' problems, and decisions regarding coordination and collaboration with other associations.

During meetings, membership fees are collected, which fluctuate between 500 and 1500 CFA (0,75 and 2,25 euro).

**In(ex)clusion of youth and women**

In most of the disability associations (six out of eight) included in the study, the level of youth involvement remains limited. In Cameroon persons are considered to be young if they are under 35 years old. In most meetings in which the researcher attended, there were either very few or no youth

present. With the exception of two associations, youth were participating in a passive manner. Passive participation refers to merely being present, even being listened to, but not taking part in making decisions or affecting collective change. In most of the associations observed, older men were centre stage. They dominated the discussions and also occupied positions of leadership. Study participants noted that these observations reflect the general situation of youth involvement in disability associations

**Table 1. Key characteristics of disability associations involved in the study**

Name	Year founded	Membership size	Location	Focus
Hope Social Union for the Visually Impaired (HSUVI)	2003	40	Bamenda III, Mezam	Visual impairment
Cameroon National Association for the Deaf (CANAD)	Early 2000s	300+	Bamenda, Mezam	Hearing impairment
North West Association of Women with Disabilities (NWAwwD)	2013	35	Savanah Street, Bamenda II, Mezam	Open
Special Needs Entrepreneur Group (SNEG)	1999	150	Fish Pond Hill, Mezam, Bamenda II	Open
Kedjom Ke-Tinguh Association of Persons With Disabilities (KKAPWD)	2013	67	Kedjom Ke-Tinguh, Mezam Tubah Subdivision	Open
Goodwill Association of persons with special needs (Parents association)	2014	50	Bambili, Mezam, Tubah Subdivision	Open
Harmonized Disabled group (Parents association)	2007	108	Bali, Mezam	Open
Luc Menora- Light Bearers Rehab Association	2016	40	Bamenda II, Mezam	Open

in the North-West.

In two associations (HSUVI and CANAD) youth participated actively during meetings. In the case of HSUVI, youth inclusion had been a conscious effort by older members and it was an established policy to award leadership positions to young members. The other association is CANAD, which is born out of the efforts of young persons with hearing impairment. Consequently, youth participation appeared stronger in this particular organization.

Socio-cultural norms on age help explain the lack of youth involvement in the disability associations in the study. In Cameroon, youth are expected to adhere to the leadership of, and decisions made by, elders. In fact, submission to the elders is considered a virtue of youth. Norms regarding inter-generation interactions and their implications for youth participation are reproduced within the disability associations, not only by older men, but also by the youth themselves. Older participants argued that young people are constrained in taking up a more pro-active role due to their lack of knowledge and experience. Youth expressed being content with passive forms of participation (simply being present, not involved in decision-making), because their mere presence would imply improving oneself by learning skills, socializing with others, and possibly benefiting from charity.

With some exceptions, women’s involvement in the disability associations also appeared to be limited. While women participated in all meetings observed, the number of men participating was often always substantially higher. It was also far more common for men to dominate the discussions and speak up with assertiveness. This, according to informants, is quite representative to what is happening in other disability associations. Notable exceptions were the two associations of parents of children with disability (Good-

will and Harmonized), and the NWAwwD, which has been set up as part of CUAPWD’s gender policy.

Socio-cultural norms also explain women’s limited involvement. Study participants explained that in Cameroonian society women often “shy away” from participating, excluding themselves, rather than being openly subjugated by men (although the latter also happens). While this holds for all females, it is exacerbated for those with disabilities. A widespread belief is that women are not expected to take up leadership roles and are only “meant to be given out for marriage”. Women with disabilities explained that it is far more difficult for them to find a husband compared to their male peers finding a wife.

**Inclusion of impairment types**

In North-West Cameroon, four types of disability are recognized: the visually, physically, hearing and intellectually impaired. A key finding is that the disability associations in this study are largely segregated by impairment type. This, according to informants, is typical for disability associations in the North-West. As shown in Table 1, two of the associations already have a particular focus (visual impairments and hearing impairments respectively). The remaining six associations are formally open to different impairment types but in practice are almost completely made up of persons with the same impairment type. This, according to study participants, is because different impairments face different types of stigma and barriers to inclusion and participation in society. It is more convenient for persons with the same impairment to get together as they face similar challenges and stigma, understand each other and can share common solutions.

The study also found that the physically and visually impaired are better able to





Mr. Nyngcho Samuel, General Coordinator of CUAPWD (second from left, wearing black) and Ms. Glory Agho, Program Manager at CBCHS (third from left, wearing green), with members of the disability movement in Bamenda.

promote their interests compared to the hearing and intellectually impaired. Firstly, the physically impaired typically dominate the 'open' associations. In four out of the six 'open' associations studied, almost all attending members, including those in leadership positions, have a physical impairment. In the North-West region, physically impaired persons are seen as being the least disabled, revealing a hierarchical conceptualisation of disability (more about this below). Study participants pointed out and observations supported the fact that in the open associations, persons with physical impairments tend to dominate. This was noted as an important reason why the visually and hearing impaired had formed 'closed' associations.

The visually impaired can also be considered a leading group inside the broader disability movement. According to informants, their associations tend to be more well organized, which is exemplified in the case of the association for visually impaired

(HSUVI) in this study. HSUVI is widely regarded as a strong association, and one of the few that openly welcomes young people's participation. Furthermore, the regional disability umbrella association (CUAPWD) is currently lead by visually impaired persons. Additionally, most of the young persons with visual impairment who participated in this study were university students, which was definitely not true for other types of impairments.

The hearing impaired is a group whose disability challenges are intensified within the broader disability community. They generally struggle with access to and participation in education and most of the young hearing impaired persons in the study had only achieved primary level education. Study participants pointed out that those who were hearing impaired face communication barriers, which keep them isolated from the rest of the disability community. This is because Sign language interpreters are scarce and costly. Of par-

ticularly note is the communication barriers between persons with visual impairment and persons with hearing impairment who simply cannot communicate with each other without assistance.

The intellectually impaired are also a group with special challenges generally and within the disability community. They have been represented in this study by their parents or caretakers. The challenges they

mentioned were predominantly about the lack of information related to this type of impairment. They noted that often parents of a child born with autism or Down syndrome have not heard of these conditions before, and simply do not know why their child is different. This makes the situation of persons with intellectual impairments particularly vulnerable to traditional beliefs of witchcraft and superstition.



The NWAAPWD holding a meeting.

The relative dominance of the physically and visually impaired has to be understood in historical and cultural terms. In the North-West region, the visually and physically impaired have received more support and for a substantially longer period of time than those with hearing or intellectual disabilities. For example, the first school for the visually impaired was opened in 1952 in the North West Region, while there has been no school for the hearing impaired until the year 2000. At the same time, the Cameroon Baptist Convention has been

working on the inclusion of the physically impaired since before colonial times. Due to this, the former two groups are better organized, tend to be better educated and are more prepared to receive further education and support. The historical divergence in support and opportunities for these two groups goes hand in hand with a hierarchal societal understanding of disability in which the physically and visually impaired are seen as less disabled than the hearing and intellectually impaired.



Ms. Veronica Ngum Ndi, President of the NWAwwD (first from right, wearing blue), with members of the association after a meeting.

#### Further reading

Boyco B. O. (2018). How We Come Together: Exploring the Participation of Youth with Disability in Disability Associations of North West Cameroon. MA-thesis. The Hague: Institute of Social Studies. See [www.barriersfree.org](http://www.barriersfree.org)



## 9

### The Disability Movement in Sierra Leone

# Fragmented Yet Together

Amélie van den Brink, Willem Elbers and Aisha Fofona Ibrahim



## 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.



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

## 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



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.

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.'

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.<sup>1</sup> 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 impairment 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 impairment 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



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

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.

### 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

<sup>1</sup> 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 aid to access education.



Illustrations: Studio Nieuwhof

## 10

### Taking stock of existing research

# Organizational capacity and advocacy effectiveness

Willem Elbers and Jelmer Kamstra



## Executive summary

Despite a growing interest in advocacy for marginalized groups within international development, the relationship between organisational capacity and advocacy effectiveness is not yet fully understood. This paper synthesises existing empirical research on advocacy for marginalised groups in the global South. It presents a framework that identifies the main enabling factors for advocacy effectiveness and the organizational capacities and requirements associated with these factors. The paper disentangles the abstract notion of 'advocacy capacity' into more concrete components and clarifies how different capacities contribute to advocacy effectiveness. Eight core 'advocacy capacities' are identified which are the capacity to (1) produce evidence, (2) inspire trust among power holders, (3) represent constituency interests, (4) analyse the political arena, (5) produce tailored messages, (6) work collectively, (7) build rapport with power holders and (8) adapt to on-going changes in the environment. Finally, the paper offers a reflection on the promises and pitfalls of applying the capacity framework in real-world settings.

## Introduction

Driven by the need to find effective solutions to poverty and injustice, researchers, policymakers and practitioners in the international development sector are showing greater interest in civil society's advocacy role. Traditional service delivery approaches are increasingly perceived as having limited structural impact. As such, there is a growing interest in a complementary political approach, which challenges the underlying power structures that perpetuate marginalisation. In taking up an advocacy role, Civil Society Organizations (CSOs) organise and mobilise constituencies, raise awareness, shape public opinion, and engage with decision-makers to influence key policies. Systematic insight in the relationship between organisational capacity and advocacy effectiveness is lacking. This paper addresses this gap by synthesizing existing academic research on the topic. It draws on an upcoming publication of Elbers and Kamstra (forthcoming) which examines advocacy research undertaken in 31 countries in Africa, Asia and Latin America. The paper discusses the following questions: (1) What organizational capacities are key to CSOs' ability to undertake effective advocacy? (2) How do these capacities contribute to effective advocacy?

## Advocacy capacity and context

We define advocacy as a 'wide range of activities that are conducted to influence decision makers at different levels with the overall aim of combatting the structural causes of poverty and injustice'. This makes advocacy especially relevant in a development context where large groups of people are left behind.

Advocacy then becomes a tool for these marginalised groups to take matters into their own hands and stand up for their rights.

While this paper assumes that organizational capacity is a major determinant of advocacy effectiveness, it is important to point out that effectiveness also depends on enabling or constraining contextual factors. Examples of such factors are the openness of the political regime, existing policies and treaties that might provide leverage, the presence or absence of allies within the government and the potential to form alliances. This means that even if an organization has the 'right' capacities to engage in advocacy, the environment may be such that chances for success are limited from the onset. The opposite is also possible: an organization may have relatively few capacities but may still be able to be effective due to a favourable context.

## Capacity framework

Table 1 summarizes the most important elements for advocacy effectiveness. It distinguishes between (1) enabling factors for advocacy effectiveness, (2) capacities needed to create these factors, and (3) the organisational requirements underlying these capacities. While the table identifies eight capacities associated with effective advocacy, their actual relevance in practice depends on the context. The same holds for the organizational requirements associated with each capacity.

**Table 1. Effective advocacy: enabling factors, capacities and organizational requirements**

Enabling factors	Related Capacities	Key organisational requirements
Credible claim	Produce evidence	<ul style="list-style-type: none"> <li>- In-house research skills</li> <li>- Relations with knowledge institutes</li> <li>- Ability to commission and critique research</li> </ul>
Credible organization	Inspire trust among power holders	<ul style="list-style-type: none"> <li>- Ability to cultivate a good reputation</li> <li>- Track record</li> <li>- Integrity</li> <li>- Capable leadership</li> </ul>
Grassroots embeddedness	Represent constituency interests	<ul style="list-style-type: none"> <li>- Clear constituency</li> <li>- Channels of communication with constituency</li> <li>- Mechanisms for participation and accountability</li> </ul>
Clear stakeholder engagement strategy	Analyse the political arena	<ul style="list-style-type: none"> <li>- Ability to conduct stakeholder and institutional analyses</li> <li>- Access to information</li> <li>- Knowledge of relevant laws, policies and treaties</li> </ul>
Clear communication strategy	Produce tailored messages	<ul style="list-style-type: none"> <li>- Ability to frame, target and time messages</li> <li>- Relations with audiences and media channels</li> </ul>
Coalition of likeminded organisations	Work collectively	<ul style="list-style-type: none"> <li>- Willingness to work together</li> <li>- Ability to maintain external relations</li> <li>- Awareness of one's added value and complementarity to others</li> </ul>
Personal relationships with power holders	Build rapport with power holders	<ul style="list-style-type: none"> <li>- Ability to find common ground</li> <li>- Ability to analyse power holders' personal and institutional interests</li> <li>- Proximity to power holders</li> </ul>
Flexible strategy	Adapt to on-going environmental changes	<ul style="list-style-type: none"> <li>- Organisational structures, procedures and culture which accommodate flexibility</li> <li>- Ability to detect and act upon relevant changes in the environment</li> <li>- Ability to reflect upon validity of tactics</li> </ul>

**Produce evidence**



A CSO's persuasiveness depends for an important part on the credibility of its claims. This requires the capacity to produce evidence. Besides making power holders more susceptible to influencing, a well-documented factual basis increases the chances of media coverage. Being able to gather evidence is particularly important in countries where governmental agencies are under-resourced and lack up-to-date knowledge and expertise. Governmental agencies may want to use CSOs as a source of knowledge and expertise, which the latter can use to gain access to power holders. In terms of organisational requirements, CSOs either need to have in-house research capacity or maintain relations with reputable knowledge institutes for producing evidence. In dealing with the latter, CSOs have to be able to commission and critique research.

**Inspire trust amongst power holders**



CSOs have a bigger chance of influencing power holders when they are perceived as credible organisations. As credibility is closely related to trust, CSOs need to

have the capacity to inspire trust among power holders. Trust is the firm belief in the reliability, truth, or ability of someone or something. It is based on relations and perceptions, and therefore has to be carefully built and maintained over time. This implies that the ability to cultivate one's reputation as a trustworthy CSO is a key organisational requirement. Trust however, is not only built on image, but also stems from substance and actions, namely from having a track record in a particular field, from integrity, and from having a reputable leadership. As a record of past performance, a track record is typically taken as an indicator of likely future performance. CSOs which are perceived to be good at what they do are more likely to be viewed as a reliable party. Similarly, act consistently in accordance with their core principles, they also are more likely to be viewed as a reliable party. Finally, capable leadership is associated with all of the above, namely, strong organizational performance, integrity and reputation.

**Represent constituency interests**



Whether advocacy is for, with or by marginalised groups, CSOs need some form of grassroots embeddedness to be seen as legitimate advocates. This requires CSOs to have the capacity to represent constituency interests. This is not self-evident as CSOs often fail to clarify in whose name they speak, why they are authorized to act, and to whom they are accountable. To be able to represent constituency



interests, CSOs first of all need a clear constituency with whom they communicate regularly. Ultimately, claims about representation are only credible when the views, needs and interests of the marginalized groups are accurately taken into account. This can be achieved by taking a participatory approach throughout the advocacy process. Besides enhancing credibility, this also contributes to a sense of ownership by constituencies, especially when paired with strong accountability mechanisms towards them. Additionally, participation forms the basis for mobilization which may be necessary for sending a strong message.

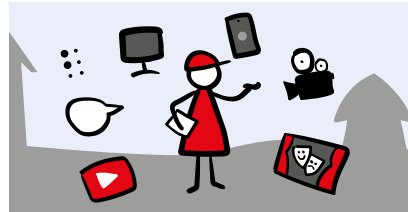
### Analyse the political arena



Effective advocacy strategies require a stakeholder engagement strategy that identifies relevant stakeholders (i.e. power holders, allies and opponents) and outlines a suitable relational approach towards them. This requires the capacity to analyse the political arena. Besides the stakeholders within the arena, also the nature of the arena itself is of importance. Relevant power holders may be located at different levels (i.e. local, regional, national) depending on the issue and the political system (i.e. centralized or decentralized). In terms of organisational requirements, CSOs need to be able to conduct stakeholder and institutional analyses, and have appropriate access to information to feed into such analyses. They need to be able to gather information from a variety of sources

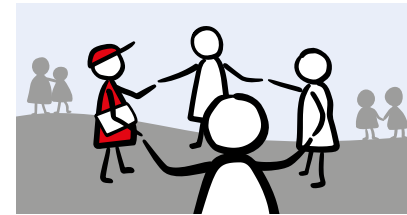
(i.e. government, media, research) to get a clear picture on stakeholder interests and positions. Knowledge of relevant laws, policies and treaties is equally important as it can provide opportunities for dialogues with power holders.

### Produce tailored messages



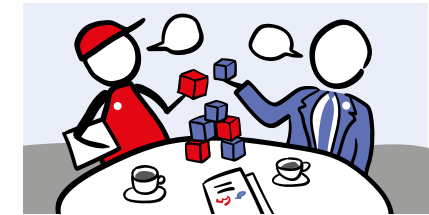
To motivate power holders, constituencies, the wider public, and potential allies to take action, CSOs need a clear communication strategy. Strategic communication is about the capacity to produce tailored messages that succeed in touching hearts (beliefs, values) and minds (interests). Regarding organisational requirements, CSOs need to be able to frame, target and time messages. This is about formulating narratives that resonate with the norms, values and interests of target audiences, whilst aligning communication with key events (i.e. elections, international summits) to maximize impact. Additionally, CSOs need to understand the pro's and con's of different communication channels for reaching different audiences. For example, some audiences are best reached through national media, while others are best reached through social media, songs or theatre. Relationships with media outlets and journalists are typically helpful for access and coverage.

### Work collectively



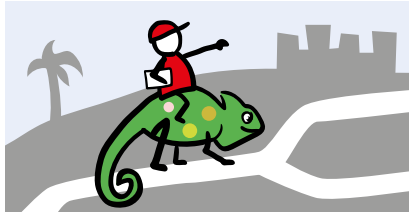
CSOs that build advocacy coalitions with likeminded organisations have a greater chance of success than individual organizations. Working collectively adds value in several ways and is therefore an important capacity for advocacy effectiveness. Working together creates the potential to combine different skillsets, share crucial information, increase campaign visibility, mobilise larger groups, increase the scope of activities and reduce risks. In terms of organisational requirements, CSOs need to be willing to work together and invest in an often complex and time-consuming relationship. In addition, advocates need the skills to build and maintain external relations. This involves coordinating joint activities, representing the organization externally and collecting and sharing information. Finally, members of advocacy coalitions require a sound understanding of both their own, and other organizations' added value to the coalition to ensure complementarity.

### Build rapport with power holders



Effective advocacy strategies often involve informal personal relationships with power holders and their staff. Capacity-wise, this is about being able to build rapport. Such rapport facilitates access to power holders which can be used for gathering information, pitching ideas, and mobilizing support. The ability to find common ground is an important organizational requirement for building rapport. A connection can for instance be made on shared experiences, membership of the same ethnic or religious group or coming from the same geographical area. Being aware of the personal and institutional interests of power holders is also crucial. For instance, CSOs that are able to generate positive press for them are more likely to get their support. As building rapport costs time and requires sustained efforts, physical presence close to power holders is beneficial. Being located in a capital city, for example, is crucial for connecting with national level decision-makers.

### Adapt to on-going changes in the environment



Effective advocacy is associated with flexibility as outcomes are shaped by rapidly changing circumstances. New opponents may rise, decisions may be delayed, allies may change, the media may become critical and original goals may lose relevance. This implies that organizations should have the capacity to adapt to on-going changes in the environment. CSOs therefore need structures, procedures and cultures which accommodate flexibility. They need to be able to analyse day-to-day political developments and respond quickly. This also implies a constant reflection upon the validity of tactics. A change in government might for instance require a change from confrontational to cooperative tactics.

### Further reading

Elbers W. and Kamstra J. (forthcoming). *Which capacities are associated with effective advocacy? Taking stock of advocacy research in development contexts.*

### How (not) to use this framework

The framework presented here can be used in several ways by CSOs, donors and evaluators/researchers. It can be used as a tool for identifying strengths and weaknesses, improving capacity strengthening initiatives, keeping track of capacity changes, and for facilitating reflection on advocacy trajectories. How the framework will be used ultimately determines its usefulness. Especially in case of capacity strengthening, it runs the risk of being used as a blueprint by donor agencies. This risk is real as many donors have embraced managerial thinking which has led to similar practices and standards for CSOs across the globe. As a consequence, CSOs become increasingly similar and 'professional', and face difficulties in maintaining their identity, values and grassroots connections, all of which affect their capacity and legitimacy to advocate for marginalised groups. Also, a blueprint approach ignores the fact that not all CSOs need the same organizational capacities. Which capacities (and underlying organizational requirements) are relevant depends on contextual factors, the nature of advocacy interventions and whether advocacy is implemented alone or in coalitions. Therefore, we argue for tailor-made and locally owned capacity strengthening trajectories.

# About the authors

**Daniel Boyco Orams** is a social researcher from Peru. He completed his Master's degree in Development Studies at the International Institute for Social Studies (ISS) in 2018. Currently, he works for Oxfam Novib in the Netherlands. He is inspired by people's resilience, especially in extreme situations, and hopes to contribute to a better society wherever he goes.

Dutch-Burkinabé, **Amélie van den Brink** received her BA in Psychology/Art Therapy from the College of Santa Fe and Master in Art Therapy from New York University before receiving a Research Master's degree in African Studies in 2018 from Leiden University. She is a staunch human rights advocate, particularly on disability rights and mental healthcare access for children. She founded the Child Behavioral Health Network in The Hague treating children with special needs and trauma related issues.

**Toke Custers** studied International Development Studies with a specialization in Communication, Technology & Policy at Wageningen University. She is interested in how strategic communication can play a role in overcoming inequity. She specialized her research into the stigmatization and negative societal views on persons with disabilities, and how grassroot organizations strategized to change these views.

Bridging academia and practice has been a common thread running through the work of **dr. Willem Elbers** on civil society, advocacy, disability, power and partnerships. In recent years, he has been the principal investigator of the *Breaking down Barriers* learning trajectory and a NWO-funded

project on power dynamics in advocacy networks. Willem also holds a position as acting programme director of the Advanced Master in International Development (AMID), a post-graduate programme in international development at Radboud University in Nijmegen.

**Emma Frobisher** holds a Master's degree in Development from the Institute of Social Studies (ISS), from which she graduated in December 2016. She specialized in Children & Youth Studies which is her primary focus of interest along with gender and disability-related issues. She is currently working for the MariaMarina Foundation, a philanthropic organization that supports charities in developing countries, and is driven by seeing the impact that comes from the work she is involved in.

**Dr. Aisha Fofana Ibrahim** is a feminist scholar/activist who works on social inclusion issues and strongly believes that power and privilege should be used in the service of others. As an academic and practitioner, Aisha straddles the divide between policy and practice, both teaching about gender and marginality and promoting women's empowerment in practice. Her current academic research focus is on gender and artisanal mining, women's access to justice and women and disability.

**Dr. Auma Okwany** is assistant professor of Social Policy at The International Institute of Social Studies of Erasmus University Rotterdam (ISS) in the Netherlands. Her teaching, research and publications centre on the relationship between policy, practice and theory for children, youth and their

families in contexts of risk and marginalization. Using this scholarship to improve policy and practice, she is coordinating several externally funded development and capacity building projects in Uganda, Kenya, Tanzania, South Africa and Mozambique.

**Zuleikha Mohammed** currently works at Oxfam as a Monitoring and Evaluation Adviser for the organization's campaigns and policy department. Before that she has worked with Frontline Aids, PAX and Independent Diplomat. Zuleikha has a Masters in International Development from the University of Amsterdam and an undergraduate degree in French and Hispanic Studies from King's College London. Zuleikha's interest in disability stems from her family's personal experience and the difficulty of finding supportive education facilities.

**Thomas Mtonga** is a disability rights activist, consultant, advocate and a visually impaired lecturer at the University of Zambia in the School of Education. He is currently finishing his doctorate degree in the education of learners with albinism. Thomas is head of the section on Special Education and holds degrees in International Human Rights Law and inclusive Education.

After a Bachelor in political sciences at the University of Turin and Sciences Po Bordeaux, **Silvia Peirola** studied International Development Studies at Wageningen University. During her studies, she became particularly interested in the inclusion of people with disabilities, especially in post-conflict settings in Africa. Silvia is currently working at UNICEF Office of Research in Florence where she conducted research on teacher absenteeism and on the inclusion of children with disabilities in primary schools in West Africa.

Before **Sebastian Potthof** finished the Master's Programme Anthropology and Development Studies at the Radboud University in Nijmegen, he completed a Master's Programme in Modern History at the University of Cologne. Potthof is a founding member, treasurer, research assistant and photographer at 'VisAbility', a non-profit association working for the empowerment of people with disabilities in the global South, using a combination of mixed-abled dance and human rights education.

**Dr. Jelmer Kamstra** is Senior Researcher at the Policy and Operations Evaluation Department (IOB) of the Ministry of Foreign Affairs since January 2020. Before that he has been Senior Policy Officer at the Ministry of Foreign Affairs of the Netherlands in the Civil Society Division since 2015. He holds a PhD on promoting civil society and democracy and has 15 years of experience in academic research and teaching at the Radboud University of Nijmegen.

**Lindsay Vogelzang** completed her Master's at the University of Amsterdam in International Development Studies as follow up of a Bachelor in Cultural Anthropology. She has worked as project manager at the Dutch National Youth Council focusing on meaningful youth participation and children's rights. Her academic and professional experience will be the basis of her new adventure as executive director of CHOICE, a youth led organization focusing on youth participation and sexual and reproductive health and rights.

# Breaking down Barriers

Effective civil society engagement in advocacy requires a clear understanding of the practices and dynamics that create success. As of yet, however, the success factors of disability advocacy in the global South remain poorly understood. This book, which is part of the *Breaking down Barriers to inclusion* learning trajectory, examines the conditions under which advocacy can produce meaningful change for persons, children and youth in particular, with disabilities. It presents a number of case studies based on research in Sierra Leone, Cameroon and Zambia and teases out practical challenges, opportunities and dilemmas. Overall, the book allows for critical reflection upon the practices of disability groups, (I)NGOs and donors, while seeking to 'push the boundaries' of disability advocacy.

*Breaking down Barriers* was initiated by the Liliane Foundation and the African Studies Centre (Leiden University) in 2015 to identify the factors leading to successful advocacy for children with disabilities. Together with One Family People in Sierra Leone, The Cameroon Baptist Convention Health Services and Cheshire Homes Society of Zambia, the programme used academic research as input to build capacity for effective disability advocacy. *Breaking down Barriers* was managed by Anneke Donker (Liliane Foundation) and Willem Elbers (African Studies Centre).

[www.barriersfree.org](http://www.barriersfree.org)

