



Willem Elbers, 29 January 2020

Redefining advocacy. Persons with disabilities as agents of change

Good morning. My name is Willem Elbers. I am the principal investigator of the Breaking down Barriers project. Today I want to share with you some of our key findings.

My central argument will be that there is a great necessity to make advocacy more people-centred. And with people-centred, I refer to advocacy that, firstly, recognizes that marginalized people have diverse needs and interests and, secondly, places these people at the driver's seat of their own emancipation. While the examples given focus on persons with disabilities, the analysis also holds for other marginalised groups.

In Breaking down Barriers we looked at the factors and dynamics that shape the success of advocacy in Cameroon, Sierra Leone and Zambia. Over time, we came to see broader patterns present in all three countries.

Mostly importantly, we found that contemporary approaches to advocacy have three biases which undermine its potential to bring about inclusion. These are: (1) a narrow focus on projects and programmes, (2) a singular target group approach and (3) a one-sided emphasis on political and legal change. I will discuss these biases, but more importantly, I will outline three directions which I feel advocacy for inclusion needs to go to.

The first direction is that the strengthening of people's movements should be a key goal within advocacy for inclusion. When people think about advocacy, they often think about projects and programmes, which are implicitly seen as central to achieving social change. As such, it does not come as a surprise that many advocacy efforts do not consider the broader struggle of marginalized people's movements. There are, however, good reasons to question the idea of seeing projects and programmes, which are often externally funded, as drivers of social change.

I would argue that lasting inclusion can only be achieved when marginalised people and their movements play a leading role in their own emancipation. Persons with disabilities, for example, 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. And the time frame of social and political change, which often takes decades, goes far beyond the funding cycles and ever-changing policy priorities of international NGOs or donors. This simply means that in the long run, deep and lasting change can only come from persons with disabilities and their movements. The alternative,

advocacy on behalf of persons with disabilities, can actually be counterproductive as it confirms the negative stereotypical view that they cannot take care of themselves.

There is a great need for movement building. The disability movements in Sierra Leone, Cameroon and Zambia are quite weak and struggle greatly to operate as a collective. In all three countries we see movements that are fragmented along impairment types. Different impairments, such as the visually impaired or the hearing impaired, face different types of stigma and societal barriers. This makes it often more convenient for persons with the same impairment to get together as they face similar challenges. We 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 groups tend to have members of the same impairment type and cooperate mostly with others of the same impairment type. This fragmentation within the movement is further strengthened by capacity differences. In all three countries, the physically and visually impaired, who historically have had more educational opportunities, tend to be better organized and have stronger organizations than other impairment groups. This hampers cooperation within the movement.

People's movements are usually not on the radar of international NGOs and donors. In fact, their practices often go against the idea of movement building. Persons with disabilities can only be agents of change if they can set their own priorities. Yet what we see is that many donors and international NGOs provide little room to local disability groups to set the agenda. Moreover, 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.

Intersectionality

My second point is that advocates should embrace intersectionality in their thinking and practices. Many advocacy campaigns demonstrate little awareness for the diversity within marginalized groups. As a target group, the phrase 'persons with disabilities' represents an enormous diversity. Yet many disability organizations only consider the disability part of people's identity. Persons with disabilities have multiple identities that are overlapping and interrelated. 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 are not only be marginalized because of their disability, but also because of their gender and age. This is called intersectionality. Advocacy strategies are rooted in an understanding of what drives exclusion. Designing effective advocacy programs therefore requires using an intersectional approach that makes it possible to acknowledge the various marginalized identities that people have.

Adopting intersectionality as a key principle also creates opportunities for new alliances that increase the likelihood of achieving results. Once disability organizations adopt an intersectional approach, it becomes possible to forge new relations with non-disability groups, such as youth or women's groups. Cooperation with such groups makes it possible to combine resources and get access to new knowledge, expertise and networks. Ultimately,

this provides opportunities to increase critical mass, mobilize more people and search for solutions that go beyond each group's vision of what is possible.

Intersectionality is equally important for making the disability movement more inclusive. While this movement plays a key role in the struggle for disability inclusion, the research found the movements in Sierra Leone, Cameroon and Zambia to be far from inclusive. The level of involvement of youth and women appeared to be limited due to societal norms regarding age and gender which are not only reproduced by men of age, but also by women and young persons themselves. This raises critical questions about whose needs and interests are considered.

Personal change

My third point is that personal change should be a key goal within advocacy. In Sierra Leone, Zambia and Cameroon, there is a huge stigma attached to disability and there is a widespread view that persons with disabilities are helpless, unable, and a burden upon society. Many persons with disabilities have internalized this view, 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. The resulting inaction then further confirms the existing negative social views on disability. Consequently, there is a great need for advocacy that focuses on the personal change of persons with disabilities, enabling them to envision a different life, providing a sense of being in control over one's life and thus a greater sense of responsibility over one's actions.

The current advocacy discourse prioritizes political and legal change, possibly at the expense of personal change. Existing approaches stress the centrality of 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 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 and mobilization of persons with disabilities.

To be successful, the disability movement needs persons who are willing and capable to stand up and challenge dominant views on disability. Once people with disabilities start working towards a better future, they also 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 movement. These role models can show others with a disability that success is possible. They can offer the inspiration needed to motivate others to overcome a state of passiveness, look differently at themselves and start taking life in their own hands.

Ladies and gentlemen, I hope to have convinced you of the necessity of moving towards people-centred approach advocacy. Of the need to embrace a value-driven approach to advocacy that puts the agency of marginalized people and their diverse needs and interests at the heart of the struggle for inclusion.

Thank you!