Advocacy for disability

Can participation enhance outcomes?

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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.

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) 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 participation 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 capacitated 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
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One Family People staff doing baseline surveys.

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

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

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, sidelined and de-valued by the majority, and are routinely considered to be ‘not there’. Multiple barriers prevent them from participating in everyday 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 forefront 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 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 emphasizes 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

Notes
1 Willem Elbers is academic project-leader of ‘Breaking Down Barriers’ at the African Studies Centre Leiden. Aisha Ibrahim is director of the Institute for Gender Research and Documentation (INGRADOC) at Fourah Bay College.