Breaking down barriers to exclusion. A research design paper

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Abstract
In most developing countries people with disabilities, including children, remain excluded from all kinds of basic services. While some civil society groups have been quite successful in putting the rights of these people on the political agenda, others have failed to achieve any success. This raises the question why. The research project 'Breaking down barriers to inclusion' at the African Studies Centre (Leiden University, Netherlands) seeks to understand the factors that explain the outcomes of advocacy for people with disabilities. The field research takes place in Cameroon Sierra Leone and is conducted by talented Research Master-students (three-four annually) from various academic institutes in the Netherlands. Local academic experts in Cameroon and Sierra Leone provide supervision during the students' fieldwork and ensure that the research undertaken is context sensitive and meets quality and ethical standards. Besides generating academic knowledge on disability advocacy, the research outputs are used to stimulate organizational learning on effective advocacy for people with disabilities. The fieldwork will take place from 2016 till the first half of 2019.

Introduction

People with disabilities are amongst the most marginalized and impoverished people in the world. The World Health Organisation (WHO, 2011) estimates that among the poor, people with disabilities represent 20% of the population. This high percentage is due to a cycle in which poverty and disability enable each other (Bruijn et al, 2012). Poor people have a higher risk of acquiring a disability, for example because they are more exposed to disabling diseases. At the same time, people with disabilities have an increased risk of falling into poverty, because they are often prevented from participating fully in the society (Reynolds, 2010). This phenomenon is known as the disability-poverty cycle (see figure 1). Children with disabilities in particular are vulnerable, considering that they often cannot raise their voice and depend on their family and caretakers (Groce 2004).

Figure 1. Disability-poverty cycle
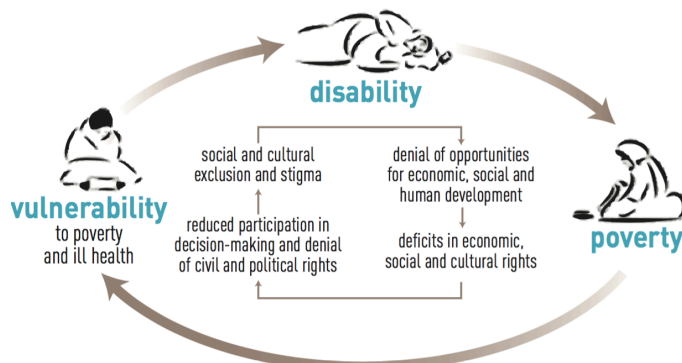
Source: Bruijn et al 2012: 16

Most socio-cultural research on disability in Africa finds that people with disabilities, including children, tend to be stigmatized and discriminated against (MacLachlana, et al. 2014). The

community often sees people with disabilities as objects of pity, helpless and unable, and as a burden upon society, because they are economically unproductive. Disability is further associated with maternal failure, witchcraft, misfortune, and religious punishment (Kuyayama, 2011). Overall, stigmatization and discrimination is 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. The inability of people with disabilities to participate in society at an equal level affects millions, including children and their caretakers.

Research has also shown that people with disabilities tend to experience difficulties in accessing services in the areas of education, employment, healthcare and social and legal support (Bruin et al., 2012). While some countries lack good laws and policies on disabilities, more often the problem is that they are not properly implemented. Relevant authorities often have difficulties addressing the situation due to limited resources, skills and a lack of coordination. Several researchers have observed a lack of political will to take action.

Advocacy
In the past decade, the rights and interests of people with disabilities have gained more attention in the international development field (Lang et al. 2009). 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 organisations 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 organizations can play in important role in promoting the rights of marginalized groups, including people with disabilities, through advocacy (Sabatallo & Schulze, 2013; Claessens & de Lange, 2016; Gormley& Cymrot, 2006; Badru & Hickey, 2014).

Advocacy can be defined as '*activities conducted to influence decision-makers in the public and private sector at international, national or local levels towards the overall aim of combating the structural causes of poverty and injustice and contributing to sustainable inclusive development*' (IOB 2015). In dialogue with governments or other power holders, civil society organizations can advocate for more inclusive policies and practices and put the rights of people with disabilities and their caretakers on the agenda. Alternatively, civil society organizations may keep a watchful eye to ensure that existing laws and policies are implemented.

Advocacy may involve different strategies (Meyer et al., 2012). One way to categorize them is to distinguish between outsider and insider strategies (Almog-Bar & Schmid, 2014). Outsider tactics, (Mosley 2011), are mostly used to send out information to get a specific message across or to mobilise people in order to weaken the position of a particular power holder. These tactics work 'outside the political system' and tend to have a more confrontational and activist character. Examples of outsider tactics include street protests, boycotts, petitions, press releases, press conferences, lawsuits and media campaigns. Insider tactics are intended to realize change by working directly with power holders 'inside the system'. While outsider is about one-way communication, insider strategies are about establishing a dialogue, finding joint-interests and investing in long-term relationships with decision-makers. Examples of insider tactics include organizing round table forums with policy makers, participating in policy formulation and legislative drafting, participation in 'official' boards and committees and personal exchanges with decision-makers (ITAD & COWI, 2012: 61).

Effective civil society engagement in lobby and advocacy requires a clear understanding of the factors that determine its success. As of yet, however, the success factors of advocacy for marginalized groups such as people with disabilities remain poorly understood (Almog-Bar and Schmid, 2014; Chapman & Fisher, 2002). This applies particularly to advocacy in the Global South. In particular, it remains unclear why some advocacy efforts have been effective at achieving their aims

and why others are not, and why other advocacy efforts have managed to achieve considerable change with very few resources, whilst well-funded groups have not had the same levels of success.

This research program addresses the above gap in the literature. Its starting-point is that effective engagement in lobby and advocacy to promote the rights of people with disabilities requires an in-depth understanding of its success factors. As such, it seeks to answer the following main question:

What factors enable and constrain local civil society organizations to promote the rights of people with disabilities through advocacy?

Research focus
As the success-factors of advocacy are shaped by many actors and factors, the project opts for a flexible design in which multiple sub-studies are carried out which each 'zoom in' on a topic that is thought to shed light on advocacy processes and outcomes. The sub-studies will be carried out be talented Research Master students from Dutch universities who each have six months at their disposal to undertake field research in either Cameroon or Sierra Leone (more about this below). Students that participate in the project will undertake qualitative social-science field research related to one of the following themes:
  - the strategies that civil society organization use to promote the rights of people with disabilities through advocacy;
  - the opportunities and constraints in the political environment and how they shape the success of advocacy activities;
  - organizational characteristics including capacity and resources of civil society groups and how they shape the success of advocacy activities;
  - the role of the media and communication in shaping the success of advocacy activities;
  - the role of networks and alliances in promoting the rights of people with disabilities;
  - the opportunities and limitations of the United Nations conventions (human rights, rights of persons with disabilities) for promoting the rights of people with disabilities;

Students can propose other themes as long as these fit within the larger framework of contributing to an enhanced understanding of the success-factors of advocacy for people with disabilities.
The project does not prescribe students to use specific theories for their research as lobby and advocacy can be examined from multiple theoretical angles.

Project-partners and roles
The research is funded by the Liliane Foundation, a Dutch foundation which seeks to empower children with disabilities in low-income countries. The implementing partners are the African Studies Centre (ASC) of Leiden University (in the person of dr. Willem Elbers), the Netherlands, in cooperation with dr. Aisha Ibrahim (Fourah Bay College, Sierra Leone) and dr. Walter Nwki (University of Buea, Cameroon). Data for this project are primarily collected by talented Research Master students (preparing for a PhD) who are recruited from Dutch universities through an extensive selection process. Practical support is offered by the local disability NGOs One Family People (Sierra Leone) and CBCHS (Cameroon), who have a good understanding of, and contacts in, the local disability context. Table 1 below outlines the key roles and responsibilities of the project-partners.

Table 1. Roles and responsibilities in the project

dr. Willem Elbers Project Manager	Dr. Aisha Ibrahim & dr. Walter Nkwi Local academic expert	Research Master students (to be selected)	One Family People (Sierra Leone & CBCHS (Cameroon) Local NGO partner
• Select students; • Supervision during proposal and thesis writing; • Co-author peer-reviewed; articles; • Synthesize existing academic knowledge • Co-identify suitable research cases; • Co-organize learning events; • Co-organize final conference;	• Supervise students proposal writing and fieldwork; • Facilitate learning events; • Co-identify suitable research cases; • Co-author peer-reviewed articles;	• Write research proposal and thesis • Data-collection • If the quality of the data permits: co-authoring an article • Participating in learning events	• Provide practical support to students during data-collection; • Co-identify suitable research cases; • Co-organize learning events;

Objectives and dissemination strategy

The academic goals of the project are to produce knowledge on the success-factors of advocacy for disabled people and publish in peer-reviewed journals. The societal goals of the project are to use the produced knowledge to stimulate organizational learning and capacity building in Liliane Foundation and its local partners, particularly CBCHS and One Family People.

These objectives will be realized through the following core activities:
- Research into the advocacy activities of organizations of the disability movements in Sierra Leone and Cameroon conducted by Research Masters students. These students are carefully selected from different Dutch universities for their talent, motivation and competences;
- Learning events at the end of the students' fieldwork periods revolving around their preliminary research findings. During these events relevant stakeholders (e.g. disability advocates, people with disabilities, authorities) participate. The meetings will (also) focus on the practical implications of the research findings for disability advocacy.

In addition to the above, a number of other activities will take place:
- The findings of the research conducted in Sierra Leone and Cameroon will be presented on a website constructed for this project. Besides being a communication platform, the starting-point of the website is that all tangible outcomes of the project will be put online for learning & dissemination beyond the project. The website will also contain project sheets, aimed at a broader audience, which will summarize the main research findings and the recommendations emanating from these;
- Towards the end of the project period, a final international conference will be organised to present the research findings. The results of the final conference will be captured in a book on disability advocacy.

Sample size and population

To understand the success factors of advocacy, the sub-studies undertaken in this project will examine (the population of) civil society groups in Sierra Leone and Cameroon seeking to advance the position of disabled people within the context in which they work. This includes both membership organizations (e.g. Association of the Deaf, Association of the Blind) and non-governmental organizations. The exact number of civil society groups in Sierra Leone and Cameroon seeking to advance disability rights through advocacy is unknown. The project will therefore start

with a mapping exercise seeking to identify the main disability 'players' in Sierra Leone and Cameroon, what they have done in terms of advocacy and what kind of results they have achieved.

Given the project's need for flexible research methods, the sub-studies in this project will use qualitative research methodology (more about this below). Unlike most quantitative studies, qualitative research does not set out to estimate the incidence of phenomena in the wider population statistically. Instead, the goal of qualitative research is to provide in-depth understanding and therefore, targets a specific group, type of individual, event or process. To accomplish this goal, qualitative research uses criterion-based sampling techniques. The nature of the research question determines which criteria will be used in the sampling. For example, the sampling of a sub-study seeking to identify the pro's and con's of different advocacy strategies would aim for heterogeneity, making sure that strategies with different key characteristics (e.g. insider/outsider, media-involvement, mobilizing people with disabilities, individual vs joint strategies) are included. Local disability experts will provide input in selecting appropriate samples (Lewis & Ritchie, 2003: 94).

Methods and data-sources

Advocacy has a number of specific characteristics which need to be taken into account during the design and implementation of research:
- it focuses on complex and dynamic change, with the consequence that action and reaction are often not directly traceable;
- it typically produces unpredictable results that are influenced by many actors and factors;
- it leads to change that can manifest itself at different levels;
- It often has multiple objectives and objectives often change during a campaign;
- it is not always possible to plan interventions in advance (Tsui, Hearn & Young, 2014).

These characteristics make research into advocacy challenging and underline the importance of a flexible methodological approach that can deal with complexity and adapt based on emerging insights and changing conditions. As such, qualitative research methods seem most appropriate here.

Qualitative research aims to understand how people think about the world and how they act and behave in it. This approach requires researchers to understand phenomena based on discourse, actions and documents, and how and why individuals interpret and ascribe meaning to what they say and do, and to other aspects of the world (including other people) they encounter. Qualitative research can also extend beyond individuals' personal experiences to explore interactions and processes within organizations or other environments. Knowledge at both an individual and a cultural level is treated as socially constructed. This implies that all knowledge is, at least to some degree, interpretive, and hence, dependent on social context. It is also shaped by the personal perspective of the researcher as an observer and analyst. Qualitative research can be useful in giving marginalized groups, such as people with disabilities, a voice (Ashby, 2011).

The sub-studies will use a combination of following methods and data-sources:
- *Secondary analysis of existing research.* Analysis of existing academic work on advocacy for marginalized groups including people with disabilities will help students in getting a sense for the topic, identity useful theoretical approaches and provide input for developing interview guides and questionnaires.
- *Formal and informal publications of advocacy organizations*. Written documentation such as narrative reports, memo's and evaluation reports provide insight into the inner workings of advocacy organizations, the work they do and outcomes they achieve.
- *Semi-structured interviews.* Semi-structured interviews allow researchers to ask a fixed set of questions while allowing new ideas to be brought up during the interview as a result of what the interviewee says. Semi-structured interviews rely on an interview guide, which is an informal grouping of topics and questions that the interviewer can ask in different ways for different participants. Relevant people to interview in this project include staff of advocating

organizations, people with disabilities, civil servants, community leaders, journalists, teachers, politicians religious leaders (Della Porta, 2015a).

- *Focus group discussions*. During a focus group discussion people from similar backgrounds or experiences discuss a specific topic of interest. For example, a focus group discussion could involve people with disabilities of staff of the advocating organization. The group of participants is guided by a moderator. The strength of focus group discussions relies on allowing the participants to agree or disagree with each other so that it provides an insight into how a group thinks about an issue, about the range of opinion and ideas, and the inconsistencies and variation that exists in a particular community in terms of beliefs and their experiences and practices (Della Porta, 2015b).
- *Participatory observation.* This is about the observer participating in on-going activities and records observations. Researchers, for example, participate in group meetings or round table forums. Participant observation extends beyond naturalistic observation because the researcher is a "player" in the action. The strength of participatory observation is that the researcher is able to get an "insider" viewpoint and the information may be much more rich than that obtained through systematic observation.

As the choice of research methodology always depends on the research question at hand, the exact way the above methods are to be used has to be tailored to the needs of each individual sub-study.

The fieldwork in this project will take place from early 2016 to early 2019. The Research Master Students who carry out the sub-studies each have six months available for their fieldwork. As they have considerable flexibility in planning their own fieldwork, an exact planning of when the sub-studies will be carried out cannot be provided in advance. A minimum of 12 Research Master Students is expected to undertake field research in the project.

Consent

Informed consent means allowing prospective participants to make informed, free decisions on their involvement by giving them sufficient information about the research (Kalwant & Ross, 2015). This ensures that there is no explicit or implicit coercion. All researchers participating in this project provide information in written form, allowing the participants time to consider their choices, and ask research participants to sign the consent forms. The person interviewed will always be aware of what will happen to any findings, whether the data will be shared with others, and whether he/she will be identified.

Where participants are not legally responsible (for example, children with disabilities), their legal representatives or caretakers will be consulted (Bhopal and Deucher, 2015). Where participants are not literate, verbal consent will be obtained. If possible this will be witnessed and recorded. In giving consent, participants have the right to withdraw consent as well as the right not to answer particular questions.

In this project, there will be no coercion of prospective participants to take part in the research. Adult research participants, however, may be given small monetary reimbursement for their time and expenses involved. The issue of making any payments to participants over and above the costs of participation, such as transport costs, will be carefully considered on a case-to-case basis, as excessive incentives to participate can be coercive. Care will be exercised in such setting where interpreters are used in data-collection or interviews. Particular care will be exercised in situations where persons with disabilities might feel pressured to participate. Where children with disabilities are involved, it can be appropriate to acknowledge their help with gifts to participating schools and/or personal gifts. One Family People and CBCHS, the local disability NGOs involved in the project, will advise on what is appropriate in the context of Sierra Leone and Cameroon.

In this project, extra effort will be made to secure informed consent from vulnerable groups such as children with disabilities or adults with mental disabilities. If possible, passive assent, including group assent (with consent given by a gatekeeper) will be avoided wherever possible although in some cases this will be practically difficult to achieve (Bhopal and Deucher, 2015).

Risk management

Risk in the context of research could include both researchers and the researched. Risk is often defined by reference to the potential physical or psychological harm, discomfort, or stress to human participants that a research project might generate. In social science research may raise a wide range of risks. These include risk to a subject's personal social standing, privacy, personal values and beliefs, their links to family and the wider community, and their position within occupational settings, as well as the adverse effects of revealing information that relates to illegal, sexual, or deviant behaviour. Research which carries no physical risk such as this project can still be disruptive and damaging to research participants either as individuals or as whole communities or categories of people (e.g. people with disabilities).

In this project, it is imperative that researchers appreciate the social, cultural and historical experiences of people with disabilities, including experiences of exclusion and stigma. This is already taken into account during the selection process of prospective researchers. Whether a prospective researcher displays sensitivity to these issues is one of the key selection criteria. In general, the research process should not perpetuate or endorse, directly or indirectly, any aspect of discrimination, stigma or exclusion. When preparing for their sub-study, researchers in this project are made aware that in-depth interviews, particularly on sensitive topics, may bring up traumatic memories. This makes it imperative that research is carried out in a respectful and private manner (Kalwant & Ross, 2015).

Not all risks can or, in some cases, should be avoided - but it is important that researchers develop awareness of potential risks. Nevertheless, researchers should endeavour to determine possible risks and their management (not least through the methodological strategy and instruments they adopt) prior to the start of a project. Guidance and advice will be provided by the principal investigators leading this project to researchers about ways in which risks can be minimised and participants protected from harm, while at the same time offering advice on the prioritisation and different degrees of risk. In this project, a risk analysis is made for each sub-study, tailored to the specifics of the research question and methodology. The involvement of a local academic expert (dr. Aisha Ibrahim) will be pivotal to ground the risk analysis in the proper socio-cultural context.

Data protection and management

Data protection entails protecting the privacy of the individual in relation to any personal information they may have disclosed in the course of the research. It also means ensuring the reliability of any information used and also using the information fairly and responsibly. Some data is more sensitive then others. Sensitive data, for example, can relate to one's political opinion, physical or mental health, involvement in activism or illegal activities.

There are risks posed to any data stored on portable devices and media - for example, laptops and USB flash drives. In this project researchers are expected to separate collected data from any information that can disclose a person's identity as soon as possible after data collection and to use codes to identify individual cases if this is necessary. The key that links such codes to identity information (such as names, addresses and telephone numbers) will be kept secure and separate from the dataset, accessible only to the researcher.

Confidentiality

The focus of the study lies with examining advocacy tactics and its outcomes (e.g. awareness raising, changed laws and governmental practices). Disabled people will play a role in the collection of data, although they are not necessarily the primary data source. As data-sources, they can shed light on the advocacy tactics and its outcomes as either participant in an, or beneficiary of, an advocacy campaign. Before data obtained within this project is published or shared with other researchers, they will be anonymised so that individuals cannot be identified from the data. Personal data will not be disclosed from research information, unless a respondent has given specific consent to do so.

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