How inclusive is the disability movement?

The case of North-West Cameroon

Daniel Boyco, Willem Elbers and Auma Okwamy

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 hierarchal 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 N-W 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 below). 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.

<table>
<thead>
<tr>
<th>Name</th>
<th>Year founded</th>
<th>Membership size</th>
<th>Location</th>
<th>Focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hope Social Union for the Visually Impaired (HSUVI)</td>
<td>2003</td>
<td>40</td>
<td>Bamenda III, Mezam</td>
<td>Visual impairment</td>
</tr>
<tr>
<td>Cameroon National Association for the Deaf (CANAD)</td>
<td>Early 2000s</td>
<td>300+</td>
<td>Bamenda, Mezam</td>
<td>Hearing impairment</td>
</tr>
<tr>
<td>North West Association of Women with Disabilities (NWAWWD)</td>
<td>2013</td>
<td>35</td>
<td>Savanah Street, Bamenda II, Mezam</td>
<td>Open</td>
</tr>
<tr>
<td>Special Needs Entrepreneur Group (SNEG)</td>
<td>1999</td>
<td>150</td>
<td>Fish Pond Hill, Mezam, Bamenda II</td>
<td>Open</td>
</tr>
<tr>
<td>Kedjom Ke-Tinguh Association of Persons With Disabilities (KKAPWD)</td>
<td>2013</td>
<td>67</td>
<td>Kedjom Ke-Tinguh, Mezam Tubah Subdivision</td>
<td>Open</td>
</tr>
</tbody>
</table>
refers merely to 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 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 intergeneration 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 (Goodwill 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 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 promote their interests compared to the hearing and intellectually impaired.
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 particularly 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 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 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 hierarchical societal understanding of disability in which the physically and visually impaired are seen as less disabled than the hearing and intellectually impaired.

Further reading
See www.barriersfree.org

Notes
1 Willem Elbers is academic project-leader of ‘Breaking Down Barriers’ at the African Studies Centre Leiden (Netherlands). Auma Okwamy is assistant professor at the International Institute of Social Studies (Netherlands).