

International  
Institute of  
Social Studies



**‘How We Come Together: Exploring the  
Participation of Youth with Disability in Disability  
Associations of North West Cameroon’**

A Research Paper presented by:

***Daniel Boyco Orams***  
(Peru)

in partial fulfilment of the requirements for obtaining the degree of  
MASTER OF ARTS IN DEVELOPMENT STUDIES

Major:

**Social Policy for Development  
(SPD)**

Members of the Examining Committee:

Dr. Auma Okwany [Supervisor]  
Dr. Willem Elbers [Reader]

The Hague, The Netherlands  
December 2018

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***Inquiries***

International Institute of Social Studies  
P.O. Box 29776  
2502LT The Hague  
The Netherlands

t: +31 70 426 04600  
e: [info@iss.nl](mailto:info@iss.nl)  
w: [www.iss.nl](http://www.iss.nl)  
fb: <http://www.facebook.com/iss.nl>  
twitter: [@iss.nl](https://twitter.com/issnl)

***Location***

Kortenaerkade 12  
2518AX The Hague  
The Netherlands

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### *Acknowledgements*

This research paper would not have been possible without the constant support of Auma Okwany and Willem Elbers. Additionally, I'm in tremendous debt with all members of CUAPWD and of the disability associations of the North West, as well as with the CBCHS.

Special thanks also to Lynn Cockburn, Wendy Harcourt, Elizabeth Ngutuku and Ryan Febrianto for their comments and suggestions.

This research paper is dedicated to all the brave women and men with and without disability in the North and South regions of Cameroon who face everyday an increasing climate of violence and insecurity. It is also dedicated to those persons with disability who have perished because of the conflict, often from being caught in crossfire or in communicational misunderstandings. Their passing and suffering speaks about the special vulnerability of those with disability during armed conflict.

*List of acronyms*

BDB	Breaking Down Barriers
CANAD	Cameroon National Association of the Deaf
CBCHS	Cameroon Baptist Church Health Services
CRPD	Convention on the Rights of Persons with Disability
CUAPWD	Coordinating Unit of Associations of Persons With Disability
HSUVI	Hope Social Union for the Visually Impaired
LSHTM	London School of Hygiene and Tropical Medicine
NPY	National Policy of the Youth
SNEG	Special Needs Entrepreneur Group
UDHR	Universal Declaration of Human Rights

## *Abstract*

Young persons with disability are a highly marginalised and vulnerable group in most societies, especially in contexts of long standing poverty and inequality, such as the North West Region in Cameroon. For this reason, it is not uncommon that young persons with disability have significant difficulties in achieving the fulfilment of their rights.

Young persons with disability, as people with disability in general, have the opportunity to fight for their rights by participating in political and public life. However, in contexts of high vulnerability and exclusion, the barriers faced to accomplish this can be multiple and multi-dimensional.

That is why this research paper seeks to examine how participation of young people with disability in a network of disability associations in the North West Region in Cameroon is constructed through a discourse of empowerment, but at the same time is recreating larger structures of exclusion in which the network is embedded in.

For this purpose, it sets to understand how notions such as ‘youth’, ‘disability’ and ‘participation’ are constructed and negotiated through social interaction. Through an intersectionality lens, this paper will examine how these issues relate to the reproduction of social inequality.

# **CHAPTER 1:**

## **PRESENTATION**

### **1. Introduction**

Young persons with disability are a highly marginalised and vulnerable group in most societies, especially in contexts of long standing poverty and inequality, such as the North West Region in Cameroon. Firstly, as persons with disability, they face multiple physical and social barriers to participate fully in society (United Nations 2006, Berressem et al 2017, Nixon et al 2015, Diez Canseco 2002, Siebers 2001, Corker and French 1999, Diez Canseco n.d.). Then, as young people, they are formed in subjugated relations to adults, which often means that decisions which affect their lives are taken for them and without them (Okwany forthcoming, Boggis 2018, Honwana 2012, Richter and Panday 2007, Shroff et al 2006, Ngutuku et al n.d., Wyn and White 1997).

For this reason, it is not uncommon that young persons with disability have significant difficulties in achieving the fulfilment of their rights, including their right to participation. Young persons with disability, as people with disability in general, have the opportunity to fight for their rights by taking part in collective action (United Nations 2006: 21-22). Participating in political and public life presents an opportunity for persons with disability to fight for their rights.

Being a human right makes participation of vital importance to development studies. It commonly accepted that certain forms of participation can lead to the empowerment of participants (Sotkasiira et al 2010, Sinclair 2004, White 1996). However, this means that participation has to be observed in context in order to examine if it is empowering.

Through an intersectionality lens we can see that what is understood by concepts such as ‘youth’, ‘disability’ and ‘participation’ are not universal, but rather constructed socially through institutionalised systems of knowledge (Yuval Davis 2016, Hankivsky et al 2014, Marx Ferree 2009). And so, there is the need to contextualize this meanings in order to understand how this participation is occurring, by which forms, and which structures of inequality it may be reproducing.

For this reason, this paper seeks to examine the participation, however its being understood, of young persons with disability, however they are being constructed by themselves and others, in the disability associations that they are part of. This will be done using an intersectionality lens.

### **2. Research problem**

Because of all the abovementioned, this research paper seeks to examine how participation of young people with disability in a network of disability associations in the North West Region in Cameroon is constructed through a discourse of

empowerment, but at the same time is recreating larger structures of exclusion in which the network is embedded in.

This will be done by observing, interviewing and conducting focus groups and having informal conversations with the members of these disability associations, both young and non-young, about the meanings surrounding young people's participation in the associations.

This research is part of the Breaking Down Barriers (BDB) project. The BDB project uses academic research to provide a base of evidence in building capacity for effective disability advocacy in different contexts. BDB is a joint project between the African Studies Centre of Leiden University and the Liliane Foundation.

As part of BDB, a partner of the Liliane Foundation, this study will contribute to understanding the factors which enable or constrain effective advocacy for persons with disability in contexts of poverty and inequality, as advocating for persons with disability also entails understanding "the role of networks and alliances in promoting the rights of people with disabilities" (Elbers 2015).

For this, the aim of this research project will be to provide academic evidence for effective advocacy in favour of young people with disability and their participation in the disability movement. It also aims to serve as evidence for informed policy-making that is inclusive and respectful of the heterogeneity of this group.

### **3. Research questions**

#### *Main research question*

How is the participation of young people with disability in a network of disability associations in the North West Region in Cameroon constructed through a discourse of empowerment while at the same time is recreating an internal structure of exclusion?

#### *Research sub-questions*

- How are young people with disability participating in their associations?
- How is passive participation of youth with disability being constructed through a discourse of empowerment?
- How is social participation young people with disability reproducing structures of inequality?

## CHAPTER 2: METHODOLOGY

For the purpose of this research, I visited Bamenda, the main city of the North West Region of Cameroon from July 4<sup>th</sup> until August 19<sup>th</sup> of 2018. All interviews and focus groups discussions presented in this paper were conducted for this investigation during this time frame.

My fieldwork was possible thanks to the support of the Cameroon Baptist Church Health Services (CBCHS), which hosted me in Bamenda, and the Coordinating Unit of Associations of Persons With Disability (CUAPWD), which showed me their work and assisted me in contacting a range of stakeholders and different members of the associations of persons with disability. Through CUAPWD, I was connected with most of the young and non-young persons with disability I talked to during my fieldwork.

### 1. Data collection

During my time in the Bamenda, I conducted interviews and focus groups, observed meeting of associations, and had plenty of informal conversations with young and non young persons with disability related to this network. I also accompanied members of CUAPWD in their advocacy activities and spent time in their office observing their daily functioning.

#### *Interviews*

I conducted a total of 29 interviews, which were distributed as follows:

- 9 with young persons with disability (mostly of visual and physical impairment, but also hearing impairment); all but one were members of the various associations of the network
- 5 with non-young persons with physical disability, members of different associations of persons with disability
- 2 with mothers of children with intellectual impairment, members of associations of persons with disability
- All 5 members of CUAPWD were interviewed, some on more than one occasion
- 4 with professionals of the Cameroon Baptist Church who worked on disability issues
- 2 with Sign language interpreters for the hearing impaired
- 1 with a government official from the Ministry of Social Affairs
- 1 with a professional from a local NGO working in development issues

Interviews are quoted in this text using the following code:

(Man=M/Woman=W) (Type of disability) (Age)

Type of disability has three categories: Visual impairment=V, Physical impairment=P and Hearing impairment=H.

In some cases, interviewees are signalled by their role in an associations. This has been done with their permission and only in instance where it was necessary for the research purpose.

### *Focus groups*

I also conducted 6 focus group discussions, which were distributed as follows:

<b>FG code</b>	<b>Number of participants</b>	<b>Type of disability</b>	<b>Gender</b>	<b>Ages</b>
FG1	6	Mixed, mostly parents of children with intellectual impairments	Mixed	All above 40
FG2	6	3 with visual impairment, 2 with hearing impairment, and 1 with physical impairment; a Sign language interpreter was present for this discussion	Women	19, 24, 25, 25, 25 and 27
FG3	4	2 with hearing impairment, 1 with visual impairment, and 1 with physical impairment; a Sign language interpreter was present for this discussion	Men	24, 25, 36 and unspecified
FG4	3	All with visual impairment	Men	22, 22 and 27
FG5	5	All with hearing impairment; a Sign language interpreter was present for this discussion	Mixed	20, 21, 23, 25 and 39
FG6	7	5 with visual impairment and 2 with physical impairment	Mixed	13, 21, 26, 25, 27, 42 and unspecified

### *Observations*

Additionally, I observed 8 meetings held by different associations of persons with disabilities.

Finally, I accompanied the General Coordinator and other members of CUAPWD in several advocacy activities directed at religious organisations, government officials and others.

## **2. Revising my own positionality**

Conducting research with persons with disability in contexts of extreme poverty can present significant ethical challenges for research (Bamu et al 2016).

At the same time, from literature we learn that responses in fieldwork are narratives, or “contingent articulations” mediated by the interpreted image the respondents may have of the researcher and his or her objectives. This means that narratives that emerge in fieldwork “unfold through the implicit negotiation process between a researcher and a research participant”, as this relation is “embedded in broader socio-material relationalities” (Lesutis 2018: 510).

In order to follow the ‘do no harm’ principle, I conducted, in collaboration with my supervisor and second reader, a reflexive revision of my own positionality might affect the research process. Now, upon writing, I can sum it up in two ways.

Firstly, because of my own intersectionality as a non-African, non-disabled, non-religious adult male. As a non-disabled person, I also faced important barriers of communication, such as not speaking Sign language, and required an interpreter in certain scenarios. I tried to mitigate this by taking Sing language classes while in Bamenda.

Secondly, during fieldwork it became evident that not only my positionality as an outsider was important, but also my linkage to the partners of the BDB project. Through this project, I was given access to the field. At the same time, this meant that all but one of the associations of persons with disability which I interacted with were associated to the CUAPWD. Even more, the recruitment of all but one of my focus group discussions was conducted by the General Coordinator of CUAPWD. For this reason, my findings are circumscribed to this network of individuals and associations.

Also, as part of the BDB project, I was also recognised as being linked to the Liliane Foundation, a donor for both the CBCHS and the CUAPWD. This gave an aura of formality to my presence and my questionings. In a way, this was productive, as this enabled the research to be conducted without problems. But at the same time, it might have meant that my research was interpreted by some as an evaluation of their activities, in which I were to establish if they were doing a good job or not based on the amount of young people participating in them.

I tried to mitigate this by making explicit that my research did not have any evaluative component, that none of my findings would ever disempower the disability movement or the work of these associations.

## CHAPTER 3:

### ANALYTICAL FRAMEWORK

This research paper sets out to analyse the participation of youth with disability through an intersectionality lens. For that reason, the academic debates surrounding these four concepts are presented below.

#### 1. Youth

The importance of youth participation in Africa has been widely recognised and it has become a recurrent topic of discussion in development studies (Honwana 2012, Shroff et al 2006). As the recognition of children and youth as active rather than passive social actors advances in academia, there is a growing interest in the role children and young people as active actors of social change (Percy-Smith and Thomas 2010).

However, the definition of youth is often elusive. Youth is commonly understood as the life-stage people go through following childhood and preceding adulthood. Although this sounds pretty straight forward, the truth is that the diversity of life-experiences of young people across the globe make it hard to actually talk about youth as a homogenous, easy to define concept (Wyn and White 1997).

Even the age brackets in which young people are supposed to be located are not universal. Age categorization often differ between organizations, and even governments (Ngutuku et al n.d.).

Because of this, I understand youth as a relational social construction. This means that, as a person goes through life, the biological changes he or she experiences are “mediated predominantly by the society and culture” in which he or she lives (Boggis 2018: 5).

Understanding youth as relational means seeing it as “a product of the relations that adults have with young people” (Okwany forthcoming: 2) or a “comparative self-perception, arising within a social, economic and cultural context” (Richter and Panday 2007: 293). Therefore, the notion of youth is constructed as comparative self-perception in relation to other actors, which means it can be negotiated depending on context.

Furthermore, I understand the relations that youth have with adults are embedded in relations of power. This is because the youth are often seen as ‘transitioning’ from childhood to adulthood, which creates a hierarchy of status between them (Jones 2009). That is why, youth are usually subjugated to adults in social relations (Okwany forthcoming).

#### 2. Disability

I understand disability as a “historical, social and cultural construction” that has strong “interrelation between power and symbolic meanings” and creates a “phenomenon of embodied difference” (Berressem et al 2017: Editorial). This means I understand disability as an evolving social discourse of exclusion.

The construction of disability as a social discourse claims that disability can take on many forms, but that they all share a common exclusion from participating in society (United Nations 2006; Nixon et al 2015; Cortez Segura 2016). That is why a common thread among all these “heterogeneous forms of disability” is that they all “involve discourses of ‘normality’ from which all disabled people are excluded” (Yuval-Davis 2006: 200).

This common exclusion means viewing disability as the “effect of an environment hostile to some bodies and not to others”, which means thinking about the issue in terms of “social justice rather than medicine” (Siebers 2001: 738). This environment is both physical and social, and can be affected through policy to make it more enabling for persons with disability (United Nations 2006, Diez Canseco n.d.).

### *The intersectionality of disability*

The intersection of disability with gender, age, class and other social categories tells about complexity of the process of social exclusion experienced by different persons with disability. This is because, as a social category, disability cuts through all other social categories. Anybody, regardless of their gender, race, religion, nationality, class, etc. can obtain a disability at some point in life, which becomes more true if approaching old age (Diez Canseco 2002, Diez Canseco n.d.). This means that those who are considered ‘with disability’ are an immensely diverse group of people (Corker and French 1999).

Even within the category of ‘with disability’ we find groups facing very different sorts of challenges. The variance between those with different ‘types of disability’ can be drastic, and can result in very different life experiences. Furthermore, within each type of disability, we will find people of multiple genders, ages, class positions, and so on, which will inevitably also create variability in the life chances of persons that share the same type of disability.

### **3. Participation**

In development practice, participation can be seen to have an unarguably positive connotation, something to be achieved in order to tackle inequality. It is often a word used by development initiatives as part of their main goals.

International organisations of the UN system, for example, propose addressing participation through policy in order to promote health equity (WHO 2018), achieve gender equality (UNDP 2018) or promote youth empowerment (United Nations 2018).

Other powerful development stakeholders, such as governments, international organisations, NGOs and private corporations also talk about participation. Often,

they have conflicting views of what participation is (and what it is not). Some even talk about the notion of participation as being “co-opted” by neo-liberal discourses (see Cornwall n.d.). Because of this, the term is being coined today as ‘buzzword’ of development practice, meaning a widely used concept that can often confer different meanings (Cornwall and Eade 2010; Sacks 1992).

### *How did participation become a global developmental aspiration?*

Participation for members of all societies becomes globally accepted as a human right with the Universal Declaration of Human Rights (UDHR) in 1948. It has since been ratified and further explained in numerous other international treaties, such as the 2006 Convention on the Rights of Persons with Disability (CRPD).

The CRPD recognises different dimensions where people participate in society, such as the cultural, political and economic life (United Nations 2006).

In the specifications of the right of persons with disability to participation in political and public life, the CRPD specifically mentions the “freedom” to participate in public affairs, which can mean “participation in non-governmental organizations and associations concerned with the public and political life of the country”, such as “political parties”, and also “forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels” (United Nations 2006: 21-22).

### *Examining participation in context*

Human rights are aspirations. Hence the importance of understanding how they are turned into practice by individuals in their context. This is because there can be different forms of participation, which can carry different meanings and produce different outcomes.

For example, Sinclair notes that participation can be passive or active; passive in the sense of someone being “listened to” or “consulted”, versus active, where involvement is expected to “make a difference” for those participating, presuming some sort of empowerment and involvement in decision-making (Sinclair 2004: 110-1).

At the same time, Sotkasiira et al make the distinction “between *participation as social activity* and *participation as influencing or creating change* in political or societal processes” (Sotkasiira et al 2010: 176).

When participation is linked to decision-making, influencing, producing change with one’s actions, it can be read as “transformative action” that leads to “structural empowerment” of participants. However, participation can also be understood as “nominal” or “instrumental”, where the presence of someone is exploited by others and in no way does it lead to their transformative empowerment (White 1996).

Taking all this into account, I shall recognize that participation can take many forms, and that these can be distinguished as either active and passive. I will understand active participation as linked to decision-making processes, creating change and

making a difference. Passive participation refers to merely being present, even being listened to, but not taking part in making decisions or affecting collective change.

Furthermore, because of the variability of what is understood by participation and its effects, I will take a deeper look at what is being understood as participation and empowerment in the context we set to observe.

#### 4. Intersectionality

This paper uses an intersectionality lens to examine the participation of young persons with disability.

Intersectionality is a social theory that explains the complexity of social inequality by acknowledging the interdependence of different socially constructed systems, or ‘locations’ or ‘categories’, in a person’s identity, such as gender or race, and how they manifest differently to empower or disempower that person in changing social and physical environments (Marx Ferree 2009)

A central idea of intersectionality is that our identity can be partitioned into distinguishable ‘institutional systems’ that are socially constructed and evolve through time. These systems are formed by narratives of social life that are embedded in unequal relations of power. Examples of these systems are gender, age, ability, religion, and others (Yuval-Davis 2006).

What’s more, although we perceive these ‘systems’ or ‘locations’ as separate, they are in fact completely interrelated, part of a major structural narrative that naturalizes the inequality of our relations, and therefore is embedded with major power structures. As explained by Hankivsky and others:

“Social locations are inseparable and shaped by interacting and *mutually constituting* social processes and structures, which, in turn, are shaped by power and influenced by both time and place” (Hankivsky et al 2014, my own emphasis)

In this sense, “an intersectional analysis can do justice to the actual complexity of political power and social inequality” (Marx Ferree 2009: 85) because it allows us to look more closely at the processes by which this discourses are constructed and reproduced, and how they often build up to time-resistant structures of exclusion and marginalization for different groups of people (Yuval Davis 2006).

## CHAPTER 4: CONTEXTUAL BACKGROUND

The young women and men I talked to were in the city of Bamenda and its surrounding villages and neighbouring districts. A few important contextual points have to be made about the current political and social climate in this the area.

### 1. Issues of age in Cameroon

Cameroon, like many other African countries, has a predominantly a young population. In 2017, 35.4% of its population was between 15 and 35 years of age, while 41.8% was below 15 ('Population Pyramids of the World from 1950 to 2100: Cameroon 2018).

At the same time, today Cameroon's leadership remains in the hands of people of old age. Paul Biya, whose held office since 1985, is an octogenarian authoritative ruler surrounded by an "ageing inner circle" (Anonymous 2018).

This makes issues of age and youth participation a critical issue in Cameroonian society.

#### *The official definition of youth in Cameroon*

For policy related issues regarding the youth, the main document informing the Cameroonian Government is the National Policy of the Youth (NPY), established in 2015. There, youth is defined as "all persons between 15 and 35 years old" (Ministère de la Jeunesse et de l'Education Civique 2005: 45).

Overall, the NPY has a homogenizing and subjugating view of the youth. Firstly, it only recognising ethnic, cultural and linguistic diversity, leaving out gender and other categories. Seconfly, the NPY problematizes youth as in need of "education and formation" (Ministère de la Jeunesse et de l'Education Civique 2005: 22).

#### *Youth in social movements in Cameroon*

Formal youth groups have been involved in Cameroonian civil society since the process of political liberalization in the 1990s. Formal youth groups have been part of the political arena, both as supporters of Paul Biya's autocratic rule as well as from the opposition (Fokwang 2007, Fokwang 2003).

Fokwang argues that, although these groups have had varied objectives and strategy, the common thread among them has been a search for recognition of young people as relevant social actors (Fokwang 2007: 309). It also concludes that "the concerns of young people in Cameroon have frequently been driven, not by hunger or disease, but by economic and socio-political issues that affect their lives in various ways" (Fokwang 2007: 321). However, in none of these youth groups the topic of disability seems to have been present.

### *Youth with disability in Cameroon*

The NPY specifically mentions “young people with disabilities”, among a large group of others marginalized groups, as it recognises their continuous “suffering” due to “insufficient social protection” (Ministère de la Jeunesse et de l’Education Civique 2005: 38).

Studies regarding the situation of persons with disability are not uncommon in the North West region of Cameroon (see, for example, Nixon et al 2015 or Mbibeh 2013). However, I could find no studies related to the prevalence of disability among young persons, only general estimates for those between 18 and 49.

The London School of Hygiene and Tropical Medicine (LSHTM) estimated in 2014 that the prevalence of disability in the North West Region of Cameroon was 10.5% of the total population. It found disability “to be strongly associated with age”, as disability was more prevalent among older ages (LSHTM 2014: 29). Although it does not specify the prevalence of disability of persons between 18 and 35, it does mention that for those between 18 and 49, the prevalence of disability is of 6.9%.

This means that issues of youth and issues of disability in the North West Region of Cameroon are of recognised importance, but have often been disassociated from each other.

## **2. The political climate in Bamenda**

The North West and South West Anglophone regions in Cameroon are currently undergoing a period of political crisis where insurgent groups are attempting to independence from Central Government using violent means (UNHRC 2018, Amnesty International 2018, Shaban 2018, Anonymous 2018). Bamenda, being the capital of the North West region, is at the heart of this crisis.

Several national and international media have been reporting on the effects that this crisis is having on civilians, who are being caught in the crossfire of the rebel and government forces. Reports of murder, torture, kidnap, rape, mass killings, burning down villages and general harassment towards the population have been very common (Amnesty International 2018; ‘Burning Cameroon: Images you're not meant to see’ 2018; ‘ ‘This is a genocide’: villages burn as war rages in blood-soaked Cameroon’ 2018; ‘ “Anglophone crisis” : 258 articles’ 2018; among many others).

Africa News reported that on 7 March 2018 the United Nations Human Rights chief, Zeid Ra’ad Al Hussein, said to the 37th session of the Human Rights Council that:

“Allegations of summary executions of civilians by members of the security forces have been reported, and are generating widespread resentment. I regret that my Office has not been given access to verify these allegations.” (Shaban 2018)

Amnesty International reports that, as a consequence of the violence in this regions, “over 150,000 people became internally displaced” (Amnesty international 2018: 5). The UNHRC, on the other hand, registered that in March 2018 over 20,000 Cameroonians had fled the North and South West to become refugees in Nigeria, a group mostly consisting of women and children (Kitidi 2018).

This climate of insecurity and political violence has profound implications on the lives and work of these young and non young persons with disability, as it creates substantive additional barriers to an already hostile environment.

### **3. The right to participation in political and public life in Cameroon**

Cameroon signed the CRPD in 2008, but has yet to ratify it (‘15. Convention on the Rights of Persons with Disabilities’ 2018). As explained by the General Coordinator of CUAPWD, this has substantial consequences to the type of policies that can be implemented in Cameroon to defend the rights of persons with disability:

“When a country just signs, it is just an indication that it agrees to these terms. When you ratify, it is that I have accepted to implement all the articles and I will report to the international community, whatever limitations you have.”  
(General Coordinator of CUAPWD 2018, personal interview)

In this sense, the Cameroonian government is currently not bound by what’s stipulated in the CRPD, but merely has a non-binding compromise to produce legislation inspired by it. As such, in April 13 of 2010, the Cameroonian Government approved the Law N°2010/002 of on the Protection and Promotion of persons with Disabilities (Ministere des Affaires Sociales 2010).

As of the time of my fieldwork, this law remained without a text of application. This means that it has no assigned budget or mechanism of enforcement. In this sense, “the law is not yet applicable; it depends on the whims and purposes of an individual to favour or not to favour you” (General Coordinator of CUAPWD 2018, personal interview).

The right of persons with disability to form associations and to participate in public life is not protected by the Cameroonian Law N°2010/002. Only Article 27 mentions that the “integration of the person with disability concerns all social and economic measures *ensuring the full participation* of persons with disabilities in society”, with no specification of what ‘full participation’ means (Ministere des Affaires Sociales 2010: 6, my own translation and emphasis), and Article 40 states that “the state, local authorities and civil society encourage persons with disabilities to establish individual enterprises and cooperatives”, relating it to the access of employment opportunities (Ministere des Affaires Sociales 2010: 8, my own translation).

This means that no Article of the Cameroonian Law on the Protection and Promotion of persons with Disabilities is set to protect their participation in the political and public life of persons with disability. At the same time, in such an authoritative political climate, associations need a certification from government to exist. All this

means that, in their registration with the local council, the associations are registered without the particularity of being for persons with disability.

## **CHAPTER 5:**

### **THE NETWORK**

The social movement of persons with disability in the North West Cameroon, as I got to experience it, is comprised of a network of Government recognised associations of persons with disability, linked together through the CUAPWD.

#### **1. The associations**

The associations that are registered with CUAPWD vary in how many members they have, on how long they have existed for, and on how active they are. In my observation of their meetings, I was able to see this diversity (author's field notes). Some were very robust, well managed and had been running smoothly for many years. Others were encountering different sorts of problems and had temporarily disbanded, for different reasons.

The meetings I observed would usually have between 5 to 20 members (author's field notes). It was common for the meetings to be cancelled abruptly, either because of weather conditions or insecurity due to the political climate.

Most of these associations are open to different types of disability. Only 2 associations linked to the CUAPWD are closed for a specific type of disability (one for the visually impaired and the other for the hearing impaired). However, I observed that those who were open to different types of disability would often mostly congregate or would be led by persons of physical disability (author's field notes).

At the same time, I observed that the associations would tend to congregate people of similar age.

I believe this homogeneity within the associations is related to issues of recruitment. Most respondents told me that they had become involved in their associations through the linkage of friends and peers. This means that these associations tend to grow organically, through people's personal networks. This would explain why existing members tend to share many characteristics, such as age and type of disability.

All these associations have 4 positions of leadership: President, Vice-president, Secretary and Financial Secretary. These positions of leadership are held for two years and are appointed by general elections among members.

#### **2. The CUAPWD**

In their own words, the CUAPWD acts as an "umbrella organisation" for all these associations. As such, it constitutes an official linkage for government officials who want to address issues of persons with disability with the disability movement. It also provides technical support for these associations, offering help in issues like

registering in the local council and information of other sorts (General Coordinator of CUAPWD 2018, personal interview; President of CUAPWD 2018, personal interview; Program Manager of CUAPWD 2018, personal interview).

Officials of the CUAPWD also conduct activities of sensitization on disability issues, such as giving lectures at religious gatherings or conversing with government officials, to talk about the nuances of the inclusion of persons with disability (author's field notes).

### *The vision of the CUAPWD*

In the words of the General Coordinator, the vision of CUAPWD is informed by a “model of social inclusion” that is “moving to rights-based approach” (General Coordinator of CUAPWD 2008, personal interview). Explicitly, he mentioned the WHO's Community-Based Rehabilitation approach to disability, where persons with disability develop their capacity while at the same time “the community is adapting to the basic needs that can give that person productivity and participation” (General Coordinator of CUAPWD 2018, personal interview).

This is also known as the social model of disability. The emphasis on the social barriers as the source of exclusion means that disability is not an inherent problem of persons holding the disability, but rather a societal problem. It also means that, in order to grant persons with disability access to their rights, these barriers have to be addressed through social policy (United Nations 2006, Callus and Farrugia 2016, Cortez Segura 2016).

At the same time, members of CUAPWD mentioned the struggle of having to push for a change of “mind set” among persons with disability, who are still focused on what is known as the charity approach:

“The unfortunate thing on the field is that we also have some people with disabilities who are betraying the cause. (...) People [who] still think that we need just be a charitable set of people. So immediately we see the next thing we are thinking about... if we see Dan around, because he is from out of the country, the next thing we need is Dan should give is 5000.”  
(President of CUAPWD 2018, personal interview)

The charity model of disability assumes the limitations of persons with disability as inherent and unmovable. This means it is not expected of them to produce anything of value or take care of their own well-being. So, persons with disability have to be taken care of by the rest of society (Block and Somers 2003).

I witnessed this struggle during a presentation of the Manager of CUAPWD's Cooperative Credit Union, during a presentation of their new credit-loan program. A visually impaired young man stated that in his view, they should fight to receive assistance from government, to which she replied:

“Persons with disability have the mind-set of thinking that help will come. Zero. You don't need none of that. You have a disability to do one thing. But

you don't have a disability to do everything. You have the same mind to think, just as I have the same mind to think.”

(Manager of CUAPWD's Cooperative Credit Union 2018, author's field notes)

### *Advocacy activities of CUAPWD*

I observed two lectures given by the General Coordinator of CUAPWD in Christian ceremonies, where, in my view, he explained how the Human Rights approach could be reconciled with Christianity. I also observed visits conducted by CUAPWD officials to Government offices to talk about inclusion of persons with disability in their programs. Finally, in more than one occasion I accompanied officials of the CUAPWD to talk in radio shows about their activities and about what it means to view disability through a rights-based approach (author's field notes).

The CUAPWD as well provides technical support for the financial activities of the associations of persons with disability. It is common for these associations to hold credit programs for its members, offering loans at special rates for income generating activities. However, these programs can also prove to be a double edge sword. In my observations, I saw more than one association that had lost an important number of their members because they had run a credit program and, as their members had been unable to repay their loans, they had stopped coming to the meetings for fear of retaliation (author's field notes).

For such purpose, the CUAPWD introduced recently a permanent member to its team as manager of their Cooperative Credit Union, a financial institution that offers loans at special rates for persons with disability, with official backing from banking institutions, as a way to give better access to finance to persons with disability (Manager of CUAPWD's Cooperative Credit Union 2018, personal interview). This is intended to replace the informal credit programs the associations maintain which, as mentioned before, can have the unwanted consequence of pushing members away.

This CUAPWD also provides counselling to the associations in their daily functioning. As an example of this, I observed a meeting between members of CUAPWD, including the President and the Manager of the Cooperative Credit Union, with the remaining members of an association that had lost most of its members due to financial disagreements. The CUAPWD members were offering counselling on how to move forward in order to rebuild the association rather than distributing blame among the remaining members (author's field notes).

Finally, the CUAPWD also conducts educational activities for persons with disability. I observed one workshop on the use of Internet for young persons with visual impairment arranged, organised and conducted by CUAPWD (author's field notes).

## CHAPTER 6:

### THE SITUATION OF YOUTH IN THE NETWORK

#### 1. Youth as a minority within this network

##### *The definition of youth*

Participants to my interviews and focus groups discussions, upon being questioned about the definition of youth, would commonly relate to the age parameter stated by the National Policy of Youth:

“In the context of Cameroon they say a young person is between 15 and 35. That’s the range we have here.”  
(President of CUAPWD 2018, personal interview)

“- Moderator: When does a young person turn into an adult?  
- WV27: I don’t know if its about age.  
- MV25: It is from 17 to 35, I think so. That is within that range.  
- Moderator: But you said maybe its not about age?  
- WV27: I said if its about age, then a youth is someone from 35 and below. If its not about age, then is about mind set.”  
(FG6)

At the same time, this age bracket was beneficial to the purposes of CUAPWD, in order for it to be categorized as a ‘youth’ organisation, at least informally:

“The fortunate thing about the CUAPWD is that the vision bearer at the time [referring to himself] was a young person. I was 33 years old when the Coordinating Unit was created. And the current President, who has taken over from me, is within that age [he is 34]. So you see how young people are involved and inspiring in the organisation.”  
(General Coordinator of CUAPWD 2018, personal interview)

There is a recognition in their words that youth is a relational category that can be negotiated. Firstly, when the young woman with visual impairment relates youth to a certain ‘mind-set’, rather than an age parameter. Secondly, when the General Coordinator chooses to adhere to the government-stated age bracket, because it allows him to say the youth are involved in the work of CUAPWD.

##### *Youth as a minority*

In my observations of the associations’ meetings, I saw that young people were a minority. People of older age would tend to dominate in most associations. In some, I saw no young people participating. In others, there were only a few, but they didn’t raise their voice (author’s field notes). Two associations were an exception to this, as we will see.

The President and General Coordinator of CUAPWD corroborated that youth were a minority and recognized that the issue had not been part of their agenda:

“Young persons, I will say, actively speaking, they are not really represented. If I can say that, in the sense that, I cannot show you any document that says that, particularly, this youth must be present here. (...) So, we don’t have any legal framework that says particularly, like we may have for gender.”  
(President of CUAPWD 2018, personal interview)

“We don’t have a particular organisation of their own as young people.”  
(General Coordinator of CUAPWD 2018, personal interview)

During informal conversations, they were both keen on stating that this omission was unintentional, simply because it hadn’t occurred to them before my research:

“I think when we got your research proposal, we started [to think] that it may be of some advantage to us, but we said lets hold on to what can be the outcome of your research and see where we have to put the focus.”  
(President of CUAPWD 2018, personal interview)

#### *Scarcity of youth in leadership positions*

I observed that in most associations, leadership roles were held by older age men (author’s field notes). This was backed by the President of CUAPWD:

“I cannot easily put my finger on the group that has a leader under 35. But within the executive, you can find one or two persons below 25.”  
(President of CUAPWD 2018, personal interview)

This was explained by two factors: lack of educational opportunities and cultural barriers, according to their responses.

Firstly, persons with disability face barriers to achieve education. This means they take longer time to transition successfully through the educational system. According to the President of CUAPWD, while they are in youth-hood, below 35, they still haven’t acquired enough “leadership skills” (President of CUAPWD 2018, personal interview).

At the same time, it was also explained that cultural factors also play a role. In Cameroonian culture, the notion of rights has yet to permeate fully in society:

“Our society is not yet embedded to the rights of children to a higher level, so decisions are taken without considering or soliciting the opinion of the young people. And specially for young persons with disability, [they are asked] ‘what do you have to offer?’”  
(General Coordinator of CUAPWD 2018, personal interview)

Despite this adverse scenario, two associations that broke this norm. This were the Hope Social Union for the Visually Impaired (HSUVI) and the Cameroon National

Association of the Deaf (CANAD). Both had extensive participation of young persons, mostly of young men.

## 2. The presence of youth in three disability associations

### *The case of HSUVI*

HSUVI is a well established association, made up entirely of visually impaired persons. It has existed since 2005 (General Coordinator of CUAPWD 2018, personal interview). Of the five permanent members of CUAPWD I interacted with, three were members of HSUVI.

It was explained to me that HSUVI openly advocates for the participation of youth (General Coordinator of CUAPWD, personal interview).

Young members of HSUVI were keen on mentioning during interviews and focus groups that there were no barriers for their participation in the association, and that youth could easily reach leadership positions:

“Most of the key posts are mostly handed to young people, for example the president, the treasurer, the secretary, the vice secretary, the social organiser, most of these key positions are handed over to young persons which train them to have good leadership skills”  
(WV24 2018, personal interview)

I corroborated this in my attendance to one of their monthly meetings. Most of the young, visually impaired persons attending HSUVI’s meeting were university students (author’s field notes).

Perhaps because of this, the idea that the youth are stigmatized or subjugated was strongly rejected during a focus group discussion by members of HSUVI in the following way:

“- WV21: Maybe when we are old people will respect us.  
- MV25: Even if you are older, as far as being stigmatized as a level of a youth, you will still be stigmatized when you are behind your breath. That is when people will be crying...  
- MV26: The very stigma that you face when you are young is still there when you are older. That lack of respect is still there from the youth. The lack of support.”  
(FG6)

My impression is that, because there is scarcity of spaces for young persons with disability to participate other associations, members of HSUVI appreciate the space granted for them. This could even explain why they are thankful, as described by another HSUVI member:

“We also gave a lot of thanks to our elders who made it possible that a young man who has a lot of skills should come up.”

(MV26 2018, personal interview)

### *The case of CANAD and the hearing impaired*

The other exception was the case of the CANAD, an association only for persons with hearing impairment.

The situation of CANAD can be described as precarious (author's field notes). According to informal conversations I had with different stakeholders, the hearing impaired associations were facing organisational problems, related to leadership disputes (author's field notes). I conversed with some of them, and corroborated this (FG5; President of CANAD 2018, personal interview).

I visited them in two occasions. The first time, the meeting was concurred by 5 young members, who had been summoned because of me, and I conducted a focus group with them. In the second meeting I attended, only their President, who is 39 years old, showed up.

Also, two young women of a different association for the hearing impaired participated in FG2. One of them mentioned she was the President of her organisations. However, their meetings weren't happening as she had assumed the role right after a crisis that dispersed all members.

I can conclude from this that there is a movement of young persons with hearing impairment trying to organise itself and act collectively, but that it is facing important barriers to achieve it. Furthermore, as will be explained, the ability of CUAPWD to provide assistance in this process is limited, due to communicational barriers.

### *The case of SNEG*

The Special Needs Entrepreneur Group (SNEG) is one of the oldest associations of persons with disability in Bamenda. They received support in the past from an Italian donor, and are now in control of a modest property in the city, which they use to conduct meetings, activities, workshops and others. The office of the CUAPWD's Cooperative Credit Union, is located in this premise (author's field notes).

SNEG is a pioneer member of CUAPWD's network (CUAPWD internal document). It is also an example of an association with very few young people participating in it. I attended one of their meetings, where I observed that most members present, including leadership positions, had physical impairments and could be considered elders.

## **3. Early remarks about the construction of youth in this network**

From all of this, I perceive there is a recognition that people below 35 are not well recognised in the associations, with HSUVI and CANAD being two important exceptions. Therefore, young persons with disability can be considered a marginalized minority within this network.

At the same time, the participation of youth was highly gendered. I observed important differences in the type of assertiveness and capability to raise their voice between young men and women. This would often convert into young men being more present and more active in the spaces that were open for young people in the associations.

In HSUVI, the support from adults has been explicit, and young persons have gained spaces to participate. In CANAD, the spaces for young persons are there, but their resources are much more precarious and they are facing internal quarrelling. The different experiences of these two associations speaks about the diversity of the challenges faced within this network.

Further on I will explain that this difference is based on a more structural divide among persons with disability, which is type of disability. For now, I take notice of how the opening of spaces for young people in HSUVI was the result of a conscious decision by adult members. This reminded me of the remarks of Sotkasiira et al, where youth participation is also seen as being granted by adults:

“As young people also seem to yearn for adult contacts, grown-ups, and especially professionals, should improve the platforms and tools with which young people can express themselves and generate their own outcomes”  
(Sotkasiira et al 2010: 182).

Finally, it stands out to me that there is a recognition that youth is a relational category. Interviewees refer to the standardized age parameter set by the government, but also negotiate with it. For example, CUAPWD's members defining their associations as youth-led thanks to this parameter. However, they themselves recognise a younger generation of youth who, unlike them, lack leadership skills. By doing this, they are moving away from defining their youth based on age, but rather on skill. In the same way, MV27 2018 mentioned being young could also be about 'mind-set'.

## CHAPTER 7:

### THE CONSTRUCTION OF PASSIVE PARTICIPATION AS EMPOWERING

#### 1. Characteristics of youth participation in this network

In my observations, I set to examine how was youth participation being constructed. Part of this meant asking myself what were the observable actions that could lead me to conclude that a young person was participating in a disability association?

Firstly, I conclude that to be participating in an association of the disability movement in the North West Region, a necessary requirement is to attend the monthly meetings these associations have. These meetings are, in a way, the materialization of the existence of the association. By participating in the meetings, therefore, a young person can be considered to be taking part in the association and, therefore, in the network.

Participating in the monthly meetings also requires a financial compromise. All of these associations require its members to pay a monthly and yearly fee for their maintenance. By paying this fee, young persons with disability are understood to be taking part in the associations. At the same time, this can effectively create a barrier to participation, as many young persons with disability, as well as non-young persons, who live in a situation of high vulnerability and marginalisation, might not be able to pay any fee, however small it may be.

Attending the meetings and paying the financial compromise can be described as passive forms of participation, not necessarily linked to decision-making processes. However, participating in discussions and debates during the meeting, can be active forms of participation.

Taking part in the election of the leadership positions of the associations is also a way to participate in these associations. As mentioned, these positions are rotated every two years among members. More so, being a candidate and being elected is also a way in which a young person with disability can be understood to be participating in the association. Voting and being elected are both active forms of participation.

Finally, by taking part and benefiting from the financial activities conducted by the associations, members can be understood to participate in them. This is a passive form of participation, as the person is benefiting personally but not actively influencing any process of the association.

As we saw in the last chapter, the youth involved in leadership roles are a minority in this network of associations. This is because there are few spaces which are open for them to occupy. Furthermore, now we see that the few spaces that open up for youth in this network, usually only allow passive participation. The associations where young people are encouraged to actively participate are a minority.

## 2. The meaning of empowerment

I chose to explore the meaning of empowerment because the term was constantly being used by my respondents. At the same time, we have seen how the literature links empowerment to participation. That is why I find it important to explain how participation and empowerment are being constructed together here.

Firstly, I saw empowerment be defined as general self-improvement. Examples of this would be “improving or emphasising [the] individual” (WV24, FG2), or “upgrading”, or “giving yourself some meaning” (WP19, FG2).

At the same time, it was also commonly linked to performing tasks or carrying out activities. Some examples would be to “engage with something” (MV25, FG3). To empower would be “to pursue somebody to do something”, “encouraging [them] to do something” (WV25, FG2), or “learning things we know we can do better, then learn from others, and keep on moving and keep consistently” (WP19, FG2). It was also described as “to exploit” what a person has inside, to “give” a person some “ability”, like carrying and moving a table (MP36, FG3).

Finally, it was also often linked to achieving personal autonomy:

“Equipping someone in the know-how in order to render that person go about his activities normally. So this empowerment could be financial, professional, or academic. But it just refers to equipping someone to make that person more autonomous.”  
(MV27, FG4)

To me, these three views of empowerment are strongly linked together. Together they speak about the level of exclusion and vulnerability that persons with disability face in this region. I see this view of empowering as very humble and oriented towards individual improvement. This will be developed further ahead. To sum up, empowerment here was defined as improving oneself by learning skills in order to achieve more autonomy.

## 3. Motivations of young people to participate in the network

A question that I asked recurrently to young people was why did they participated in these associations. Sometimes I framed the question in terms of what were the benefits to being in an association.

Most of the answers I received can be grouped into three categories. These are socialization, self-improvements and receiving gifts. In all groups, the answers relate to persons with disability’s exclusion from social and economic life. However, the political dimension of their struggle does not come upfront. I don’t find in their responses an upfront claim for social recognition or social justice. I do see a claim for inclusion into social and economic life.

*Socialization*

A common response I received upon asking what were the benefits of being in an association was ‘to be with people’. I found this to be strongly related to receiving emotional support. As a highly marginalized group, persons with disability are neglected from society and face constant prejudices that stigmatize them and alienate them from society. This leads them to (in many cases) live lonely lives. Participating in these associations helps them bond with others, find peers, create emotional connections, such as friendship, and increase their self-esteem.

“One of the advantages [of being in an association] is I’ve benefited from knowing other persons around. It gives me access to other persons around the town.”

□(MV25, FG3)

“When you see only one person like that you will think there are people that do not love you, you are just left alone. But when you are interacting with people, you will know that you are among people.”

(WP30 2018, personal interview)

This means that associations are being seen as spaces of socialization. In my observations of their meetings I was able to witness this (author’s field notes). These meetings could have a very formal, structured format, with clear roles dictated among members and leader, and where the opportunity to speak is not free but is granted by a moderator. However, it was before and after this formal procedures where I would see the young and non-young members of the associations conversing, laughing, talking about their lives and sharing their daily struggles. From their responses in my interviews, I was able to see the importance of these spaces for them.

“Its good for me to come here. When I come here I can involve in all the activities, I will see my brothers and sisters, I will see other persons with disabilities. That would be very helpful for me, to go as a person in the future.”

(MH24, FG3)

Furthermore, this opportunity to socialize was also linked by some to enhancing their socializing capabilities and increasing their self esteem:

“I’ve learned many things. Even by talking I’ve learned that to be a among people is a good thing, to interact with people, don’t keep yourself behind because you are not working, don’t keep yourself behind, you have to be among people, and you have to do things that able people can do. Yes, don’t say that [because] you are handicap you cannot do this, you cannot do this, those things are only be backing, backing, backing.”

(WP30 2018, personal interview)

“As I said, I’ve gained leadership skills, I’ve gained sociability of persons, know how to interact with others in terms of discussion, then I’ve also... my mind is in such a way that I know that I’m also with people that are like me, and I don’t have to feel bad.”

(WV24, FG3)

I believe this importance also comes from the lack of other spaces young and non-young persons with disabilities have to socialize. As they are commonly marginalized from social life, they tend to not be able to access spaces such as schools, institutes, universities, or employment centres, which is where most of us tend to meet our friends outside our homes.

It also speaks about the type of overall exclusion persons with disability face in contexts such as this one. Hence the importance of these meetings as spaces to meet peers, discuss shared challenges, make friends and learn how to interact with others. For many, this might be their only space to socialize.

### *Self-improvement*

The opportunity to learn new things was another reason mentioned repeatedly as why it was important to participate in these associations. The presence of workshops and learning activities was highly valued. Some associations organise workshops for their members to learn, for example, craftsmanship, either by external providers or amongst their own members.

“I think belonging to associations opens, makes your knowledge wide. You know other things that you are able to do.”  
(MV25, FG3)

“We try to empower each other. Like for example, even I work here, I do cane chairs, cane baskets, weaving. I can offer my skills to a member who wants to learn. In the group I offer my skills. Another man can know how to fix shoes. A member may come, in order to empower ourselves, first of all. To be independent, self-reliant.”  
(MP39 2018, personal interview)

These learning opportunities were also strongly related to the hope of becoming income generating activities.

“Maybe persons that hear they have job opportunities, and its difficult for a deaf person to get a job. But here, we will be encouraged and we will learn more about other things. Maybe embroidery, sowing, carpentry, all those things to get ideas here. People will share their ideas in this association.”  
(MH20, FG5)

The opportunities for generating income were also referred to other dimensions of life, such as having a partner and forming a family, or improving one’s communicational skills:

“When I come here I learn much about business and work, and I see people who are handicap and they are able to do something, and then they save some money and they do business. I think in the future that will also help me to be involved and also work, maybe get married and I will live happily in family. Its not only about job, but its also about how to communicate. How you can advise the person, the deaf person, to save money, you can save money together and help each other.”

(MH23, FG5)

For the hearing impaired, it was commonly mentioned that belonging to their association was a way to improve their communicational skills, basically by improving their knowledge of Sign language:

“In our association we can start to encourage people who are deaf to learn Sign language. That will promote the deaf and it will never change. Then we start sharing together with people who learn sign language. Identity will be better.”  
(President of CANAD 2018, personal interview)

### *Receiving gifts*

Other benefits mentioned were related to gaining visibility in the eyes of society and of the Government. In the cases this was mentioned, I could observe traces of the charity model, as they relate to ‘obtaining benefits’. This is because receiving gifts or assistance is easier for persons with disability when they are congregated in groups.

“The advantage that you get is to have benefits that come as a community, as a group. If somebody has to give you something, they give it to the community, they give it faster.”  
(NMP36, FG3)

“Forming associations for people with visual impairments might equally attract the government to easily locate them and assist them.”  
(MV25, FG3)

It is worth mentioning that these kind of mentality was contested by members of the CUAPWD as not good for persons with disability, who in their view, based on a rights-based approach, should focus more on their self-empowerment rather than on receiving assistance.

### *Do these motivations entail active or passive participation?*

Viewing the associations’ meetings as spaces of socialization for me denotes passive participation. This does not mean that it’s not of enormous value. It means that it doesn’t put those young or non-young persons with disability in a position where they can take command and make decisions about the association. The same can be said about widening one’s knowledge (as a form of self-improvement).

Obtaining skills which can turn into income generation is also a passive way of participation. Especially taking into account that the skills commonly mentioned are simple and generate low income, such as craftsmanship and repairing shoes. Gaining these sort of skills does not change a person’s position of power in an association as a result of it.

Finally, forming associations for receiving gifts in a way formalizes the relation of subjugation of persons with disability in society. As such, it does not denote any major decision making. Therefore, it denotes passive participation.

#### **4. Constructing passive participation as empowering**

By contrasting these two analysis, I conclude that what I am calling passive participation is being interpreted by my respondents as empowering participation.

On one hand, empowerment is being seen as improving oneself by learning skills in order to achieve more autonomy. At the same time, the motives for participation are oriented towards gaining skills and socializing with people. I see these meanings and motives as coinciding. To me they both speak about the level of exclusion and vulnerability persons with disability face, specially in a context of almost no social protection and ongoing armed conflict.

Disability is a social construction, born out of the interaction of a person's condition with the environment. Three environmental realities of Bamenda stand out for me. Firstly, the condition of extreme poverty and almost non-existent social protection. Secondly, the authoritarian rule, which limits freedom of speech and of association. Thirdly, the ongoing armed conflict, which limits freedom of movement and threatens people's lives, particularly if they hold a condition of disability (author's field notes).

In my view, these three issues conflate to create a scenario which limits greatly the freedom of persons with disability to live their lives and fight for their rights. The barriers faced in this scenario are multiple and multi-dimensional. In this scenario of overpowering oppression, small improvements can make huge differences. Hence their definition of empowerment. At the same time, this conflictive scenario also creates the real risk of isolation. So simply being present and interacting with others becomes an aspiration.

I believe this would explain why the reasons given to participate in the associations are geared towards socialization and economic opportunities, even to receiving gifts, and not necessarily towards social recognition or social justice.

Of course, this construction of passive participation as empowering is not only limited to youth participation in the associations. It also applies to children:

“The young girls, if they are sent to school, if they are allowed to take part in every activity, in church, in school, in social events, it gives them that confidence, make them to have the sense of belonging, make them to be able to speak out when they have a sense of self-worth. Then because they are in their peers of the same group, they can have an idea on a vision in life.”  
(Program Manager of CUAPWD 2018, personal interview)

## CHAPTER 8:

### THE INTERSECTIONALITY OF YOUTH PARTICIPATION

As we have seen, not all young persons with disability can participate equally in the associations that make up this network. As mentioned previously, young people are a minority in most associations. However, age relations are embedded in a broader structure of institutional systems. In order to understand how participation is differentiated according to certain categories of identity, I have distinguished four categories. The most notorious is type of disability, but I also see age, gender and religion playing an important role.

#### 1. Type of disability

##### *Participation of the visually impaired*

By my observations and conversations, I conclude that the visually impaired are currently the most successful group inside the disability movement. This can be exemplified by the fact that the CUAPWD is lead by visually impaired persons and that HSUVI is the most organised association, openly welcoming young people's participation.

Most of the young persons with visual impairment which I talked to were university students, which was definitely not true for other types of impairments. It also seemed to be the case that it had consciously made an effort to include young people since a long time ago, not only as members but also in leadership positions. Furthermore, most of the members of CUAPWD, who were mostly visually impaired, had been previously members of HSUVI.

I believe this can be explained by the fact that the visually impaired, along with the physically impaired, have received more support and assistance in the North West Region, and for a substantially longer period of time, than those with hearing or intellectual disabilities. This was explained to me by professionals of the CBCHS.

The CBCHS is a faith-based organisation focused on health-care provisioning and disability advocacy that has been present in North West Region since colonial times. After independence, its management was handed over to Cameroonian officials. As a health service provider, it focused from the beginning on the physically impaired, through rehabilitation programmes inspired by the medical model of disability, and on the visually impaired, through educational programmes. By its initiative, the first school for the visually impaired in the North West Region was opened in the 1952 (Program Manager of CBCHS' Empowerment and Disability Inclusive Development 2018, personal interview; Program Manager of CBHS' Socio-economic Empowerment For Disabled Persons 2018, personal interview).

This means that education for the visually impaired has been available for many generations now. As an example, the same is not true for the hearing impaired, who face serious barriers to education. As a consequence, several generations of visually

impaired persons have had the opportunity to 'empower themselves' through education. The fact that HSUVI was so well managed and maintained can perhaps be a direct consequence of this.

### *Participation of the hearing impaired*

Overall, I found the hearing impaired to be a specially challenged group within the community of persons with disability. This is, in my view, a consequence of their lack of opportunities for education. Most of the young persons with hearing impairment I got to talk to had only achieved primary education, and only one had reached secondary level. This is perhaps because, if the first school for the visually impaired was opened in 1952, in the North West Region there has been no school for the hearing impaired until the year 2000.

Another critical issue that reinforces the exclusion of the hearing impaired is the lack of a professional body of Sign language interpreters. This was mentioned to me by all the youth with hearing impairment I talked to, and as well by the Sign language interpreters I interviewed, and by members of CUAPWD. There is no school that offers Sign language courses for somebody who wants to pursue it. Those who do, have to do it mainly out of their own initiative.

The lack of Sign language translators accentuates the exclusion of the hearing impaired from educational and job opportunities, as well as from other activities such as religious ceremonies and social gatherings.

It also presents an effective barrier to having a unified disability movement. As it turns out, persons with visual impairment and persons with hearing impairment simply cannot communicate with each other without the assistance of an interpreter or a technological device. The visually impaired use their voice to speak, which the hearing impaired cannot hear, and the hearing impaired use their hands and gestures, which the visually impaired cannot see. Given that most of the members of CUAPWD are visually impaired, including the President and the General Coordinator, their ability to assist the associations of the hearing impaired is limited (author's field notes).

During my time in the North West Region, I learned about the existence of two associations of hearing impaired persons. I learned by the CUAPWD officials that none of them was conducting meetings at the time. Through my own efforts, I got in contact with one, and managed to visit them in a meeting they summoned for me. There, I conducted FG5 with the help of an interpreter.

Almost all of the persons present in this meeting were young. They mentioned to me the managerial problems they were facing in order to sustain their association, which was having trouble keeping its members.

Upon mentioning this to the CUAPWD, they responded that, indeed, it seemed that the hearing impaired were finding trouble in organising themselves, particularly on how to rotate their leadership positions. The associations they formed were constantly disbanding due to internal quarrelling.

To be able to provide assistance to them, the CUAPWD mentioned need for Sign language interpreters which are scarce and cost resources:

“We are planning to hold a meeting with Sign language interpreters that we know around, because they are the ones who can really assist us in bringing them together. There is no way we can hold a meeting with a hearing impaired without the sign language interpreter being present. It would be very challenging for us. So we are planning to meet them next week, with sign language interpreters, to see if they can assist us.”  
(President of CUAPWD 2018, personal interview)

Furthermore, using Sign interpreters as intermediates also creates an issue of dependency, as the hearing impaired are dependant of for their participation in open associations and other activities.

#### *Participation of the physically impaired*

The physically impaired were commonly described by persons with visual and hearing impairments as being the “least disabled” among the community of persons with disability (WV24, FG2). It was also mentioned that, in open associations (to different types of disability), persons with physical impairments would tend to dominate (WV25, FG2). Perhaps this is why the visually and hearing impaired had formed ‘closed’ associations. Because most of the open associations really concentrate a single type of disability, that is physical disability.

“Like for instance, in the university where am I, there is an association of persons with disabilities. Now, the issue is persons with physically challenged, it seems to be to be taken all the leadership position, and they tend to dictate, they seek to protect their own right, and not the general rights of persons with disabilities. And so we as visually impaired in the University of Bamenda we turned to be very disgruntled. It already creates a problem. It goes along the fact that there is mistrust, there is mismanagement, and that.”  
(WV25, FG2)

Additionally, all of the associations I observed which congregated persons with physical disability were made up of mostly non-young persons, such as SNEG. Upon being questioned about this, they would answer that it was not the case, that they youth had simply not turned up that day.

#### *Participation of the intellectually impaired*

The intellectually challenged have been represented in this study by their parents or caregivers. I was not able to conduct interviews with any intellectually challenged persons directly. These parents were part of associations of parents of persons with disability, which mostly means parents of children with intellectual impairments. The challenges they mentioned to me were predominantly about information related to intellectual impairments. It was mentioned that more than 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. To me this means that the needs of families of persons with intellectual impairments are very much related to the need of information, something which the associations can effectively help with, as exemplified by a caregiver of a child with intellectual impairment:

“I kept my child in the house. But since I came here, she’s really improving now. Because you can only keep her in the house, I would not know what to do with her. But when she is here, and she is really improving. She even can walk now. Before she was not even walking.”  
(W, FG1)

### *The challenges to collective disability identity*

“As for collective identity, it is our optimal goal, but it has challenges.”  
(General Coordinator of CUAPWD)

I used the concept of ‘collective identity’ in my focus groups to talk about the challenges of having open associations versus associations that would be specific to a type of disability.

The visually impaired, all members of HSUVI, were the most keen to talk about the challenges of having open associations. This was often related to having shared needs:

“I think having an association with one kind of disability, like just for visual impairment, it helps them to address their challenges better. Because its normal that the challenges that I face, because of my visual impairment, are going to be the same ones that my sister faces. Because I face those challenges because of my disability. So coming together now as persons with that type of disability makes it easier for us to see maybe our plight and see solutions to it.”  
(MV24, FG3)

They also talked about having formed other associations only for the visually impaired, apart from HSUVI:

“- WV27: Let me just put it. This association started as a people with visual impairment, because we were all students at the time. As time goes on, many people coming closer so we could not reject, we see we are all one no matter the situation.  
- Moderator: Why did you create that group?  
- MV25: We were not the ones that wanted to create. The main motive for this was to bring us together, see how to empower ourselves.  
- Moderator: Was there not other group around you could join?  
- MV25: The initial purpose was for visual. He wanted to unite [the] visual impaired. Then, we saw that it could not only be to visual impairments living here. The problem is not that others were far, but to unite visual impairments.”  
(FG6)

The hearing impaired mentioned the issue of communication:

“If they come together, and deaf persons do not have a Sign language interpreter, what will happen? If there is absence of sign language interpreter, deaf persons will not be happy. Because they will be passing out a lot of information and they will not be able to understand.”  
(MH25, FG3)

This was also mentioned as a challenge by a participants of physical impairment during a focus group which included persons with different disabilities:

“Firstly, like this, we need somebody to sign for the deaf. Second, I want to run. If you want to move faster, like me, to go faster, having other types of disability limits the movement you are doing. You need that person to sign for him, [you have to] organise it.”  
(MP36, FG3)

Participants also recognised the value of uniting different types of disability, mentioning that meeting more people meant creating more opportunities and also that opening to different disabilities might meant making their associations stronger as they would be bigger, although it could also meant more difficulties in organising the meetings (FG2, FG3, FG4, FG5, FG6).

However, in practice what has been priming in the network is the fragmentation by type of disability. At the same time, internal structural divides within each type of disability also reproduce inequality in other complex ways.

## **2. Age**

Another structural divide in the participation of persons in this network is age. I can distinguish three generations between the actors I've interacted with. Firstly, an elder generation, made up of members of older associations of persons with disability, mostly of physical impairment, but also some of visual impairment.

Secondly, I've also encountered a new generation of persons with disability, roughly in their thirties or forties. These are the General Coordinator and President of CUAPWD, as well as the President of CANAD. I see them as are currently leading the movement.

Thirdly, there is the younger generation, which they pointed at me when I asked them about youth participation (the purpose of my research). That is, those who are in their twenties.

The first generation started the movement. That is why they hold today most leadership roles, which they have not surrendered to younger generations. However, a new generation of young visually impaired emerged, the middle generation, which has taken over the leadership of the movement by creating and installing the CUAPWD, linking the associations together and creating a disability network.

This generation is opening the movement to the younger ones through associations such as HSUVI and CANAD, although with different results.

As we have seen, there is a recognition here of youth as a relational category. This exemplifies how age boundaries are fluent and contextual. As pointed by Yuval-Davis:

“Age (...) shows even more clearly than other social divisions how categories and their boundaries are not fixed and how their social and political meanings can vary in different historical contexts as well as being continually challenged and restructured both individually and socially.” (Yuval-Davis 2006: 200)

Furthermore, this does re-create a structure of hierarchy among people based on their age. This is related to a culture of respect for the elderly. Within the movement, this discourse is reproduced by the middle generation towards the third by stating that young people need to be mentored, need to learn leadership skills, which are to be taught by those older and more experienced than them, before they can take leadership positions:

“Its because professionally, the adults or the elderly, have the professional know-how to do advocacy. It is those elderly people in the leadership positions that can teach the young ones how to do advocacy assertively, how to understand how to fight for their rights without hurting anyone. So the young ones, they think they are still growing, and they need more mentorship.”  
(Program Manager of CUAPWD 2018, personal interview)

### **3. Gender**

It became evident to me that marginalization of women is deeply rooted in Cameroonian society. Because men tend to dominate different dimensions of life, women’s voices are often hard to hear (author’s field notes; Gender Officer at CBCHS 2018, personal interview; Program Manager of CUAPWD 2018, personal interview). At the same time, not surprisingly, men participate extensively in these associations and show no barriers to accessing positions of leadership.

“And it gets worse for women with disabilities because most parents think that women are meant to be given out for marriage. And as a woman with a disability, if they are empowering you, for what? You will not bring them any dairy to the family, so they tend to maybe neglect you from benefiting from the opportunities.”

(General Coordinator of CUAPWD 2018, personal interview)

The CUAPWD explicitly has a gender component (General Coordinator 2018, personal interview; President 2018, personal interview). For this reason, they created an associations only for women with disabilities. The President of this association was also the Program Manager of CUAPWD. She explained to me that often women “shy away” from participating, excluding themselves rather than being pushed behind by men (Program Manager of CUAPWD 2018, personal interview). To me,

this means that patriarchy is overtly present in the interactions of the persons of the network, and that it shapes the self-perception of both men and women.

Women in positions of leadership were also a minority. Although women do participate actively in the network, positions of leadership are typically held by men.

#### *Participation of other genders*

I asked how or if other types of gender were welcomed in the associations of persons with disability. Specifically, I asked about members of the LGBT+ community. The responses I have received varied from explicit rejection to these community to the denial of their existence in Cameroonian society.

It is worth to remember that homosexuality is criminalized in Cameroon, and therefore we can expect members of this community to have to hide their sexual identity in order to participate in society.

To me, this means that this group remains excluded from participating in the disability movement. My conclusion is that gay, lesbian, bisexual or transsexual persons with disability might be among the most excluded or marginalized (and even persecuted) groups in this society.

## **4. Religion**

Something that became evident for me during fieldwork was the strong weight Christianity on the lives of people I interacted with. The weight of Christianity in social life makes it permeate into the activities of the disability associations. For instance, all the meetings I attended were opened and closed with prayer. Sometimes prayer would happen in the middle of the meetings too. To the extent that was possible for me to observe, I concluded that all persons participating in these associations were Christian.

First, it meant people of the Muslim faith, which are a minority group in the North West Region, might not feel welcome to participate in the network. Second, that there was an interesting conversation happening between the Human Rights approach and the Christian view of disability..

#### *Exclusion of the Muslim population from the disability movement*

There is a small Muslim minority in Bamenda. They are congregated in a specific neighbourhood, which coincidentally is where the CUAPWD's office is located. I inquired CUAPWD officials about the possibility that Muslim persons with disability would be discouraged to participate in the associations of persons with disability, given the prime role Christianity had to play in their activities. They said it might be true. Additionally, the CUAPWD had no knowledge of any association of Muslim persons with disability. There was, however, a development NGO which was run by people of the Muslim faith and focused on the development of the Muslim population of the North West Region, in Boskuda. The CUAPWD had conducted advocacy activities with them in order to persuade them to include an inclusive

approach to disability in their activities. A meeting was organised for me to come and meet them. I talked to a representative of this NGO. From what he explained to me, I understood that through certain contacts they had had with CUAPWD, they had started to include a disability inclusive approach in their programs. But, from what I could get from our conversation, this was mostly a nominal thing and had not yet turned into practice.

From this, I can conclude that people with disabilities of Muslim faith in the North West Region are not being reached by the advocacy activities of CUAPWD or any other association of persons with disabilities, and remain excluded from the disability movement. This, of course, includes young people with disability of the Muslim faith.

### *Debating the human rights approach with Christianity*

During the lectures given by the General Coordinator of CUAPWD in Christian ceremonies about the Human Rights approach to disability, which were conducted as part of his advocacy activities, I observed how certain beliefs rooted in Christianity can be challenging from to a human rights based approach.

For example, apparently, it is a common practice that, during a religious ceremony, a moment is given to collectively pray so that the condition of disability of a specific person present in the room ‘disappears’ by the power of prayer and the grace of God. This comes from a literal interpretation of the Bible. When the condition of disability does not disappear, this is explained by the lack of faith of this person, as was explained by the second speaker in one of the ceremonies I attended, which was a woman with physical impairment, also present to advocate for the rights of persons with disability:

“I stopped coming to Church because I would be held in a corner until the time would come for them to pray for me. I would be put in the centre and everybody would start praying for me to walk. And then I would be blamed, I would be told it is my lack of faith, that I should have more faith and continue praying. This made me feel ashamed, that’s why I stopped coming to Church.”  
(Non-young woman with physical disability, speaking at a Christian religious ceremony)

The Church offering this ceremony was open to changing this practice, as was obvious by the fact that they had invited CUAPWD officials and other persons with disability to talk about these issues. It did allow me to see, however, how the way Christianity is lived in the North West Region can be detrimental to the rights of persons with disability.

Finally, it was very interesting to observe the General Coordinator of CUAPWD answering the questions of aspiring Ministers, who would ask if it was expected of them to “stop praying for him to see”, which he would answer ‘no’. In his response, I would sense an effort to marry the human based approach, which he was advocating for, with Christianity, a faith that he also shared. He would say “you can pray for me to be strong, don’t pray for me to see, I do not wish to see, if I could see, I would not have accomplished what I’ve accomplished in life”, and so on (author’s field notes).

I conclude from these observations that certain forms of Christianity can be problematic for persons with disability, and can promote their exclusion rather than their inclusion. I say 'certain forms', because this is by no means an absolute. Like I said, all persons I met in the associations of persons with disability were Christian, and all of them, in their responses to me, would undoubtedly mention their faith as a source of strength in their struggle.

## **CHAPTER 9:**

### **CONCLUSIONS**

Because of all of this, the participation of young people with disability within this network has to understand youth in all its diversity and complexity.

Youth, like women, are marginalized group in this network. Their spaces for active participation are few. Only two examples serve as youth-led associations, although with different results.

The definition of youth is strongly influenced by official age parameters set by policy. At the same time, this definition can be instrumentalized, which shows youth to be a relational, negotiable category.

Hierarchies between those of different ages are maintained through discourses of mentorship and acquiring leadership skills. These relations can be productive, which leads to some young persons, the visually impaired, to say that they are not in subjugated positions.

Generally, the participation of young persons remains mostly in passive form, from what I saw of this network. With some notable exceptions, I found little youth involvement in activities that implied making decisions or bringing change.

I also found this participation to be highly gendered, as young men's participation was favoured over women's.

However, this passive participation is being constructed as empowering. This speaks about the level of vulnerability and exclusion persons with disability face in the North West Region today. Their environment is increasingly hostile because of the convergence of extreme poverty, authoritative rule and armed conflict. Because of how this context limits the opportunities for participation, meetings of the associations, with their sociability and learning opportunities, become an empowering activity.

Passive participation, such as socializing or obtaining skills, is being appreciated and is being found encouraging by the participants. The mere presence of persons with disability in certain activities is described as a forms of self-improvement, which makes it a form of empowerment. The humbleness of this aspiration relates to the level of oppression persons with disability live in Bamenda, an increasingly hostile environment to disability and human rights.

Notwithstanding the above, the participation of youth in this network is also reproducing larger discourses of inequality, based on type of disability, age, gender and religion. In this sense, it is also creating marginalized groups, such as women, LGBT+ persons, persons with hearing impairment and Muslims. All these groups have issues that limit or constrain their participation in this network of disability, which is dominated by adult Christian men, primarily of visual and physical disability.

This means the relations young people have with adults within this network is constructed not only in relation to their condition of disability, but also as part of larger structural relations of gender, age, religion and type of disability, which are unequal and embedded with relations of power.

Despite CUAPWD having a gender program, for example, gender inequalities are being reproduced in the network as the active participation of young men is favoured over that of women, which is preferred to be passive. At the same time, those who don't adhere to the heterosexual principle are explicitly not welcome to participate.

Regarding age-relations, I have pointed out that power dynamics between age groups, reproduce the discourse of the wise elderly who need to be treated with respect. Even among those who below are 35, age plays a role in determine who can find themselves in leadership positions and why. The situation is naturalized by saying that those 'younger youths' currently lack preparation and skills.

Finally, these relations are also embedded in larger religious structures that influence people's lives greatly in the region and often go unchallenged. The network reproduces Christianity's discourse willingly. This presents the challenge for Muslim persons with disability, who might be discouraged to participate. At the same time, the dominance of Christianity, informed by the charity model, creates a debate with CUAPWD's human rights approach, based on the social model. These present opposite views on disability. A positive note is that I saw this conversation happening in CUAPWD's advocacy activities.

The structure of inequality created by type of disability is also of central importance. This is because of the different contextual histories each type of disability has in the region. This divergences are critical. The distance between the experiences of HSUVI and CANAD speak about this difference. This critical divide can determine weather one group achieves university education (such as the visually impaired) versus only primary school (such as the hearing impaired).

For that reason, if we are to fully understand what participation of youth with disability mean, it is necessary to accept youth as fluent and relational, but also as intersected by gender, age, religion and type of disability. The forms of participation young persons with disability have available to them are shaped by how these different interrelated systems of knowledge mediate the interactions between them and their environment. This means understanding youth participation as embedded with multi-dimensional power dynamics, that are expressed in locations such as type of disability, gender, age and religion.

At the same time, to understand the construction of passive participation as empowerment, it has to be examined in its own context. It is a reminder that, although young people may participate differently, they all share a harsh reality of exclusion, discrimination and vulnerability.

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