Leave no one behind; C4D and the Humanitarian Sector’s Involvement with the Deaf Community in Sub Saharan Africa. Focus on the Republic of Congo and Senegal.

How is the Humanitarian sector making use of C4D in projects dealing with deaf individuals? What can be done to enhance the communication strategies and make them more effective, inclusive and beneficial?

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Communication for Development
One-year master
15 Credits
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Abstract

This paper deals with the Deaf community in sub-Saharan Africa, with particular focus on the Republic of Congo, and Senegal. It explores how the humanitarian sector is reaching out to this community, especially regarding Sexual and Reproductive Health. Projects set up by UNFPA Congo and Senegal’s ONG Jeunesse Et Dévelopement, are examined within the framework of communication for development. By researching the nexus between the international organizational world and the deaf community, the plan is to gain understanding through methodological approaches such as semi structured interviews, a focus groups and document analysis including videos, that eventually will provide input that can lead to a more comprehensive and informative communication strategy for this group. As a large part of the Deaf community in the developing world isn’t able to read and write, their fundamental human rights are undermined, this is especially true when it comes to Sexual and Reproductive Health. Research from Kenya and Senegal have shown that people living with disabilities got slightly higher HIV seroprevalence compared to the rest of the population, while a study from Cameroon demonstrates that deaf individuals are three times more likely to contract an STI. Communication for development, behavior change communication, communication for social change as well as media development, got a significant role to play in leading the deaf community towards integration, inclusion and better access to information on Sexual and Reproductive Health. By including the deaf community and let them define their own needs through genuine participation, it is possible to strengthen their rights. Researching the deaf community in the developing world is like studying a micro-cosmos of the entire development debate, as many of the main challenges are present. By empowering the deaf community in Africa, the whole continent is empowered.

Keywords: Communication for Development, Participation, Sexual and Reproductive Health, Deaf Community, Sign language, Humanitarian Sector, Congo, Senegal
# TABLE OF CONTENT

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>2</td>
</tr>
<tr>
<td>TABLE OF CONTENT</td>
<td>3</td>
</tr>
<tr>
<td>ABBREVIATIONS</td>
<td>4</td>
</tr>
<tr>
<td>DEFINITIONS</td>
<td>5</td>
</tr>
<tr>
<td>1. INTRODUCTION</td>
<td>6</td>
</tr>
<tr>
<td>2. BACKGROUND</td>
<td>9</td>
</tr>
<tr>
<td>2.1 THE HISTORY OF DEAFNESS AND THE DEVELOPMENT OF SIGN LANGUAGE</td>
<td>9</td>
</tr>
<tr>
<td>2.2 THE INTRODUCTION OF ASL IN THE PRE &amp; POST COLONIAL ERA</td>
<td>10</td>
</tr>
<tr>
<td>2.3 FOSTER AND FRENCH SPEAKING AFRICA</td>
<td>11</td>
</tr>
<tr>
<td>2.4 HUMANITARIAN AID AND DEAF EDUCATION</td>
<td>12</td>
</tr>
<tr>
<td>3. METHODOLOGICAL APPROACH</td>
<td>13</td>
</tr>
<tr>
<td>3.1 DATA COLLECTION</td>
<td>13</td>
</tr>
<tr>
<td>3.2 CHALLENGES</td>
<td>14</td>
</tr>
<tr>
<td>3.3 ETHICS</td>
<td>15</td>
</tr>
<tr>
<td>3.4 LEGAL FRAMEWORKS FOR PEOPLE LIVING WITH DISABILITIES</td>
<td>16</td>
</tr>
<tr>
<td>4. THEORETICAL PERSPECTIVES</td>
<td>17</td>
</tr>
<tr>
<td>4.1 PAULO FREIRE</td>
<td>19</td>
</tr>
<tr>
<td>4.2 COMMUNICATION FOR DEVELOPMENT</td>
<td>21</td>
</tr>
<tr>
<td>4.3 WHY C4D IS IMPORTANT FOR THE DEAF COMMUNITY</td>
<td>22</td>
</tr>
<tr>
<td>5. CASTE STUDY 1 - THE REPUBLIC OF CONGO</td>
<td>25</td>
</tr>
<tr>
<td>5.1 PEOPLE LIVING WITH DISABILITIES IN CONGO</td>
<td>25</td>
</tr>
<tr>
<td>5.2 DEAFNESS IN CONGO</td>
<td>26</td>
</tr>
<tr>
<td>5.3 ORGANIZATIONS WORKING FOR THE DEAF COMMUNITY</td>
<td>27</td>
</tr>
<tr>
<td>5.4 ANSDACO</td>
<td>27</td>
</tr>
<tr>
<td>5.5 INSTITUT DES JEUNES SOURDS DE BRAZZAVILLE</td>
<td>27</td>
</tr>
<tr>
<td>5.4 SEXUAL AND REPRODUCTIVE HEALTH</td>
<td>28</td>
</tr>
<tr>
<td>5.4 UNFPA</td>
<td>29</td>
</tr>
<tr>
<td>6. CASE STUDY 2 – THE REPUBLIC OF SENEGAL</td>
<td>31</td>
</tr>
<tr>
<td>6.1 PEOPLE LIVING WITH DISABILITIES IN SENEGAL</td>
<td>32</td>
</tr>
<tr>
<td>6.2 DEAFNESS IN SENEGAL</td>
<td>32</td>
</tr>
<tr>
<td>6.3 CHALLENGES</td>
<td>33</td>
</tr>
<tr>
<td>6.4 SEXUAL AND REPRODUCTIVE HEALTH</td>
<td>35</td>
</tr>
<tr>
<td>6.5 ORGANIZATIONS WORKING FOR THE DEAF COMMUNITY</td>
<td>38</td>
</tr>
<tr>
<td>6.6 CONSULTANT FRANCOIS MANGA</td>
<td>39</td>
</tr>
<tr>
<td>7. ANALYSIS</td>
<td>40</td>
</tr>
<tr>
<td>8. CONCLUSION</td>
<td>48</td>
</tr>
<tr>
<td>9. REFERENCES</td>
<td>51</td>
</tr>
</tbody>
</table>
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADS</td>
<td>Adamorobe Sign Language</td>
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<td>ASL</td>
<td>American Sign language</td>
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<tr>
<td>ANSDACO</td>
<td>Association Nationale des Sours et Déficient Auditifs du Congo</td>
</tr>
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<td>AMCRE</td>
<td>l’Association des Amis des Centres de Ressources Educationnelles,</td>
</tr>
<tr>
<td>ANASSEN</td>
<td>Association Nationale des Sours du Senegal</td>
</tr>
<tr>
<td>ANCS</td>
<td>l’Alliance Nationale des Communautés pour la santé</td>
</tr>
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<td>BSL</td>
<td>Bamako Sign Language</td>
</tr>
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<td>CMD</td>
<td>Christian Mission for Deaf</td>
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<td>C4D</td>
<td>Communication for Development</td>
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<td>CFAS</td>
<td>Centre de Formation et d’Alphabetisation des Sours de Pikin</td>
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<td>CNLS</td>
<td>Centre National Lutte Contre le Sida</td>
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<td>ESL</td>
<td>Ethiopian Sign Language</td>
</tr>
<tr>
<td>GBV</td>
<td>Gender Based Violence</td>
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<td>FSAPH</td>
<td>Federation Senegalaises des Associations de Personnes Handicapees</td>
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<td>ICT</td>
<td>Information Communication and Technology</td>
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<td>ICSECR</td>
<td>International Covenant on Economic, Social and Cultural Rights</td>
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<td>IJSP</td>
<td>Institut des Jeunes Sourds de Brazzaville</td>
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<tr>
<td>LSFA</td>
<td>Langues des signes Franco-Africaines</td>
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<tr>
<td>NGO</td>
<td>Non-governmental organization</td>
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<tr>
<td>ONG JED</td>
<td>Organisation non gouvernementale Jeunesse et développement</td>
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<td>OPH</td>
<td>Organisations de personnes handicapées</td>
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<td>PRA</td>
<td>Participatory Rural Appraisals</td>
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<td>RGPH</td>
<td>Recensement General de la Population et l’Habitatation</td>
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<tr>
<td>RGPHAES</td>
<td>Recensement General de la Population et l’Habitatation de l’Agri et de l’Elevage</td>
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<tr>
<td>SDG</td>
<td>Sustainable Development Goals</td>
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<td>SGBV</td>
<td>Sexual and Gender Based Violence</td>
</tr>
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<td>SASL</td>
<td>South African Sign Language</td>
</tr>
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<td>STI</td>
<td>Sexually Transmitted Disease</td>
</tr>
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<td>SRH</td>
<td>Sexual and Reproductive Health</td>
</tr>
<tr>
<td>UNCRDP</td>
<td>United Nations Convention on the Rights of Persons with Disabilities</td>
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<td>UNFPA</td>
<td>United Nations Population Fund</td>
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<td>UNESCO</td>
<td>United Nations Educational, Scientific and Cultural Organization</td>
</tr>
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<td>UNDP</td>
<td>United Nations Development Programme</td>
</tr>
<tr>
<td>WFD</td>
<td>World Federation of the Deaf</td>
</tr>
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<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>WSL</td>
<td>Wolof Sign Language</td>
</tr>
</tbody>
</table>
Definitions

**Deaf**
“Deaf’ people mostly have profound hearing loss, which implies very little or no hearing. They often use sign language for communication.”¹

**Hard of hearing**
“‘Hard of hearing’ refers to people with hearing loss ranging from mild to severe. People who are hard of hearing usually communicate through spoken language and can benefit from hearing aids, cochlear implants, and other assistive devices as well as captioning.”²

**Sexual and Reproductive health (SRH)**
“Sexual health, which is also a component of reproductive rights, comprises of “the enhancement of life and personal relations, not merely counselling and care related to reproduction and sexually transmitted infections. It refers to the integration of the somatic, emotional, intellectual and social aspects of sexual being in ways that are positively enriching and that enhance personality, communication and love”.³

“Reproductive health refers to the “state of complete physical, mental and social well-being, not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capacity to reproduce and the freedom to decide if, when and how often to do so.”⁴

**Sexual and Gender Based Violence GBV (SGBV)**
Sexual and gender-based violence refers to any act that is perpetrated against a person’s will and is based on gender norms and unequal power relationships. It encompasses threats of violence and coercion. It can be physical, emotional, psychological, or sexual in nature, and can take the form of a denial of resources or access to services. It inflicts harm on women, girls, men and boys.⁵

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¹ [https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss](https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss)
² idem
⁴ ibid
1. Introduction

“Both gender and disability are constructed, in the sense that on top of the biological facts of sex and impairment such as lack of sight there are social expectations which determine the options for those concerned.”6

My interest in the deaf community started when I heard about a group of deaf people who got killed during the civil war in Congo in 1997. As they could not hear the sound of the gun fire, they ran straight in to it. Ngugi wa Thiong'o, in *A grain of wheat*, wrote about a similar story that is said to have been about his deaf step-brother. “An admirable young deaf labourer, Gitogo, ’handsome, strongly built', popular with other young men, who cared for his elderly mother, and ’spoke with his hands'. During a government raid on Gitogo's village, he ran to protect his mother. A soldier shouted ’Stop!’. Gitogo ran on and was shot.”7

In Disability, Liberation and Development, Peter Coleridge writes; “The situation of disabled people provides a microcosm of the whole development debate and process. Disabled people are oppressed and marginalized in every country of the world, in both North and South. They are oppressed by social attitudes which stem from fear and prejudice. By examining these prejudices and studying examples where they have been overcome, we gain an insight into the process of liberation and empowerment that lie at the heart of any development effort.”8

The above statement by Coleridge couldn’t be truer, by studying the deaf community in the light of communication for development one is reminded, time after time of the validity of his statement, as the field is related to a range of development debates.

The deaf community in sub Saharan Africa have in many ways been overlooked. The “voice for the voiceless discourse,” a popular mantra used by a number of humanitarian sector organizations, is one proof that the deaf community in the developing world, has been left behind. By making use of the “voice for the voiceless,” slogan, which at a first glance might sound noble, one is in reality creating a hierarchy, divided in what Freire would call, the upper and the lower. No one is voiceless, the deaf community might not be able to speak with an audible voice, but they got a voice like everyone else.

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7 Miles, M, Deaf People Living and Communicating in African Histories, c. 960s - 1960s, Independent Living Institute Library 2005: 9
8 P. Coleridge, *Disability, Liberation and Development*, An Oxfam Publication 1993: 4
The aim with this thesis will be to look on the humanitarian sector and its work with the deaf community in sub-Saharan Africa with focus on Congo and Senegal. This will be done by studying the activities of UNFPA in Congo, along with those of ONG JED in Senegal in the sector of SRH. Material from research in sub Saharan Africa touching on SRH and SGBV as well as maternal health in relation to the deaf community are part of the research. Through interviews and a focus group, a picture describing the challenges of the deaf community will be created.

The title of this thesis starts with a slogan, *leave no one behind*. Studying academic reports on the deaf community and by engaging with the community, it soon became clear that the deaf community has been left behind. Not much research has been done on the deaf population in regard to SRH, and if one looks on the HIV seroprevalence of the disabled community at large, it is higher compared to the general population in both Kenya and Senegal. In Cameroon the seroprevalence for the deaf community is almost on pair with the general population. Despite this, there aren’t many programs on SRH in place for people with disabilities. The deaf community encounters hurdles while visiting hospitals, and girls and women who are sexually abused find it difficult to report these crimes due to communication barriers.

On the World Federation of the Deaf website, one is able to read similar stories to what was encountered during the research. “*Janis was locked up for five years just for being deaf.*” “*Sterilized without her consent for being deaf.*” “*Maria endured years of abuse just for being deaf,*” and to further shine the light on the discrimination encountered, we can look on what a feminist academic said about women living with disabilities. “*Why study women with disabilities? They reinforce traditional stereotypes of women being dependent, passive and needy.*” If one is to believe some of the voices from the deaf community in Senegal, their community is found on the lowest place in the hierarchy within disabled organizations themselves. Deaf people are perceived as weak and fearful as they aren’t able to speak.

The thesis will start by giving a *Background* to deafness in Africa and as we will see, Christian groups has historically played an important role in the development and assistance of the deaf community. Andrew Foster, a pan-Africanist and missionary, also known as the father of deaf education in Africa, will be studied, as will the development of deaf education

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9 P. Coleridge, Disability, Liberation and Development, An Oxfam Publication 1993: 34
in French speaking Africa. After this the *Methodological approach* will be highlighted, data collection, challenges and ethics are some of the points that will be treated, before the *Theoretical Perspectives* of the thesis will be emphasized, here Paulo Freire will play an important role. Thereafter, *Case Study 1 - the Republic of Congo*, will give a description of the situation for the deaf community in Congo in addition to UNFPA’s work in the country. *Case Study 2 – the Republic of Senegal* will explore the deaf community in Senegal as well as ONG JED. It has to be mentioned that one of the purposes with the research, was to learn from Senegal in order to bring back acquired experience to Congo. The work of each organization as well as videos created by UNFPA Congo and ONG JED will under the section *Analysis*, be analyzed within the framework of communication for development, where participatory communication and ideas from Freire, Tufte and Mefalopolus will play a leading role. The thesis will be summed up in a *Conclusion*.

Deaf development could very well be the next big thing within the development sector. If so, it offers the development community an opportunity to do things right. Robert Chimedza, a Zimbabwean academic has talked about the importance “to resist the cultural imperialism of foreign aid agencies dictating agendas, for Southern deaf organizations, that suit the ideologies of far distant societies.” Hopefully, deaf development will become a different development trend, one where the community will be in the center through genuine non institutionalized participation and where the deaf community will be in charge of its own development.

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1. Background

According to the World Health Organization, WHO, over 466 million of the world’s population, has one form of hearing loss, a number estimated to reach 900 million in 2050.11 A study from 2012 states that there were some 36,8 million individuals living with disabling hearing loss in sub Saharan Africa, 6.8% of them were children.12

The causes of hearing loss are often divided in two groups, congenital or acquired. The prior which we will focus on, refers to a person being born with hearing loss or deafness, or that he or she gets it soon after birth, as a result of genetic factors or complications during the pregnancy. Maternal rubella, syphilis or other infections during pregnancy, low birth weight, lack of oxygen at the time of birth, or inappropriate use of particular drugs during pregnancy such as antimalarial drugs are some of the causes.13

It has been estimated that in low and middle-income countries, 75% of all hearing loss is preventable, and prevalence of deafness among children, is highest in South Asia, Asia Pacific as well as in sub-Saharan Africa.

2.1 The History of Deafness and the Development of Sign languages

Ancient historical sources such as the Ebers papyrus states that deafness was well understood, and that several words describing deafness existed in ancient Egypt.14 Plato is mentioning deafness in one of his dialogues, the Cratylus where Socrates is discussing with Hermogenes; "If we hadn't a voice or a tongue, and wanted to express things to one another, wouldn't we try to make signs by moving our hands, head, and the rest of our body."15 More recent stories date back to the 18th century and the slave trade from Africa to the Arab world where it is recorded how deaf servants were sent from the northern parts of Nigeria, Chad and Sudan destined to serve the rulers in Istanbul.16

11 https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss
12 https://www.who.int/pbd/deafness/WHO_GE_HL.pdf
13 https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss
14 Miles, M, Deaf People Living and Communicating in African Histories, c. 960s - 1960s, Independent Living Institute Library 2005: 6
15 http://brianrabern.net/Plato-Cratylus.pdf: 139
Just like audible languages come in different shapes and forms, so it is with sign languages. The number of sign languages spoken in the world today is unknown, and estimations range from 138-300.17 In the same manner, and just like there were hundreds of local languages spoken in Africa before English, French, Portuguese and Spanish became official tongues across the continent, there were also local sign languages before the introduction of western sign languages. Today, the American Sign Language, ASL, is widely spoken across sub Saharan Africa, but apart from this one, there are a multitude of African sign languages such as the Adamorobe Sign Language, (ADS) in Ghana, BSL in Mali, SASL in South Africa, ESL in Ethiopia, or WSL in Senegal, the latter has not yet been codified. According to Okyere and Addo, the first African deaf people known to have used a sign language were the people of Adamorobe, a village in Ghana, their research claims that ADS dates back to 1733.18

2.1 The introduction of ASL in the Pre & Post-colonial era

Andrew Foster, (1927-1987) also known as the father of deaf education in sub-Saharan Africa, was a deaf African American born and raised in Birmingham, Alabama. During his life time, Foster founded some 32 schools in 13 countries in sub-Saharan Africa. Despite his achievements, he is less celebrated than the three men often considered to be the pillars of deaf education, Thomas Hopkins Gallaudet, Laurent Clerc and Alexander Graham Bell. Foster lost his hearing at the age of 11 as a result of spinal meningitis and was therefore enrolled at the Alabama School for the Colored Deaf. With time he came to graduate from the University of Gallaudet in Washington DC, the only university in the world for deaf students.

There is a debate as to what triggered Foster to move to Africa and open up schools for deaf individuals. Some claim that his motivation was based on his urge to spread the Gospel, while others hold that he set out as a result of pan-African ideas. According to Fosters son, his religious conviction was the leading driving force. “I do wish that more people understood the source of my father’s passion. Yes, he wanted to help fellow Deaf people advance in the world by education, employment, etc. but more than this, he cared about the souls of men.”19

17 https://www.k-international.com/blog/different-types-of-sign-language-around-the-world/
18 M. Miles, Deaf People Living and Communicating in African Histories, c. 960s - 1960s, 2005:14
Agbola is emphasizing Fosters pan-African drive, he had “a vague longing in his boyhood to go to Africa…the reported interest in his boyhood-prior to his religious awakening-to go to Africa suggests an early curiosity per his ancestral roots.” R. Panara and J. Panara are in their turn stating that it was during his work with the inner-city ghetto neighborhoods that he discovered that there only were 12 schools for deaf in Africa.

Foster arrived in Ghana in 1957, shortly after the country gained its independence. Agbola argues that once in Africa he was challenged by “chronic shortage of funds to support his mission, inadequate infrastructure in most countries, skepticism by local officials, low expectations of deaf children, difficulties explaining abstract Bible concepts, difficulty in finding and training associates, long separation from family and language barriers.”

2.2 Foster and French Speaking Africa

Marcius Rock Titus, a deaf man working alongside Foster, made the following comment; “French-speaking Africa was a forgotten area, at the bottom of the list when it came to development of educational opportunities for deaf people.” With time, and Fosters influences, deaf learning institutions were created in a range of former French colonies. By 1976 Foster had launched a 4-week deaf education course, delivered in French, to train deaf and hearing cohorts from across Francophone Africa to work at his mission schools for deaf in that region. This 4-week course which came to be known as “the summer course,” was held at Nigeria’s Ibadan School for Deaf, and was specially designed for Africans from French-speaking nations across West and Central Africa. Thanks to the “summer course,” Foster was able to train a total of 110 teachers, which led to the opening of schools all over French speaking Africa.

“From an historical context, educational activities have existed for deaf children in 11 French-speaking African countries sponsored by the Christian Mission for the Deaf (CMD), which has been managed by Deaf Americans and Africans. The combination of French literacy education and the use of ASL in the classrooms has led to the birth of a new sign language
that exists neither in the United States nor in France, but only in Africa. This new sign language “Langue des Signes Franco- Africaine” (LSFA), defined as a “generic term for sign language widely used among French-speaking West and Central Africa with two distinct characteristics, loan signs from ASL and influenced based on spoken/written French.”

Foster died in a plane crash over Rwanda in 1987. He played a major role in the creation of deaf education in both Congo and Senegal.

2.3 Humanitarian aid and Deaf Education

During the course of the thesis, 13 well known humanitarian organizations were contacted in order to find out about their engagement with the deaf community. Three of these responded and gave a description on their work with the community. One of them explained that as their organization is decentralized it is hard to know what each office are doing on a country basis, adding that their work is to protect and ensure the rights of children living with disabilities, and that they through their work with C4D, are committed to eliminate discrimination in the form of negative attitudes, and support and promote their full integration and fulfillment of rights.

The second organization responded that they were aware of individuals living with hearing impairments, but that it is nothing that their organization are specializing in. They forwarded a link to a UK based NGO who are running a number of projects for deaf children throughout Africa. (Not in Congo and Senegal).

The third respondent, working with people with disabilities, went in to detail and even gave examples of projects for deaf people within the field of sexual and reproductive health, but none of them had been carried out in Africa. They further responded that a program focusing on family planning, WISH, aimed towards the deaf community, is soon to start in East Africa. Other projects were in the process of being developed in the Democratic Republic of Congo, RDC, in the area of maternal health, but not aimed towards the deaf community. They also mentioned that Vietnam have been engaged in projects on comprehensive sexuality education for the deaf community.

3 Methodological approach

3.1 Data Collection

This thesis is built on qualitative research, with a methodology based on semi structured interviews, document analysis and a focus group. The data collection for Senegal was conducted during my stay in the country in March of 2019, where time was set apart in order to get to know the deaf community in the country. Upon arrival, an initial contact was established with the Association Nationale des Sourds du Senegal, ANASSEN. As it is a deaf organization all conversations were conducted by text messages and WhatsApp. Eventually I met with Sambodj Bodj, who got reduced hearing but is able to speak. A meeting was arranged, and Sambodj turned out to be a valuable gatekeeper.

The data collection started with a semi structured interview with Sambodj at the Ministry of Health, where he met with the Ministry’s contact person for people with disabilities. He gave me a birds eye view of the community’s structure, deaf organizations, learning institutions, interpreters and challenges. He set up meetings and helped organize a focus group with young leaders from different deaf organizations in Senegal. Material for the analysis also consists of a newly produced document developed by a number of civil society organizations aimed to sensitize the disabled community in Senegal. The document consists of 19 different themes. A special version has been created for the deaf community in the format of videos which also will be part of the analysis.

During one of the conversations with Sambodj, it was revealed that during his almost 30 years’ working with the deaf community, he had never worked on a project with the UN, except a workshop with UNESCO in 2015.26

A meeting with UNFPA Senegal and a member of their communication team was also done, and through discussions it became clear that the national office never had worked with the deaf community.

26 http://www.unesco.sn/node/376
The initial plan was to find out how the UN are working with the deaf community in Senegal, but after Sambodj’s revelations and my meetings with UNFPA, I understood that the research question had to be modified. As a result, plan B was executed, and I eventually managed to find an organization, ONG JED, working with the deaf community on questions related to SRH. Instead of focusing on UNs involvement with the deaf community, attention was turned towards the humanitarian sector and their involvement. UNFPAs role in the Republic of Congo remained unchanged.

When it comes to the data collection in Congo, I based myself on my own experience from the deaf community from earlier visits, and a number of interviews and observations done in the country in 2016-2017, mainly with teachers and students from IJSB. An interview was conducted with UNFPA in Congo via WhatsApp call. The same set of questions that were asked in Senegal were sent to a contact at the Ministry of Health in Congo, who visited the president of the organization for the deaf community in the country as well as IJSB, in order to collect data in the form of semi-structured interviews. In the case of Congo, a video found on UNFPA Congo’s website produced by the organization, as well as their experiences, forms the basis for analysis.

3.2 Challenges

Unfortunately, the vast majority of the voices recorded in both Congo and Senegal, were from an urban setting, but due to both time constraints and financial means the situation for the deaf community in the rural areas could not be explored.27

An initial concern was the challenge of communication, but as soon as the research started and much thanks to Sambodj, who became my interpreter, it didn’t take long before the challenge of communicating with the community disappeared. ICTs such as text messages and WhatsApp were of immense help. Another challenge, especially for Congo, had to do with the statistics. Reliable statistics when it comes to the number of deaf in Congo are hard to find. Last census for Congo took place in 2007, and in 2013 for Senegal.

27 It is worth mentioning that the situation is even more difficult for the community in rural settings as the main deaf learning centers are based in the capital.
3.3 Ethics

Ahead of each interview, the interviewees were briefed on the objective with my paper, whereafter verbal consent was sought and agreed upon before a recording of each conversation could start. None of the interviewees asked for anonymity and were eager to contribute and share their experiences.

Another critical point to highlight deals with the impact of translation. Given that the majority of the interviewees were deaf, and the fact that I am unable to speak sign language, an interpreter, Sambodj Bodj, vice president of the leading deaf organization in Senegal were present to help with translation. Sambodj is himself deaf but able to speak. The process was somewhat complex, whereby I wrote down my questions for the interpreter who signed the matter to the interviewee. The interpreter gave a verbal response in French that was recorded and later transcribed into English. With such a process one could argue that some of the meaning could be lost in translation, but as the interpreter got more than 30 years’ experience, works with the community daily and is well acquainted with the issues and challenges at hand, as well as with the cultural aspects of the deaf community, misinterpretations were avoided. Also, my findings correspond with the results of similar research done on the deaf community in Africa.

A third point worth mentioning deals with my first research question, which I learned could be perceived as offensive. Initially, I made use of the expression “deaf and mute.” After discussions with the World Federation of the Deaf; it became clear that the language was not correct. “We do not use the term deaf and mute because it is quite offensive. The appropriate term should be deaf,” it was explained. During the research in Congo and Senegal, no one reacted to the phrase deaf and mute. Congo’s Census report from 2007 is making use of the term.28

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28 Email exchange with the World Federation of the Deaf, April 16, 2019.
#### 3.6 Legal Frameworks for People living with Disabilities

In October of 2015, the UN launched the Sustainable Development Goals. Goal 16 and 10 are concerned with ensuring public access to information and the protection of fundamental freedoms. These freedoms are outlined in Resolution 59 of the United Nations General Assembly and defined in Article 19 of the Universal Declaration of Human rights and Article 19 of the international Covenant on Civil and Political Rights.

Deaf individuals in sub Saharan Africa are often exempt from this freedom due to lower education and communication barriers. The lack of sign language services is another factor preventing the deaf community to acquire relevant information. As a consequence of language barriers, a number of rights are violated. These include: the right to health, right to information, to participate in decisions, to give informed consent, to confidentiality and to be treated with respect and dignity.\(^\text{29}\)

In one study the authors ask themselves if it is possible to talk about the right to health care without a language? What about deaf people’s dignity and right to health? Without a verbal language, aren’t there severe consequences such as incorrect diagnosis and improper treatment jeopardizing deaf individuals right to questions concerning their health in general, and sexual and reproductive health in particular?\(^\text{30}\)

There are two leading frameworks, human rights documents for the right to sexual and reproductive health, for persons living with disabilities. The UNCRDP, United Nations Convention on the Rights of Persons with Disabilities.\(^\text{31}\) As well as article 12 of ICSECR, the International Covenant on Economic, Social and Cultural Rights.

Despite these laws, people living with disabilities, including the deaf community in sub-Saharan Africa, are still facing barriers to receiving adequate SRH care.

\(\text{29} \) H. Haricharan, M. Heap, F. Coomans, L. London. Can we talk about the right to healthcare without language? A critique of key international human rights law, drawing on the experiences of a Deaf woman in Cape Town, South Africa, Disability & Society, 2012:54

\(\text{30} \) ibid
4 Theoretical perspectives

During the focus group with leaders from the deaf community in Senegal, a comment from one of the participants struck to the core. “What we need is to be in charge of our own development process, it is only through our participation and involvement that things can change for our community.”

Participation is central to the field of communication for development, and this thesis, will thus be analyzed within the framework of participatory communication.

A defining trait with communication for development is that of participatory communication and “a resistance to top down, prescribed styles of learning.” Focus is no longer on how to disseminate information in order to change individual behavior, but rather to “facilitate the inclusive expression of community’s needs.”

Participation is a multifaceted term, and there is no consensus in regard to its meaning, making its definition a difficult task. “It is a malleable concept that can be used to signify ‘almost anything that involves people’ and encompasses a wide diversity of practices.” Participatory communication is, according to Tufte and Mefalopulos “an approach based on dialogue, which allows the sharing of information, perceptions and opinions among the various stakeholders and thereby facilitates their empowerment.” While free and open dialogue remains the core principle of participatory communication, they consider participatory communication as a voice to the poorest and the most marginalized. Tufte and Mefalopulos are mentioning two strands of participatory communication, strands that we will make use of further down the line. They divide the term in a social movement perspective as well as a project-based or institutional perspective. The prior refers to participation as an empowering process while the latter one moves away from genuine participation towards one where pre-established goals are defined by external/upper forces.

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32 Focus group Khar Yalla, Dakar, Senegal. Home of Ousmane Diao, March 24, 2019
34 idem: 49
37 idem: 18
In Evaluating Communication for Development, Lennie and Tacchi explains that participation first hit the development mainstream in the 70’s but that it truly took hold in the 80’s. It became a popular approach as a result of past dominant behavior by outsiders who had been guided by modernization theories.

Richard Chambers one of the foremost scholars on participation, captures the meaning of participatory communication with a few words, “knowing better together.”

Chambers believes that a sharp reduction of poverty “can be achieved if powerful professionals become more participatory and get closer to and learn more from those who live their lives in poverty; and then act on what they experience learn and feel.” In Whose Reality Counts? he is calling for community driven and process oriented methods, which should be led by the lowers and not the uppers. Development should hence be done “with and by the people” and not “for or to the people.” In order for genuine participation to take root, a new type of professionalism is needed, built on new methods and approaches.

Participatory communication is for Cambers a way to “enable the poor and marginalized people to express their realities.” By developing his own method, Participatory Rural Appraisals, he has been able to empower and encourage local people to become masters of their own destiny. “The essence of PRA is changes and reversals – of role, behavior, relationship and learning. Outsiders do not dominate and lecture; they facilitate, sit down, listen and learn. Outsiders do not transfer technology; they share methods which local people can use for their own appraisal, analysis, planning, action, monitoring and evaluation. Outsiders do not impose their reality; they encourage and enable local people to express their own.”

In Can We Know Better? he highlights the fact that the participation game has changed in the last few years as a result of ICTs, where participatory video, photo voice and digital storytelling have got a huge role to play. This as we will see, can help the deaf community in several ways.

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41 R. Chambers, Participation and Poverty, Society for International Development, 2007: 20
42 R. Chambers, Ideas For Development; Reflecting Forwards, IDS Working Paper 238, 2004: iii
4.1 Paulo Freire

Paulo Freire was a Brazilian educator and philosopher. He was concerned with structural change and redistribution of power, and developed a model built on genuine participation that enabled the oppressed to liberate themselves.

Freire is mostly known for his book, *Pedagogy of the Oppressed* where he outlines and defines the true meaning of participation. Freire was a fierce opponent of the neoliberal view that promoted the notion of the end of history, and he dreamed of transforming what Frantz Fannon termed ‘the wretched of the earth,’ from ‘being for others’ to ‘being for themselves,’ and that way create a world that was more round, less ugly and more just.44

He was in the business of liberating pedagogy which dealt with acts of cognition rather than the transfer of information. Freire’s approach was built upon the concept of dialogue, he defines dialogue as “the encounter between men in order to name the world. Those who have been denied their primordial right to speak their word must first reclaim this right and prevent the continuation of this act of exclusion.”45 It is through dialogical communication that the process of reflection and action starts with ‘conscientizacao,’ or conscientization as a result. Tufte and Mefalopulos translated conscientizacao into action-oriented awareness raising.46 Transformation can never take place without action; true reflection leads to action as the two are organically integrated. This can never be achieved unless the people are allowed to fully participate in the development process. Here Freire is not talking about pseudo or symbolic participation, but a genuine fully committed involvement in the participation process. Freire further argues that subjugated people must be treated as fully human subjects in any political process.47 To alienate human beings from their own decision-making is to change them into objects, it is therefore important to keep the receiver in focus.48

Another scholar, Jan Servaes, echoes Freire’s above-mentioned words when he claims that participatory methods should be egalitarian and stress reciprocal collaboration throughout all levels of participation with a special emphasis on cultural identity in local communities.49

45 idem: 88
47 J. Servaes, *Participatory Communication (Research) from a Freirean Perspective*: 78
49 J. Servaes, *Participatory Communication (Research) from a Freirean Perspective*: 75
Genuine participation as developed by Freire, an approach emphasizing the importance of information exchange rather than persuasion in the diffusion model, started as a philosophy meant to liberate the oppressed. Throughout the years the original idea has been diluted and sometimes even hijacked by groups making use of the approach to fulfill the interests of individuals, political parties, corporations or organizations.

Lennie and Tacchi claim that participation holds both the potential for tyranny and transformation because it implicates the political and exists in relations of power.50 Studying participation from an historical perspective, the term made a major class journey from its humble beginnings in Brazil during the 50’s and 60’s to its transformation in the 80’s and the 90’s. According to Majid Rahnema, participation “became ‘a redeeming saint,’ development’s failures were now to be explained by its top-down, blueprint mechanics, which were to be replaced by more people-friendly, bottom-up approaches that would ‘put the last first’.”51

Today, participation has acquired what have been called buzzword status, as it, according to Cornwall, was reduced to a series of methodological packages and techniques, and slowly lost its philosophical and ideological meaning.52 “During the greater parts of the 1990’s participation stood side by side with such giants as ‘sustainable development’, ‘basic needs’, ‘capacity building’, and ‘results based, not to mention innovation.’”53

Servaes, highlights the danger of using the approach as a tool of manipulation, which can be done by all political colors. Knowledge and perspective gained may well empower exploitative economic and authoritarian interests instead of local groups. The result can be dependency instead of empowerment. Another important point raised is that participatory communication is a time-consuming business, oftentimes because it takes time to develop rapport and trust, where development of social trust precedes task trust.54

Finally, Tufte and Mefalopulos, raises an important point that can decide the outcome of projects based on participation. For it to work, a politically conducive environment, allowing open and transparent communication is necessary, they claim.55 They continue by

52 idem:89
54 J. Servaes, Participatory Communication (Research) from a Freirean Perspective: 77
highlighting a set of other roadblocks which might stand in the way for genuine participation as understood by Freire and which very well could be of importance while studying the deaf community in Senegal and Congo. “Within the current structure of the development aid system it is rather difficult to have a high degree of participation. The agenda of projects and programs is often set by a few individuals with very little input from other stakeholders. Rigid management procedures and tight deadlines for planning and funding required for approving and implementing projects allows little flexibility needed for participatory processes.”

4.2 Communication for Development

From a present-day perspective, the term communication for development was first coined in the 1960’s by Nora Quebral, a Pilipippine scholar often referred to as the “mother of development communication.”

She came to define the concept as the “art and science of human communication applied to speedy transformation of a country and a mass of its people from poverty to a dynamic state of economic growth, so as to achieve greater social equality.” Today her book, Development Communication, is seen by many as the magna carta of development communication. While Quebral is widely considered to be the author of development communication, various postcolonial movements searching for another kind of communication to address poverty and inequality in the global south, were also among the early contributors to the field. Others claim Everett Rogers, an American communication scholar to be its initiator.

Lennie and Tacchi, describes communication for development as being a process concerned with people rather than technologies, a two-way system “promoting the importance of enabling dialogue and discussion and the sharing of knowledge and skills, rather than information or message delivery.”

“It is a soft and social science that has to do with listening, building trust and respecting local cultures.”

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56 idem: 18
57 https://en.wikipedia.org/wiki/Nora_C._Quebral
58 L. Manyozo, Media, Communication and Development: Three Approaches, Sage India 2012:5
60 idem: 15
For Quarry and Ramirez, communication is like a chameleon which is embedded in international development, it changes color to reflect the development thinking of the day. 61 Manyozo in his turn, refers to communication for development as communication participation which “explains a holistic, collective and dialogical process that brings together relevant stakeholders, engaging them in critical deliberative dialogues about a development problem. Ideally, the praxis should be inclusive, as it requires creating sustainable collaborations with local communities, without manipulating them to accept outsiders’ thinking on solving particular problems.” 62 Tufte claims that most models of communication for development are derived from institutionalized practice, tied up with an organization’s logic of thinking. “Organizations tend to narrow their attention to their own singular impact, leaving aside considerations about broader, deeper and more complex questions.” 63

4.3 Why C4D is important for the Deaf Community

As shown below, the deaf community in the developing world, are exposed to a range of different challenges endangering their health. When it comes to SRH as well as SGBV, there are almost no information available for the community. Here C4D plays a crucial role, not only in the development of communication tools, but also in sensitization classes which eventually can lead to social change for the community.

Stories about men raping young deaf girls thinking that they can get away with it, are common throughout the developing world. Talking with people within the deaf community in Senegal, similar stories came up, witnessing of the vulnerability of women and girls living with deafness. One research from South Africa concluded that acts of sexual violence are higher towards the deaf and hearing impaired compared to the general population. 64 Another study shows that deaf individuals in Cameroon are three times more likely to contract an STI compared to the general population. 65 Kvam and Braathen explored perceptions of sexual relationships among disabled women in Malawi. Their participants described themselves as

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vulnerable to sexual abuse due to their disability; some participants said their partners had left them because of their disability, thus the rejection made them feel isolated and lonely and possibly put them at risk of entering an abusive relationship.\textsuperscript{66} A research conducted with deaf children in the Nordic countries found that they are at higher risk of sexual abuse.\textsuperscript{67}

The story of Neliswa, a young deaf South African woman, embodies all important factors, and shows why C4D is relevant in regard to the deaf community and the area of GBV and SRH specifically. Neliswa was raped and as a consequence she became pregnant and contracted HIV. Had her rights been looked after, and had she received the proper information, she might not have contracted the disease. After the rape Neliswa were taken to the hospital, but due to communication barriers she was unable to understand the staff at the hospital, as a result she did not take the post-exposure prophylaxis, that could have prevented an HIV infection. “I threw the tablets away when I came back home because I did not know what they were for and I did not feel sick. I did not feel that I needed them. I did not know what I had. If I had known, I would have taken them (the tablets.)”\textsuperscript{68}

Her rights were violated a third time in relation to the delivery of her results. “I did not receive any counselling. The nurse just told me that I was HIV-positive. I did not have an interpreter. I tried to find out more, but the health professional just scolded me for not bringing an interpreter. I did write things down. She, the nurse, wrote HIV positive on a piece of paper. I did write down questions. But the terminology was very difficult to understand. I did not have a chance to ask questions when I tested.”\textsuperscript{69}

This study illustrates in multiple ways, how poor communication can lead to serious consequences for deaf patients. In another study, Mall and Swarts holds that deaf individuals are excluded from HIV services and information, as this isn’t available as sign language, in addition, inadequate schooling means that written material is of little use.\textsuperscript{70}

\textsuperscript{66} S. Mall, L. Swarz. Perceptions of educators of Deaf and hard-of-hearing adolescents of HIV-risk factors for these youths, AJAR 2015: 343
\textsuperscript{67} idem: 347
\textsuperscript{68} H. Haricharan, M. Heap, F. Coomans, L. London. Can we talk about the right to healthcare without language? A critique of key international human rights law, drawing on the experiences of a Deaf woman in Cape Town, South Africa, Disability & Society, 2012:59
\textsuperscript{69} ibid
\textsuperscript{70} S. Mall, L. Swartz, Attitudes toward condom education amongst educators for Deaf and hard of hearing adolescents in South Africa, Alan J Flisher Centre for Public Mental Health, Department of Psychology, Stellenbosch University South Africa, 2014: 2
A 2010 study on HIV/AIDS, and the deaf community in Yaoundé, Cameroon, showed that the seroprevalence among the deaf in the capital, is almost on pair with the general population. While the Kenya Disability Association, estimates that the seroprevalence is higher among people with disabilities, 10%, compared to 7%. The study further states that people living with disabilities have been excluded in the management of the health crisis generated by the AIDS pandemic, as the majority of the existing programs aren’t designed to help people with disabilities.

Several studies claim that deaf people face a similar risk to other disabled people in regard to contracting STIs including HIV. A Brazilian research states that deaf individuals are more vulnerable to HIV as a result of the lack of information, and if one is to believe a French study, claiming that adolescents with a physical disability had more sexual partners than adolescents without a disability, the importance of sensitizing is crucial.

Maternal health is another important issue where deaf women often are left out. They face higher rates of adverse outcomes including pre-term births and low birth weight babies. Few studies have focused on the pregnancy outcomes of deaf women, and none have been conducted in low- and middle-income countries. When it comes to the experience of maternity services, deaf women report lower satisfaction with overall quality of antenatal care, fewer antenatal appointments, and poor communication with physicians, but when provided with access to the interpretation services they need, they report higher satisfaction. This was confirmed by several deaf women and their husbands in interviews and a focus group in Senegal.

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72 idem. 6. I am aware of the fact that these are small statistical variations, but these are the numbers as presented by Kenya’s Disability Association. Page 2 of the same document states that a 2010 literature review on disability and HIV/AIDS in Africa indicates that the only African countries in which at least three studies on HIV and disability have been conducted are: South Africa (13 cases of research work); Zimbabwe (six cases); Kenya (four cases); Uganda (three cases); and Nigeria (three cases) No country from west and central Africa is mentioned, suggesting that the information gap is more critical there. Lack of data darkens an already blurred area.”
75 ibid
A common problem for both Congo and Senegal is an inadequate supply of Sign Language interpreters. As of 2016, there were only five registered interpreters in South Africa.\footnote{M. Gichane, M. Heap, M. Fontes, L. London. “They must understand we are people”: Pregnancy and maternity service use among signing Deaf women in Cape Town. SPECIAL ISSUE: Sexual and Reproductive Health of Women with Disability Research paper, Disability and Health Journal, 2017: 435}

5. Case Study 1. - The Republic of Congo

The Republic of Congo is located in Central Africa and hosts a population of 5.5 million inhabitants, (2019.)\footnote{http://worldpopulationreview.com/countries/republic-of-the-congo-population/} Its capital, Brazzaville, is home to 1 284 609 inhabitants.\footnote{ibid} The country has experienced several coup d’états, and the current president, Denis SassouNguesso has accumulated 35 years in power.

Following Transparency International’s 2018 report, Congo ranked 165 out of 180 countries on the corruption perceptions index.\footnote{https://www.transparency.org/country/COG} In regards to press freedom, the country comes in on the 117:th place on the World Press Freedom Index, with Reporters Without Borders stating that since 2014, several journalists have been threatened, forced to flee the country, or were summarily deported for criticizing the government or inviting opposition politicians to express their views.\footnote{https://rsf.org/en/congo-brazzaville} Since 2015 internet has been cut twice for several weeks in relation to a referendum and a presidential election, this affected both the population and the humanitarian sector in various ways.

5.1 People living with Disabilities in Congo

According to the Recensement General de la Population et l’Habitatation, (RGPH) from 2007, 1.4% of the Congolese population are living with a handicap, that is 14 of 1000 Congolese.\footnote{Le RGPH-2007 en Quelques Chiffres, Ministère de l’Economie du Plan, de l’Aménagement du Territoire et de l’Intégration, 2010:16} According to the same report, the most common handicap is related to lower limb disabilities, i.e. difficulties to walk.

The 2015 constitution is mentioning individuals living with a handicap stating that; \textit{“The aged persons and persons living with handicap have the right to measures of protection in relation to their physical, moral or other needs, in view of their full development”}
[épanouissement] within the conditions determined by the law."\(^{82}\) The constitution is further mentioning the institution of a Consultative Council of Persons living with an Handicap and their role with making suggestions to the Government aimed at better support of the person living with handicaps.\(^{83}\)

The country has ratified a number of international conventions in regard to individuals living with disabilities such as the United Nations Convention on the Rights of Persons with Disabilities, CRPD. It is further emphasizing the right of handicapped individuals in the Convention of the Rights of Children, as well as in the African Charter on the Rights and Welfare of the Child.

### 5.2 Deafness in Congo

According to the national statistical agency, the 2007 census registered some 4632 deaf individuals.\(^{84}\) As the numbers are old, it is difficult to know the exact number of deaf individuals residing in the country today. While the community is up against a host of challenges, the lack of education seems to be the most pressing issue.

The first deaf school in Congo was established by father Marie-André Nganga member of the St Gabriel Brothers in 1971. Congo as so many other African countries are using ASL as a result of Andrew Fosters work, and apart from ASL there exists a range of local sign languages. Foster had a huge influence on deaf education in Congo, he never visited Brazzaville, but in 1980, a number of teacher and students assisted in a seven weeks course organized by Foster in Nigeria, at their return they founded Communauté Chrétienne des Sourds du Congo. It was in the wake of their return that the fore runner to Association Nationale des Sourds et Déficient Auditifs du Congo, ANSDACO was created.\(^{85}\)

In 1993 the World Federation of the Deaf organized a congress in Brazzaville, and a whole range of activities and exchanges were made with other African countries.\(^{86}\) In the aftermath of this congress, a project aimed to promote the local Congolese sign languages was set up, but the Congolese civil war that erupted in 1997, turned the development of the deaf

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\(^{82}\) Congo (Republic of the)'s Constitution of 2015, 22 Aug 2018: 8

\(^{83}\) ibid: 44

\(^{84}\) Le RGPH-2007 en Quelques Chiffres, Ministère de l'Economie du Plan, de l'Aménagement du Territoire et de l'Intégration, 2010:17


\(^{86}\) ibid
community backwards. A teacher at IJSB who himself studied at the school in the 70’s explained that the school used to be a point of reference for the whole Central African region. The civil war brought not only the deaf community, but the whole country backwards.

5.3 Organizations Working for the Deaf Community

5.4 ANSDACO

Alain Mercier is president of ANSDACO, the organization in charge of the deaf community in Congo, and the one recognized by the WFD. Alain reveals that the deaf community in the country are facing a range of difficulties, but that one must look with positive eyes on all the challenges. Alain is emphasizing the importance of funds destined to form health personnel, as well as police officers in sign language in order to embrace the human rights of the deaf community in Congo. “While in hospital, the doctors are often addressing us with their backs turned, they don’t know how to communicate with deaf people, and they need to be sensitized on this subject.” “Midwives, as well as a group of law enforcement officers need to learn the sign language, that way if something happens, we will know to what police office or health center we can go to get help, it comes down to sensitizing the community at large. Deafness will never finish, and it is therefore crucial that we find a solution to this problem as soon as possible.”

Mercier further revealed that the UNDP in relation to the 2016 presidential elections, provided ANSDACO with training and funds that enabled them to travel around the country, to teach the deaf community about the importance of voting. “In the future we would like the candidates to think about the handicapped community. “While organizing their meetings they need to understand that some are unable to climb steep stairs, while others are blind and as in our case, unable to hear.”

5.5 Institut des Jeunes Sourds de Brazzaville

According to Mesmin Lekoubi, director of IJSB, one of two schools catering for deaf students in the country, deafness in Congo are due to different causes, with meningitis, the rubella virus as well as badly treated malaria as the leading causes. According to Mesmin, the deaf

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87 Interview in Brazzaville 11/5/2019
88 Phone interview with Mesmin Lekoubi, director of IJSB, via phone 6/5/2019
community is up against a host of challenges. Education wise they are unable to obtain a high school diploma, as IJSB as well as l’Institut des Déficient Auditifs de Pointe-Noire, aren’t offering classes up to that level. Communication is another leading problem preventing the community to live a normal life. Mesmin mentions the many problems encountered while visiting hospitals, and in regard to the women, he mentions another interesting observation. “Deaf women giving birth, are not only facing communication problems. I have seen several cases where their husbands are abandoning them shortly after birth.”

Mesmin, being director of the largest school for deaf in the country, with around 300 students, reveals an additional issue that can be found on the way to and from the school. “The question of transport for our students is crucial, every now and then some of the children get hit by cars as they are unable to hear the sound of the traffic. The road that leads to school can be lethal if your deaf.”

“Historically, the catholic church has been active in the assistance of the deaf community in Congo, the government are trying to assist as well as they can, and in the last years we have received help from UNFPA in particular, as well as the WHO, who offered us a school bus. I am pleased to have a relationship with UNFPA in regard to sexual and reproductive health. The teachers, the parents as well as the students have received training on STDs, HIV/AIDS, teenage pregnancies as well as on SGBV. The fact that the students can’t hear, constitutes a double handicap, but as they have received information on the topic, their world is now a little bit safer. The fact that they cannot hear correctly is making them extremely exposed and vulnerable, and all information that they can get on the topic are therefore of importance.”

IJSB are further working with the parents of the deaf students, assisting them and trying their best to teach them how to communicate with their children. Basic education starts from home, and it is therefore important that the parents are able to communicate with their children.

5.4 Sexual and Reproductive Health

UNFPA Congo has for a number of years sensitized the students at IJSB on SRH and SGBV. While much work remains to be done, it is a first step in the right direction. In an interview from 2016, one of the teachers at IJSB explained that these students living with their handicap got the same rights as hearing adolescents. “They need to be able to take part of the existing
information on sexual and reproductive health and family planning which is a human right. It’s not because they are deaf that they should be ignored and put aside. They are like all other human beings and they go through the same bodily changes, early pregnancies and the risk of getting sexual transmitted diseases. “The fact that UNFPA is focusing on young girls with hearing impairities makes me happy, some discriminate against them, but we need to empower them and develop their full potential.”

UNFPA is the only organization working with the deaf community in this area. ACBEF as well as AAISC/AMSCO are two national NGOs also dealing with SRH. In discussion with the prior it became clear that they had tried, but due to some difficulties encountered on the road their project was interrupted. AISEC on the other hand, answered that they never had worked with the community, but that this was something that needed to be discussed in upcoming meetings.

5.5 UNFPA

In a 2018 report, Women and Young Persons with Disabilities, produced by UNFPA and its partners, several references are made to the situation of deaf people. Numerous challenges similar to the ones encountered during the research are highlighted.

UNFPA is often referred to as UN’s SRH agency. One of the organizations most often used slogans states that UNFPA are here; “To deliver a world where every pregnancy is wanted, every childbirth is safe and every young person’s potential is fulfilled.” Congo started its collaboration with UNFPA in 1972 and has since then worked to inform and prevent STDs including HIV/AIDS. UNFPA are further sensitizing the population on questions related to gender, including GBV, maternal health, and obstetric fistula. Capacity building among midwives, along with the empowerment of young people in various areas.

During an interview with the Congolese program manager in charge of Gender and Human Rights, it became clear that the organization started to work with the deaf community in 2016.

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89 Interview conducted with Mesmin Lekoubi during the International Day of the Girl Child, 11/10/2016
90 Information obtained during discussions via WhatsApp call with Jyer Magnondo, ACBEF, and Pachnelle Bongo, AISEC, on the 11/5/2019
91 Women and Young Persons with Disabilities, Guidelines on GBV and SRHR 2018
This happened in relation to the International Day of the Girl Child, held at the IJSB, an event attended by UNFPA’s Regional Director, Mabingue Ngom, heads of UN agencies in Brazzaville, as well as the Congolese Minister of Social Affairs. During the event, the Regional Director launched a call to help young deaf individuals in Congo and urged the various UN agencies along with the international community to do their part, so that all needs expressed by the institute would be seen to in an efficient manner. This event helped to put the deaf community in the spotlight, and afterwards, WHO, equipped the institute with a school bus enabling students to get to school safely.

Throughout the work with IJSB, UNFPA Congo has learnt about the challenges, not only of the school, but of the community in general. When sensitizing on SRH in schools, UNFPA are normally making use of civil society organizations that have been trained on the topic, but as the organization lacked direct experience from work with the deaf community, the organization took a different way. With the help of a process of trust building and by getting to know the teachers, parents and students of the school, a consultant, (with no previous experience from the deaf community) was hired, and sensitization classes could begin. It was emphasized that as soon as the work started, execution was handled IJSB and their staff, while UNFPA’s role were more of a financial and administrative nature.

“UNFPA are sensitizing the students at IJSB on sexual and reproductive health as well as gender-based violence. The deaf community have been left behind, and it’s important to include them as well.”92 It was further highlighted that participation is key, as no one is able to define a challenge better than the one living it and that bureaucratic procedures and other issues limits the level of participation.

“They are in need of an ocean of things, first of all I think that the communication needs to be strengthen, they need visibility, and capacity building among the journalist in our national media is therefore crucial. They need to learn about the deaf community and write and report on their daily challenges and rights. The government is also in need of sensitization, they have offered some support, but it’s far from enough. The statistics we got dates back to 2007, so we are actually in the dark in regard to the number of deaf individuals in the country, some

92 Interview with the UNFPA Congo’s head of program for Gender and Human Rights, via Whatsapp, 9/11/2019
people are ashamed of having deaf children and hides them away which in past censuses might have reduced their number.”

“Secondly we are dealing with a cultural problem. The sign language comes with a set of new cultural aspects. The deaf community are unable to communicate with the judiciary and health systems, and if they are sexually harassed, they are unable to report it. When they are giving birth, they are forced to bring a friend, which is a breach on their confidential health rights, and communication has a crucial role to play here as well. Their rights and their challenges need to be known by the public in order for a social change to take place.”

“Thirdly it is important to note that historically, churches have played a leading role in helping the community, but the work of the church is often based on charity. It is almost like they feel sorry for the deaf community, but you should not assist out of pity. What is important is to provide assistance in order to protect their human rights, they are people as us and therefore need to enjoy the same rights as we do. The strategies must therefore be based on human rights and not on charity.”

6. Case Study 2 – The Republic of Senegal

The Republic of Senegal is located in West Africa and hosts a population of 15,7 million inhabitants, (2017.) Its largest city and capital, Dakar, is home to 2,47 million inhabitants. The country is led by Macky Sall, who recently won his final five-year mandate in the 2019 elections.

The official language is French, with Wolof being the lingua franca and the most common language spoken. Apart from Wolof, there are a range of tongues holding national language status, such as Diola, the Malinké the Pular, and the Sérère to mention but a few.

Following Transparency International’s 2018 report, Senegal ranked 67 out of 180 countries on the corruption perceptions index. In regards to press freedom, the country comes in on
the 49:th place on the World Press Freedom Index, with Reporters Without Borders stating that abuses against journalists have been relatively infrequent in recent years.96

6.1 People living with Disabilities in Senegal

According to the Recensement General de la Population et l’Habitatat de l’Agriculture et de l’Elevage, (RGPHAE) from 2013, 5,9% of the Senegalese population are living with a handicap, that is 59 of 1000 Senegalese.97 The most common handicap is related to difficulties of walking and seeing. Of the country’s handicapped population, the majority are women, 3,1%, while the men represent 2,8%.

In Article 17 of the 2001 constitution, individuals living with a handicap are directly mentioned. “The state and the public collectively shall have the social duty to watch over the physical and moral well-being of the family and, in particular, of the handicapped and the aged. The state guarantees families in general and those living in rural areas in particular access to health and welfare services.”98 The country has further ratified a number of international conventions in regard to individuals living with disabilities such as the United Nations Convention on the Rights of Persons with Disabilities, CRPD, in April of 2007 and September of 2010. Senegal are further emphasizing the right of handicapped individuals in the Convention of the Rights of Children as well as in the African Charter on the Rights and Welfare of the Child.

6.2 Deafness in Senegal

In the 2013 census, 81 052 deaf individuals were registered, and as the numbers are old it is hard to know the exact number of deaf individuals residing in Senegal today. Senegal as so many other African countries are using ASL as a result of Fosters work. ASL may be the official sign language in Senegal, but there are a number of local sign languages, and one is in the process of being codified. While there are a host of challenges for deaf people in Senegal, the lack of education seems to be the most pressing issue and the one that holds the key to inclusion and integration into the society. This is one of the many tasks that the Association Nationale des Sourds du Senegal, ANSSEN, the umbrella organization of the

96 https://rsf.org/en/senegal
97 Agence Nationale de la Statistique et de la Demographie, Recensement General de la Population et de l’Agriculture et de l’Elevage (RGPHAE) 2013 : 140
deaf community in Senegal are preoccupied with. ANSSEN was founded in 1990 and is the first organization for deaf individuals in Senegal, Sambodj Bodj was one of its cofounders. ANSSEN is further a member of the Federation Senegalaises des Associations de Personnes Handicapees, FSAPH, the organization representing people with all kinds of handicaps across Senegal. Despite a restricted budget, (ANSSEN receives USD850 from the government each year), they are doing its best to assist the deaf community as well as it can.99

The first deaf school, Ephrata, was established in 1977 in the aftermath of Andrew Foster’s work. From its beginnings till 2003, it received funds from the Christian Blind Mission, CBM. Apart from Ephrata, today functioning under another name, the Renaissance School for the Deaf, financed by Canada, and AMCRE, an alphabetization center aimed to help educate deaf individuals and their parents, are working for the community. The majority of Senegal’s deaf schools are privately run, except for the Centre verbo-tonal, a state-owned school catering to people with reduced hearing abilities.

Just like in so many other development countries, meningitis seems to be the cause of deafness. One interviewee also blamed marriage within families, where cousins are marrying one another, on deafness.

6.3 Challenges

With the help of Sambodj Bodj, a focus group consisting of young leaders from Dakar was set up in Khar Yalla, a neighborhood of Dakar. The focus group consisted of both men and women from the age of 18 till 35.100 The majority of the individuals in the group were born deaf, while some of them became deaf as children.

Many of the same challenges that have been reported in academic papers from South Africa, Zimbabwe, Cameroon, Malawi and Nigeria came up during the discussion. Ousmane Diao, the President of ANASSEN, who took part in the focus group explained that the major problem for the deaf community can be found in basic services which has to do with the health and judiciary system. Whereas deaf individuals have no other choice than to participate in court without a deaf interpreter. Diao mentions one example of a deaf man who was

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99 Government grant of CFA500 000 per year
100 Focus Group with the deaf community in Khar Yalla, Dakar. 24/03/2019
wrongly accused, and as he had no idea about what was said in court, he couldn’t defend himself and was sentenced to prison.

Pape Sow, a 31-year-old plumber and president of an organization for deaf people in Rufisque, explained that more interpreters are needed. “We are unable to communicate with the authorities. When we approach them, they don’t understand us, and we don’t understand them. There is a real need for interpreters in all government offices.” Sow explained that the very same problems exists within FSAPH, the organization representing all people with handicap in the country. “All handicapped people are able to hear, people with physical disabilities, the blind and the albinos, but not we who are deaf. We don’t understand what is said during the meetings as there is no one there to interpret. It feels like they are taking advantage of us, they get the information first and we are ignored. They even consider us to be weak and shy, as we are unable to speak.” “If the UN or other organizations are inviting the handicapped community, we are never informed about it until it’s too late. I believe that the deaf community only can develop if we are separated from FSAPH, we need our own organization.”

Aloiune Guey agreed with Sow, saying that when talking about people with a handicap it almost never concerns the deaf, which can be extremely frustrating. He continued by explaining how difficult it can be to practice one’s religion as there are no interpreters in the mosques. “I go to the mosque and I pray like the rest, but as I can’t hear I don’t know what the imam is talking about. I know how to read, but a lot of the people in our community are unable to read, so you can imagine. There needs to be interpreters in the mosque, we are humans like the others and also want to practice our belief. Communication is key, we don’t understand what is said on the TV, on the news, or in presidential speeches, the only thing we can understand is football, but not politics.”

One of the keywords that came up numerous times during the focus group was the important issue of education, and that education is a powerful tool for liberation. The group explained that it is hard to find deaf individuals who have finished high school. Mamadou Gaye is studying in a class for hearing student. “It is extremely difficult; I have no interpreter and it’s hard to get information from my fellow classmates. The only chance I have is to take notes from my classmates and study the books, that way I might be able to finish high school next year.” Mamadou is heading a newly created organization for young deaf individuals, and he
dreams about going abroad, educate himself and one day return to help the deaf community in Senegal. “For me, the ideal project is one where deaf people are helping the deaf, and that’s why I want to educate myself, education is important for integration, and who knows, maybe one day I can get in to politics.”

“Today there are no deaf schools in Senegal where you can obtain a high school diploma, the level stops at the last year of high school, Deaf people in Senegal are in need of education, we want to reach the same level as our hearing brothers and sisters. Twice I have tried to get a high school diploma but failed, hopefully I will be successful a third time, but if my teacher can’t speak sign language, how can he teach me.”

El Hadj Sy who leads an organization in the region of Kafrine in the interior of the country agrees with the rest and explains that education is key in his district as well. Sy has found work as a welder, and after work he is doing his best to teach people from the deaf community how to read. “There is a clear disproportion as all deaf schools are concentrated in Dakar and not in the regions. Young people are important, it is the future of the nation and one must invest in them.”

The focus group touched on the most crucial questions related to deafness in Senegal and emphasized the importance of education and the lack of interpreters within the judicial and public health systems.

6.4 Sexual and reproductive health

A UN flagship report on development and people living with disabilities states that “Access to health-care services remains a challenge for persons with disabilities, who are more than three times as likely to be unable to get health care when they need it.”

Another report, created by Handicap International and the Centre National Lutte Contre le Sida, (CNLS), dealing with the exposure of HIV on people living with a handicap shows that sensitization within this group is of importance. The seroprevalence, according to the report,

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is higher among people with a handicap, 1.9%, compared to 0.7% for the rest of the population.102

During the focus group the participants were asked if they had been attending sensitization classes on SRH and been informed on the different dangers in regard to sexual diseases. In discussions with the group there seems to have been efforts made in the past to sensitize the deaf community, as one attendant remember how an individual some years back, had received training from an organization, but that he never fulfilled his responsibilities to transfer his knowledge to the rest of the community.

Sambodj explained that he last February in cooperation with JED, helped organize a sensitization class in Rufisque, where some 50 deaf individuals received information on the dangers with HIV and Aids, a topic that briefly will be treated in the analysis.103 In addition, they were offered free HIV screening. Sambodj explained that the plan is to carry out the same sensitization session four times a year in different locations of Senegal. As far as he recalls this was the first time ever that the deaf community had been approached by an organization working with questions related to sexual health. Another expert within the community, with more than 30 years’ experience, revealed that when it comes to SRH it is a new area for the deaf community and that not a single project had been conducted.

El Hadj Sy, explained that he has learnt a bit about SH in school, but only the parts that he could understand himself as there was no interpreter. “I learnt a bit about it in school, but I have never assisted in a sensitization session organized by an organization. For me, we are already dealing with a host of challenges, so it is important for us to learn how to escape others. The deaf community, and I am talking for the youth, are more than open to information on sexual and reproductive health. We need to learn as much as we can on the topic in order to protect ourselves.”

Several of the participants raised the case of a girl in Pekin, a suburb to Dakar, who had died from AIDS as she had no information about the disease. Another participant explained that he some time back had been offered an HIV screening but that he categorically refused as he did not know what it was all about. He explained that as no one had informed him what the test

102 Rapport d’Analyse, Enquete Bio-Comportementale Handicapees Face au VIH au Senegal, 2015: 7 I am aware of the fact that these are small statistical variations, but these are the figures presented by HI and CNLS in Senegal. Statistics on HIV and the disabled community in Senegal didn’t exist back in 2010 as highlighted in an earlier footnote, while the variations are minimal, they communicate that the inclusion of the disabled community have advanced compared to 2010.
103 https://www.youtube.com/watch?v=lhMtUtQLhZTA&t=266s
was about, he did not know the difference between testing and treatment. The refusal was once again an example of the lack of interpreters and misunderstandings that the deaf community is faced with on a daily basis.

On the question on how to best communicate sexual health to the deaf community the participants claimed that the best way was through videos. “The best way is to create adapted videos with a clear message that can explain how HIV and other diseases are developed. Others know about this but not our community, there are brochure but not all deaf are able to understand them. We also need to take part of the information, so that we know about the dangers,” another of the participants explained.

In a discussion with Khadidja on the best way to transfer the message, videos were a good idea, but according to her they are only secondary, a good compliment. “Videos are good, and we need them, but for the videos to be as effective as possible it is important to have an interpreter able to answer the questions that will arise. It is also important to remember that subtitles might not be helpful as most people are unable to read.” She continued by explaining that there has been an NGO at the school, CFAS, that she is heading, teaching the older students about HIV and AIDS, but that she was unable to remember its name.

Questions on GBV, also came up, and one participant mentioned a story from a Senegalese newspaper dealing with an individual who believed that sleeping with a handicapped person could heal HIV. Another discussion treated the issue of deaf women who had been raped, but as they lacked the ability to communicate the rapists were never pursued by the police and the judicial system. “In the case of violence between a deaf and a hearing individual the deaf can never win.”

Apart from sexual diseases and GBV, challenges related to health services were also discussed, especially the reality for pregnant women visiting the hospital for checkups or giving birth. “When I was pregnant it was extremely difficult,” one woman explained, “I went to the hospital with a friend of mine, but as she was deaf, we didn’t understand anything of what the midwife told us. I then returned with a friend who is able to write, and that way I was able to understand.” All women explained that they were accompanied by someone and highlighted the importance for the hospitals to employ people who knows the sign language.
Khadidja added that being a deaf woman can be difficult, “it is very hard being woman and deaf in Senegal, if you are a young girl you stay at home and take care of the house while your brothers and sisters go to school, and you have to keep in mind that the majority of the parents don’t know the sign language. Sometimes people from our community are victims of violence on the streets, some are sexually violated but are unable to report it as they can’t speak.”

“I had tears in my eyes when I listened to a group of women talking about their experiences at the hospital,” a hearing individual working with the deaf community explained. “They feel unliked and looked upon as less intelligent. Their experiences in the hospital are extremely difficult.”

“The obstacle of communication is key for us in order to receive good health services and integrate us in to the society,” said one woman in the group, adding the need for information on HIV and other STDs. “There is even the risk that the doctors provide us with a prescription that we don’t need as we are unable to communicate, so the number one problem for our community is communication.”

6.5 Organizations Working for the Deaf Community

ONG Jeunesse Et Développement

Jeunesse et Développement, JED, is a Senegalese NGO that was created in 1988 and headquartered in Dakar. JED is following the ideas and principles of the scout movement and its aim is to work for sustainable development among the communities, and that way improve the living conditions of its people, especially in the areas of health, education, socioeconomic integration and the environment.105

In 2015, l’Alliance Nationale des Communautés pour la santé, ANCS, received finances from the Global Fund, aimed towards helping 14 organizations working to help people living with disabilities, a project carried out within the framework of SDG 3, “to ensure healthy lives and promote wellbeing for all at all ages.” JED was tasked with the responsibility to execute the project, hence, to sensitize these groups on HIV and Aids as well as sexual violence. One of

104 Interview in Pikin with Khadidiatou Mariane Samba, director of CFAS 12/3/2019
105 https://www.jed.sn
the tools used to make this happen, is based on the community’s participation and capacity building surrounding the field of communication. A special sensitization document consisting of 19 themes, was produced over a period of more than three years. For the deaf community the document was turned in to a video, while for the blind community it was developed in braille. This document will be in focus during the analysis, as will be a video posted on a newly created YouTube channel destined for the deaf community. Ousseynou Ndour, project manager for the project explained that when the project started in 2015 it was the first time that JED had worked specifically with the deaf community, projects had been done before, but not on this level. Ndour also highlighted the importance for the deaf community to be in charge of their own activities and that his role is mainly to supervise while they execute the project. “Without a strategy based on participation we will not be able to reach the full potential of the project; we teach individuals from each community, and their job is to execute.”

6.6 Consultant Francois Manga

Francois Manga is one of the country’s foremost experts on sign language with more than 30 years in the field, and has been seen interpreting for Senegalese presidents such as Macky Sall and Abdolaye Wade. He explained that throughout Senegal there are only three professional individuals that knows how to sign, and that the country got a lot of work to do in order to catch up to the level of its neighboring countries, such as Burkina Faso, Ghana, and Ivory Coast, countries far ahead of Senegal when it comes to deaf education. The Senegalese government lack a clear vision for the deaf community, and that is probably why the UN and other organizations aren’t working with the community. Despite the challenges he has noticed a change within the deaf community, as they are getting more organized their voices are heard.

As a result of his close relationship with the deaf community and his expertise in the sign language, Manga has throughout the years created a number of videos on a range of different topics and was recently involved in the making of ONG JED’s sensitization video. When asked about how he normally produces videos with the deaf community he describes a

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106 Interview with Ousseynou Ndour via Whatsapp 13/5/2019
process based on trust, in a language similar to C4D. “When I plan for a video on a certain topic, I gather a number of people from the deaf community and together we discuss what to produce. Participation among the deaf is important. I work for the deaf and with the deaf, and it’s important to highlight this. Working with the community on such projects leads to empowerment.”

7. Analysis

A comparison between the two communities in Congo and Senegal reveals a set of differences as well as similarities. The two countries are making use of ASL, as a result of Andrew Foster’s work. When it comes to daily challenges, both communities are struggling with the same issues, education, communication during hospital visit, errands in the judiciary system and a lack of sign language interpreters. In neither Congo nor Senegal are deaf students able to obtain a high school diploma enabling further studies at the university. Reliable statistics revealing the size of the deaf community are not up to date, the census in Congo dates back to 2007, while the Senegalese goes back to 2013. Without information on the size and composition of the deaf community it is extremely hard to set up objectives and work towards goals. SGBV is another problem that the two countries have in common.

Another common denominator relates to the period when the humanitarian sector began to work on projects related to the community. ONG JED together with other civil society organizations began to work with the community back in 2015. UNFPA Congo carried out their first project in 2016 and has since then been helping IJSB sensitizing students on SRH and SGBV.

Maternal health is another critical area, with no sign language interpreters available to help pregnant women visiting a midwife or a doctor. The deaf community witnessed of this challenge and explained how deaf women often has to bring a friend or communicate on a piece of paper while visiting hospitals. This is undermining their human rights.

The most fundamental lessons about life are taught in the family, but if parents are unable to communicate with their children, they miss out not only on institutional education, but on the most basic education. In Senegal AMCRE are helping parents to learn how to sign so that they can communicate with their children, in Congo parental groups are trying to assist the parents.
One major difference comes down to the organization of the deaf community in both countries. The Senegalese community is far ahead of the one in Congo. Organization is key, the deaf community might never have worked with the UN before, but who is to blame for this, the UN, the government or the deaf community? It is important to mention that UN’s role is to support the government of its host country, and if the government in the country aren’t actively working with the deaf community there is a risk that they will be left behind. All three actors therefore got a responsibility to play in the equation, and an important step to further inclusion lies within the way the deaf community is organized. “The process of attitude change starts with disabled people: their attitude towards themselves and their own disability. The harsh reality is that if disabled people see themselves as victims they will be treated as victims, or as Rachel Hurst from Disabled People’s International said: “Social change initially comes from us, from disabled people. It has to.” While much work remains to be done, the deaf community in Senegal is on the rise, and it won’t take long before it will start to improve. The work of Sambodj who helped start the first organization for the deaf community in the 90s is starting to bear fruit, as the community seems to have understood the power of organization. Add to this, the stable political and financial situation in the country.

The deaf community in Congo on the other hand is less organized, and not yet on the same level as Senegal. This can be explained by the 1997 civil war and the political situation in the country since then. The organization of the deaf community thus reflects its country’s political and financial situation.

Another difference is found in the way several members of the deaf community wanted to valorize the local Senegalese sign language, another proof of development. While ASL is popular in Senegal, there are voices fighting for the codification and upgrade of the leading local sign language to national language status. It could hence be argued that ASL is viewed upon as a form of linguistic imperialism, as it was transferred from the north to the south. In Congo on the other hand, no such discussions could be heard today, but during the 90’s, as we have seen, a project aimed to valorize the Congolese sign language were in place but interrupted by the war.

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In all, the basic needs for the deaf community in Congo and Senegal are very similar, but as a result of the political and financial situation the Senegalese community is ahead of the Congolese one. Congo’s deaf community got much to learn from the one in Senegal, even though it appears to be less developed compared to Ivory Coast and Burkina Faso. The humanitarian sector in Congo can learn from their counterpart in Senegal, and in a similar way develop a sensitization instrument benefitting the whole disabled community.

Normally when UNFPA are sensitizing at a school, one of its partner organizations from the civil society are doing the work. In those cases, the element of participation is clearer, these teams often consist of young individuals who have been trained in the area, and participated in the production of key messages etc. This time, as UNFPA Congo have never worked with the deaf sector, and the process looked different. UNFPA began by establishing contact with the school in order to develop a process. The first phase consisted of discussing the project with the director, explain the project and develop trust, etc. The second step consisted of meeting with the teachers, as well as the parents of the students to find out more about their situation. Questions related to sexuality is taboo in Congo, and it’s rare that such questions are discussed between parents and children, in addition, not many parents are able to speak sign language. It was therefore important to first of all have a good dialogue with their parents and teachers. Thereafter a consultant was hired, a specialist in sexual and reproductive health. It is important to note that the consultant does not speak sign language and that he lacks experience from work with the deaf community. With the help of sign interpreters’ sessions on everything from STD’s, puberty, menstrual cycles and what to do in the case of sexual violation could begin. Each theme was followed by a discussion where the students had the opportunity to ask questions, participate in exercises and with the help of a sign interpreter, one of their teachers, the message was transferred.

UNFPA Congo’s work with the deaf community must be seen as a first step on a longer journey, as it’s a new experience for both UNFPA Congo and as IJSB. Development must be seen as a process, and the long-term goal is to eventually make people from the deaf community able to sensitize the deaf community themselves throughout the country. As it’s a first step, and deals with sensitization session at a school, it is difficult to talk about participation in the same way as if one were dealing with a civil society organization. Nevertheless, participation has played an important role in the organization and planning of
the sessions at IJSB. Many of the teachers and instructors are deaf and sit on valuable information, and as a result they were involved in order to understand the challenges ahead.

For UNFPA Congo, participation is important, as no one can define a challenge better than the individual living with it. That is why discussions were carried out with IJSB and its teachers, as well as a number of students, already at an early stage. It was further emphasized that UNFPA’s role was more of a facilitator in charge of administration and finances, while the community itself were responsible for the creation of messages and the execution of the activities.

However, one cannot avoid the reality on the ground, and the various roadblocks hindering what Freire called genuine participation. After all, UNFPA Congo as so many other actors from the humanitarian sector are faced with numerous administrative hurdles that automatically is reducing the level of participation. Tufte and Mafalopulos explain that the agenda of projects and programs is often set by a few individuals with very little input from other stakeholders. Rigid management procedures and tight deadlines for planning and funding required for approving and implementing projects allows little flexibility needed for participatory processes. As a result, UNFPA Congo’s cooperation with IJSB can clearly not be considered genuine participation as described by Freire. It is true that UNFPA Congo searched out the deaf community and in many ways managed to put the community on the map, but it cannot be denied that the whole process was carried out under what Tufte and Mafalopulos refer to as institutional participation, where pre-established goals are defined by external/upper forces. In fact, the administrative hurdles were mentioned as an obstacle for increased participation by a number of humanitarian workers related to UNFPA.

While the leadership of IJSB were involved in the planning and execution of the project, it was still carried out under a preset plan. This project was different from one carried out by the civil society organization, as it dealt with teenagers at a school and not the deaf community of a civil society organization. Considering this fact, UNFPA did a good job as they included both parents and teachers already at an early stage. It was further a bit of a pilot project which in the long run will lead to a more concrete plan.

109 Ibid: 4
Participation is a moving target, and what is participation in country X is not participation in country Y. The development of the democratic system and level of transparency, as well as the cultural setting plays an important part in the level of participation, therefore participation is not a one size fits all universal concept. In regard to the sessions, the consultant made sure that all participants had a chance to participate in the different exercises, as well as the discussions, and they were all given the opportunity to ask questions. Questions dealing with sexuality can be a sensitive area for students all around the world, and so also for the deaf students in Congo.

In addition, UNFPA Congo got a number of videos on their website pertaining to the deaf community and the work carried out since its first project in 2016. These videos can also be said to fall under the umbrella of participation, as the students are participating in form of interviews. While UNFPA’s project with IJSB is laudable, one particular video is less impressive. First of all, it can be said to fall within the persuasion in the diffusion model rather than information exchange, exactly what Freire says that C4D should not be about. It is shot at IJSB and are showing a number of deaf students delivering various messages of promotion, such as “we are the future of tomorrow,” and “leave no one behind, because everyone counts,” well established slogans used by UNFPA.

It was posted on February 2, 2019, and is called, “Hope of inclusion – Leave no one behind.” It’s a video of 4:14 minutes which shows UNFPA’s activities and work with the most vulnerable population in the country.110 While the video is first and foremost talking about the deaf community, projects carried out with blind and albinos can also be seen. The video starts by a group of young deaf women signing, they are talking about the importance of taking care of pregnant women. The second appearance consists of a videoclip where a teacher from IJSB, explains that UNFPA Congo are teaching the students about sexual and reproductive health in order to protect them from disease and teenage pregnancies. The third scene is showing deaf students being engaged in what seems to be a workshop. On one occasion a young girl, from IJSB, is being interviewed. She is signing and is being simultaneously interpreted; “We the students of IJSB have taken a resolution to abstain from all sexual relations before marriage,” she explains. Later in the clip, the video is showing another student, who in front of IJSB is giving his interpretation of UNFPA’s flagship slogan, “leave

110https://congo.unfpa.org/sites/default/files/Compile%20vidéos%20de%EF%80%A0Ne%20laisser%20personne%20de%20côté%EF%80%A0%20-%20SMedia.mp4
no one behind;” “For me its means that all are given a chance to develop themselves.”
Whereafter another student explains that for her, “leave no one behind means that no one is rejected.”

The objective with the clip is clear, to show that UNFPA Congo is taking care of the most vulnerable, the deaf community in particular, and most viewers will get the message. Unfortunately, some of the scenes makes the participants appear as bystanders, as controlled objects, and as if they are speaking with someone else’s voice. A top down impression is transferred to the viewers. This feeling is much due to the music, which creates an atmosphere with emotions of sadness and victimization. One can even argue that the music brings the clip towards what Scott called pornography of poverty or what has been referred to as shock effect. The message that should be transferred is one of empowerment and inclusion, but in its current form it could be contra productive to its cause.

The interview where a girl is being simultaneously translated would have been more powerful if her message had been delivered with the help of captions. The way it now comes across is as she is represented as someone who is helpless, dependent and in need of an audible voice in order to get her message across. Had she herself been filmed without interpretation and with the help of a simple caption, she would have appeared as a young independent girl with her own voice. Arjun Appadurai states that one of the poor’s gravest lack is the lack of resources with which to give voice, and that the voice plays a crucial role in the development game. It has further been claimed that the developing world suffers from “voice poverty,” i.e. the inability of people to influence the decision-making process. The objective with communication for development should be one where the whole process of voice and value is considered. It was therefore a good idea to create a clip, nevertheless, it should have been created in order to boost the dignity of the girls.

With all this said, UNFPA Congo’s project with the deaf community is proof of their awareness of the situation as well as their willingness to help the community. A first step has been made, UNFPA Congo has opened up the door with its projects and media coverage. In this way the office is ahead of other actors in the region. What needs to be done in order to
Further advance is to follow in the steps of what the civil society organizations have done in Senegal. I.e. to produce communication support that can be used in order to further sensitize the community, and here, participation will play a crucial role.

In the future while creating videos and in order to send a more positive message to the audience, participatory video could be of interest. That way the students will feel secure and will be able to express themselves freely without fear or nervousness.

In the case of Senegal, a number of civil society organizations got together and during a period of more than three years, worked on a product which is more bottom up compared to the activities done in Congo. The work of ONG JED is more in line with what Tufte and Mefalolopolus refer to as a social movement perspective of participation. Their project is one that has taken time but which in the long run will assist the deaf community as well as empower it and look after their rights.

The tool consists of 19 different themes and deals mostly with issues related to sexual health. Each theme is illustrated by drawings created by the well-known Senegalese caricaturist, Oumar Diakité, and each of them is made up of technical explanations. All major handicaps are included in the drawings. The tool is first and foremost created for educators, and the plan is that each community will train a number of educators that will be able to travel throughout Senegal in order to teach their respective community in sensitization sessions. The guide comes with clear instructions, in seven steps.

In order to cater to the deaf community, the whole material have been transformed into videos. The fact that videos were created, confirms the lessons learnt during the focus group. Each of the 19 videos starts with a black text on a white background and logos explaining who has been involved in the production.

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114 1. Greet the participants, offer a brief introduction, individual presentation and break the ice exercises. 2. Introduce the first theme, 3. Show the image and start a discussion around it. 4. Continue the discussion based on the right answers given by the group. 5. Summarize the session and the key messages. 6. Evaluate the session and make sure that it has been understood. 7. Close the session and thanks. A number of websites to organizations working with sexual health are also included in the document and can be shared with the participants.

115 l’ANCS, Humanité et Inclusion, Handicap Form Educ, l’ONG JED, les OPH, CNLS.
The video is simple, with the interpreter standing on the right-hand side of the screen, dressed in a blue shirt in front of a white background. This leaves room for a text on the left side of the screen. Each time a text appears it is accompanied by a voice, and thereafter the interpreter is signing what has just been said. This is followed by a presentation of the theme with a white text on a red background. Part two of each video shows the same drawing as in the paper document. The video continues by giving relevant information of each theme with text, voice and an interpretation by the sign interpreter.

The objective with the document is to make sure that before 2020; 90% of the individuals living with a handicap will know if they have been affected by HIV or not. 90% of the individuals that tested positive, will receive a form of treatment. 90% of the people receiving a treatment will maintain the treatment. The document comes with a slogan; 90, 90, 90. Treat, Test and Maintain. Together let’s mobilize to achieve objective 2020.\textsuperscript{116}

In order to produce the videos, ONG JED made use of Francois Manga, consultant and expert in sign language. In discussions with Manga surrounding the production, he explained a process falling within the norms of communication for development. For Manga, gaining trust from the community is key as well as to include them from an early stage.

In addition to the videos, a YouTube channel, SOURD SN TV, was recently been created. The plan is to upload the 19 videos discussed above, and that way, making it possible for the community to take part of the information 24/7. Some videos are filmed by individuals from the deaf community, an example of participatory video. Making use of YouTube is an example of how ICT can help the participatory process for the deaf community. On the channel one is able to find a video from March, showing JED’s first sensitization event on HIV and AIDS with the deaf community. The video of about eight minutes and shows how the deaf community is being sensitized on HIV and AIDS. The whole video gives the impression that the deaf community is in charge of the process and it is all filmed by a mobile phone.\textsuperscript{117}

\textsuperscript{116} The videos have not yet been introduced to the public, and the participating partner met for a validation workshop from May 20 and 21. The tool has now been validated and will soon be introduced to the public.

\textsuperscript{117} https://www.youtube.com/watch?v=ItMtuQLhZTA
In regard to the first document explained above, it is a work that has taken time to develop. It is also a work where a lot of different actors has been involved. It could be argued that in order to further empower the deaf community, a deaf individual should have been the one to offer the explanations in the video. Normally Manga makes use of deaf individuals in his videos. Talking to the community, Manga is well respected and trusted as a result of his commitment and long experience and is therefore considered an integral part of the community. It is a good production which in reality only is secondary, it is the discussions within the deaf community and their participation in the process of learning which counts. What Freire refers to as conscientizacao,’ or conscientization, a dialogical communication process where reflection and action starts and where they are “naming the world.”

The political stability in the country has also helped the process. In Senegal, one has been able to work in peace and without fear. This has been done in cooperation with a number of civil society organizations as well as the different representatives from the disabled community. Add to this a rather well-organized deaf community. In Congo on the other hand, internet has been cut twice for several weeks since 2015, a referendum on the constitution as well as a presidential election caused instability and affected the lives of the whole nation, including the humanitarian sector. This proves that a politically conducive environment allowing open and transparent discussion is beneficial for participation, as stated by Tufte and Mefalopulos.

8. Conclusion

As stated in the introduction; Researching the deaf community in the developing world is like studying a micro cosmos of the entire development debate. As we have seen, everything from discrimination, inequalities, representation, voice, injustice, colonialism, linguistic imperialism, pan-Africanism as well as participation, to mention but a few of the topics, were present. The title of the thesis was taken from a well-known slogan used by a range of humanitarian sector organizations; Leave no one behind. It is important to remember that slogans are understood differently deepening of where they are used. A slogan in Congo is not understood in the same way as in Senegal or Sweden, and just like participation they are dependent of the openness and transparency of the society. The thesis further focused on a

group, the deaf community, which according to themselves have been, in a sense, left behind. Through a number of examples, we saw that the HIV seroprevalence were on pair or slightly higher, compared to the general population in Cameroon, Kenya and Senegal. In Cameroon, deaf individuals are three times more likely to contract an STI. There was further a lack of information on STD’s, including HIV, as well as SGBV, in the deaf community as shown in studies from South Africa and Brazil. In addition, numerous UN reports confirms the vulnerability of disabled groups. The next step was to find out what the humanitarian sector is doing to include this population. An effort was made to reach out to 13 leading humanitarian organizations in order to get an idea of their work to help this population, answers were received from three of these, with only one able to show proof of projects catering to the deaf community in areas which can be qualified as SRH. While there are a number of smaller NGOs working for the deaf community, such organizations are not at the moment, active on a larger scale in Senegal and Congo, except for smaller faith-based projects led by churches, these are not active within the field of SRH. The deaf community have historically been looked after by Christian organizations, sometimes these organizations have cared for this community out of charity and pity, and human rights have not been in the driver’s seat. Another remark has to do with the differences of deaf education when it comes to former English and French colonies. As we have seen above, the French were not as concerned with the deaf community as the English, and today several individuals claimed that the situation for their communities is much better in English speaking Africa compared to the French speaking parts.

Two players from the humanitarian sector were identified and analyzed, as were their work with the deaf community and SRH and SGBV. They were analyzed within the framework of communication for development and more specifically, participatory communication. In the case of UNFPA Congo, traces of project based and institutional participation were found. As their work were limited to one school it was hard to drill down in to the nitty gritty of the participation process, but participation was definitely part of the sessions where the students were eager to participate and ask questions which eventually enlightened them. Participation could also be seen in one of their films posted on their website, where unfortunately the production of something that could have empowered the community instead woke feelings of poverty porn and shock effects.
In the example from Senegal, ONG JED and their partners provided a good example of participation from a range of different civil society organizations including representatives from each disabled organization in Senegal. A document, which can be classified as a communication for social change or a behavior change communication tool, dealing with sexual health consisting of 19 themes or lessons were analyzed, especially a video which had been developed for the deaf community in sign language. This was an example of a project which looked more like a social movement perspective of participation. ONG JED has also created a YouTube channel for the deaf community where the 19 videos eventually will be posted, an example of ICT helping the deaf community. Again, with the help of this tool and with the training of educators, the deaf community will be able to engage in dialogical communication and that way create awareness about SRH. Hopefully ONG JED’s document will be well received by the humanitarian sector and create a ripple effect that reaches the UN offices in Senegal and beyond, and that can lead to the development of additional sensitization videos that can help the deaf community. Finally, an underlying desire was to study the work in Senegal and with the help of found experiences transfer the knowledge to the work that has begun in Congo. Before developing their own sensitization videos, the ones already created by ONG JED and its partners could be used in Congo. A range of more uplifting videos empowering and securing the dignity of the deaf community in Congo should be created, and the Senegalese example of making use of ICTs in the form of YouTube is also recommended. A long-term plan could be to use these videos, and create additional ones on other topics and eventually integrate them in to a mobile app.

In a concluding remark, it would be interesting to know why some humanitarian practitioners are making use of “the voice for the voiceless discourse,” a slogan often seen on social media channels, if they believe that there exist a people without a voice, haven’t yet done more for the deaf community? With that said, it is important to understand that all human beings got a voice, it doesn’t matter how poor you are or if you are a member of the deaf community. The problem is not the voice, but the process or the channel that can transform the voice to a value. Or as Freire would say; “Any attempt to unify the peasants based on activist methods which rely on "slogans," and do not deal with these fundamental aspects produces a mere juxtaposition of individuals, giving a purely mechanistic character to their action.”

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