Addressing the Needs of People with Disability During the COVID-19 Pandemic

Akosua K. Darkwah speaks with Comfort Mussa, founder of SisterSpeak

The World Health Organization estimates that 15% of the world's population has a disability of one form or the other (WHO, 2021). With a population of approximately 1,390,000,000 people on the African continent (Worldometer, n.d.), this translates to 220,000,000 or roughly the entire population of Nigeria, Africa's most populous nation. Life for Africa's citizens with disability is not easy. Their needs are rarely taken into consideration in the organisation of everyday life on the continent; buildings are not wheelchair accessible, sign language interpretation is missing in health and educational facilities, as is the provision of Braille services in many institutions. As the COVID-19 pandemic ravaged the continent, governments and civil society organisations rallied to provide support of different kinds to large segments of the population. For the most part, however, these service providers did not make any effort to reach out to the population with disability; they were simply forgotten. In Cameroon, though, SisterSpeak is one organisation that has consistently championed the cause of persons with disability. In this conversation, Akosua K. Darkwah speaks with the founder about her motivations for starting the organisation and the nature of their work during the pandemic.

The conversation has been edited for length and clarity.

Akosua K. Darkwah: Let's start with a bit about yourself.

Comfort Mussa: I am Comfort Mussa. I am Cameroonian and I live and work in the capital city, Yaoundé, as a journalist. I report extensively on social justice issues. As a journalist, my niche over the last 13 to 14 years has been to explore social injustice and tell such stories because this is missing in mainstream Cameroonian media. So, I started SisterSpeak as a platform for people to tell their stories. Then, over time, I discovered that not too many people had the skills to organise and tell their stories, so progressively it grew into a local organisation legally registered in Cameroon to train people to tell their stories and, beyond that, to engage in community activities to address the challenges described in the stories. We have grown so much that I've launched a TV show, Spotlight, which also focuses on telling untold stories and amplifying minority voices.

Akosua K. Darkwah Okay, so let's go back to your community activities to address the issues that you describe in your stories. When did you start that?

Comfort Mussa: The social work aspect of my work really started with SisterSpeak because you would tell stories about, say, women who have been raped and when you went back to the community, they would say, "Now I'm afraid, I don't have a place to go to." Knowing that the reports amplify the problem but do not address them, I wanted to do something more. The women pushed me to want to do more than just tell the stories.

Akosua K. Darkwah: Do you have another group of people working with you on the social work side of it or you do that on your own?

Comfort Mussa: It's a full organisation with a team. We've been working together since 2015. In 2014 it was a blog, a website for stories and events. Now, it's an organisation: we have teams, and we have people working on the various projects. We have the disability needs coordinator who focuses on activities for women with disabilities and so on. We also have several volunteers who come in from time to time to work on different projects.

Akosua K. Darkwah: Okay. Do you then look for funding to run it?

Comfort Mussa: Yes.

Akosua K. Darkwah: What prompted the TV show?

Comfort Mussa: We wanted to have the farthest outreach that we can have. There is a lot that is happening, but you cannot find powerful voices speaking to these issues in Cameroon. The first topic we addressed on the show was backstreet abortions. If you Google it, there is very little information because it is not a comfortable subject. It is a taboo, so to speak. Yet, many women are dying. I spoke with the Society of Gynaecologists in Cameroon. They told me that six out of ten maternal deaths are the result of unsafe abortions. And I've spoken with doctors who tell me numbers that will just blow your mind. Doctors see it in the hospital every day, but if you go online, it is not an issue in the sense that you will not have people speaking about this issue. The spotlight is designed to bring attention to the issues that are important. So for example, in the month of March 2021, we dedicated three episodes of the programme to talking about unsafe abortions. People are not comfortable with it, but if women are dying and having severe complications, then somebody has to talk about it. This is what Spotlight is about. It looks at the issues that are critical, but are not discussed in mainstream media, and brings the spotlight to it. The response has been great. Editors are asking, "Is this really happening? I didn't know about that, what can we do about it?" And this is what we want to do with Spotlight, make people aware of issues and get people engaged to address the issues. Others are working to address these issues and we want to celebrate these people also. That is the spirit behind Spotlight and that is what we seek to achieve.

Akosua K. Darkwah: How often do you run it?

Comfort Mussa: Once a week, every Sunday for now. It's online. And what we do is that we share our content with local media houses that do not have the resources to produce such a programme. We make sure we produce it professionally and then offer it to these stations to re-publish on their platforms for free. We are also aware that not every Cameroonian may have data to stay on to watch the show online for an hour. So, after the show, we create three-minute extracts of the key bits of the programme which we share with our networks on WhatsApp.

Akosua K. Darkwah: Are you inviting other journalists to come in and share their stories about the marginalised?

Comfort Mussa: Yes, we try to be very inclusive and diverse, we want as many voices as possible. So the hosts for the conversations and the panels are part of our organisation, but the guests come from outside the organisation. And we partner with a German-Cameroonian TV station that has the equipment needed to do very professional work. I have known this team for a while. I had a TV show from two or three years ago. It was very expensive to work on. The vision was the same: to tell hidden stories. My co-host was a woman with disability, an amazing journalist. We were funding it out of pocket. So, after the first two or three episodes, it was difficult to keep going. Advertisers are often not interested in stories or programmes about disability or taboo subjects. Advertisers will tell you that it's not sexy. It got too expensive to run on our own so that's how I reached out to that TV station. Luckily enough, they had watched previous programmes, knew our work and bought the idea to work with us.

Akosua K. Darkwah: Where does your interest in disability come from? How did that start?

Comfort Mussa: In 2014, my father had a stroke, a very intense one. And it affected his mobility. My dad led a normal life, he could walk, he could drive on his own. And then one day he had a stroke and his life turned around completely. Seeing him with a disability made me much more aware of the ways in which our cities are disability-unfriendly. In my city, he would find it difficult to get into many banks because of how inaccessible they were. Most public structures were not built with people with disability in mind. So, I wanted to do more, not just for my father, but for other people who were experiencing the same difficulties. I learnt from my father that his grandmother, my great-grandmother, was also a woman with disabilities who had to go through life with little support for her disability. I wished I could go back in time and give her a wheelchair, but I cannot, so I want to do that for other women. When I provide support for other women, I feel that I'm doing it for my great-grandmother.

I started reporting extensively on disability issues because I spent a lot of time in the hospital when my dad was admitted. I was exposed to a whole range of issues that people with disability faced: people with visual impairments unable to write final exams because a Braille version had not been prepared; women with hearing impairments unable to report their rapes because nobody at the police station understands sign language, and so on. This became a priority for me, I started reporting on disability. I also volunteered at a local organisation focused on disability issues because I wanted to do more, not just for my family but for other people who had difficulty accessing spaces in the city. So, that's how my advocacy for disability started.

The first thing we did when we started SisterSpeak was to launch The National Essay and Story Writing competition, and one of the categories was disability because, in the media, very few people were reporting on that and, while I could write the stories, I did not want to be a lone ranger, the only person writing about disability. So this story writing competition with the subcategory on disability was to get people to write stories about social inclusion with a focus on disability. We gave cash prizes to the winners, and they also had the opportunity to intern with some partner disability organisations. That was a beautiful way to get more people interested in the issue of disability and exposed to the real-life challenges of people with disability. What is more beautiful is that young journalists with disability joined the contest and one won first prize. This became national news. More importantly, a lot more people began to report on disability and today the story is not what it was five to six years ago.

Akosua K. Darkwah: What kinds of things have changed?

Comfort Mussa: There is more reporting on disability. Many people may not get the terminologies right, but they can learn and grow. It is a good thing to know that more people are showing an interest in writing about disability and that more people are mainstreaming disability in their organisations.

Akosua K. Darkwah: You did mention that when you first started your TV show, you were hosting it with a woman with disability. Can you tell us a little bit about her?

Comfort Mussa: She is a journalist as well, a very fine Cameroonian journalist, Hilda Bih, who works for the national radio station. When we started the programme, we wanted to focus on inclusion. Typically, women with disability do not feature on television. We wanted to challenge this stereotype. Hilda is an intelligent and fully capable journalist. In co-hosting the show with her, we wanted to redefine what representation should be on television. It is a pity that cost prevented us from keeping it running.

Akosua K. Darkwah: Is she part of the new version airing online?

Comfort Mussa: Unfortunately, no. Hilda no longer lives in Cameroon.

Akosua K. Darkwah: So now that we have heard about your general work as SisterSpeak, we can move on to your COVID-19 work specifically. Did you focus on women with disability from the very beginning?

Comfort Mussa: Yes, inclusion is a key part of our work. One person on our team at SisterSpeak is herself a woman with disability and her job in the organisation is to ensure that we focus on inclusion in everything we do. If we organise a workshop, we include female journalists with disability, we ensure that the space in which the workshop is organised is accessible, that the material is accessible and so on. We organised the first ever fashion show that had people with all types of disabilities in Cameroon. We wanted to change what representation means, we want to see women with disability on billboards, on TV. We want to see them in our local communities, we want to see them on national platforms. We are constantly thinking about people with disability. If I go to a bank and it is not accessible, I will tell the managers about the need to fix that. For me, working on disability is not simply a funded project, it is how I function, and members of my team think that way too.

So, when COVID-19 started, my team had a meeting to discuss how we could ensure that the needs of women with disability were met during this period. At first, we mostly talked to journalists, encouraging them, in their reportage, to think about the voices that are missing and to include them in their programmes. We also went into our communities to understand the needs of women with different disabilities because the needs of the women with visual impairments will be different from those with mobility challenges. When we did the first COVID-19 outreach, a sister-friend from Ghana donated hand sanitisers and we brought masks as well as detergents and donated these items to them. We learnt from them and when we came back to the office, we looked at the different issues raised and decided to act in our own small way to ensure a gender- and disability-inclusive approach to COVID-19 programming. Many of the care packages being donated did not reach women with disability; those with hearing impairments could not hear the announcements for the packages, those with mobility challenges were not in the markets or public squares when the goods were distributed, and so on. We therefore donated care packs to women with disability in particular. We also distributed a document in Braille, that explained what COVID was and how it could be prevented, to over a 1,000 visually impaired people in certain regions of Cameroon. We also pointed out the inadequacies of different approaches to handling the pandemic. For example, many of the hand-washing points are not accessible to people in wheelchairs. Without an SMS option, those with hearing impairments with COVID-19 symptoms cannot access the information provided by the health service. Similarly, how is a person with visual impairment supposed to interpret the social distancing rule of one metre apart? Eventually, we developed a toolkit in English and French to explain what the problem is, how persons with disabilities were being excluded and how they could be included in programming. The tool kit is available on our website for free download (www.sisterspeak237.com).

We also did what we call "a feast of senses" to engage people to understand why inclusion in the COVID-19 response is important. The truth is, if you have not lived with a person with disability or do not have a disability yourself, you have no idea what their needs really are. It is hard to know the needs and to mainstream them. So we did a feast of senses, an idea we got from Access Israel and adapted to our local context. A feast of senses is basically a dinner party, where our guests (people from civil society, NGOs, the diplomatic corps) were invited to a three-course dinner. At each course, we made them lose one sense. For the first course, for example, they had it blindfolded and then we asked them, what does it mean to eat without seeing what you are eating? They understood everything we had been preaching about for years in five minutes. Their perceptions changed, and the testimonies of change were really powerful. So we encouraged the grant officers in our midst to include persons with disability on their checklist for accessing grant applications. If grant officers make it a requirement when giving grants, organisations will be compelled to do it. It worked, because a good number of them included this requirement and shared the feedback with us.

Akosua K. Darkwah: I was struck by your point about the one-metre distance. What kinds of solutions have people come up with to convey that to people with visual impairments?

Comfort Mussa: So the solution actually came from a friend who has a visual disability himself. I asked him how to communicate the one-metre distance. So, he stretched both hands out and it suddenly clicked. If you stretch both hands out and can't touch anybody to the left and to the right or in front of/behind you, then you know that the one-metre rule has been obeyed. Another solution is to actually measure the distance and arrange the chairs in a meeting setup such that they are already distanced.

Akosua K. Darkwah: What other kinds of things have you encouraged in your toolkit?

Comfort Mussa: We have encouraged churches and governments to include persons with disabilities on their response planning committees. If they are not included at the level where organisations are planning a response, chances are that they will be excluded. Our toolkit is gender- and disability-inclusive. When we had the lockdown and people flying into Cameroon were quarantined straight from the airport, I had a female friend who was quarantined for 28 days, not the usual 14. And during this time, she complained about the lack of water and sanitary pads. Clearly, those who planned the quarantine probably didn't think that women would need pads. If you're not a woman, it is hard to think periods when you're thinking about quarantining. However, if the planning committees were diverse and inclusive of persons with disability, women, people from indigenous communities, they could all then share their needs and ensure that these needs were addressed in the execution of any programme. There is also the need for evaluation. As at March 2021, Cameroon is experiencing a new wave which is more severe than the first one. And this week I was asking myself, "What are we doing differently? Did we evaluate what we did during the first wave? Can we improve?" Copying recommendations posted online from other contexts is not enough. We have to evaluate what works and does not work in our communities. So, in terms of tips, include a diverse group in planning, evaluate what you have done, and improve on it. COVID-19 is not going to be over for anybody until it is over for everybody, so we need to think about including everybody in our response.

Akosua K. Darkwah: Indeed. What would you say has been the impact of the work that you have done?

Comfort Mussa: Our major impact has been creating awareness. For me, that's powerful because we acknowledge the fact that our organisation is smal, and there are other bigger organisations in Cameroon that are working hard to promote the rights of women as well as persons with disability. While we do not have the resources to do a national outreach, in getting people to make small changes in their little corners, we will ultimately have a big change. Also, the number of people that have downloaded our toolkits is encouraging, as is the number of newspapers that now report on inclusion. Even the fact of this conversation with FA suggests that we have had some impact worth recognising.

Akosua K. Darkwah: Given your current successes, what are your plans for the future?

Comfort Mussa: Our plan with SisterSpeak is to keep disrupting and challenging the status quo. In the future, we want to have a community centre for women with disability. We have a programme to train and help women with disabilities get jobs. We have done it once and want to do a second phase of the programme. Ultimately, we want to offer the training on a more regular basis, not just once in a year. We also would like to have our own media resource centre in the future.

Akosua K. Darkwah: We at FA wish you well in your efforts to improve the life chances of women with disability in Cameroon.

References

World Health Organization. 2021. *Disability and Health*. Available at https://www.who.int/news-room/fact-sheets/detail/disability-and-health.

Worldometer. No Date. *Africa Population (Live)*. https://www.worldometers.info/world-population/africa-population/.