

"No one is listening." Experiences of women with disabilities during Covid-19 in Nigeria

This paper is based on consultations that took place during 16 focus group discussions and 10 individual interviews that were conducted with women with disabilities in two Nigerian states (Lagos and Kano) in June 2021. A diverse group of women with disabilities were involved. The participants had different impairments, came from a variety of age groups and lived in peri-urban and urban areas. Mothers of children with disabilities also took part in the consultations. At the time of writing restrictions had been lifted in Nigeria, although concerns about rising cases of COVID-19 still exist.

In West Africa, the incidence of COVID-19 has been low (to April 2021) when compared to many other world regions¹. However the pandemic, and the subsequent response, has had far-reaching consequences on the health, wellbeing, education and economic situation of individuals and communities, interrupting the livelihoods of many populations globally including those in West Africa².

The full extent of the COVID-19 pandemic is yet to be fully understood. However, it is clear that the health, social and economic impacts have not been equitably distributed and that the negative effects will compound in the long-term. The disproportionate consequences and increased inequalities for people with disabilities are stark and have been widely recognised. It is critical that lessons are learnt from the exclusion of women with disabilities and that more inclusive emergency and long-term responses are developed.

¹ Tackling Coronavirus (COVID-19), contributing to a global effort. COVID-19 in Africa: regional socio-economic implications and policy priorities, OECD 2020, Accessed 31 August 2021

² Saalim K, Sakyi KS, Fatema-Tuz-Zohra, Morrison E, Owusu P, Dalglish SL, et al. (2021) <u>Reported health and social consequences of the COVID-19 pandemic on vulnerable populations and implemented solutions in six West African countries: A media content analysis.</u>

This paper intends to provide a better understanding of the experiences of a diverse group of women during the COVID-19 crisis in Nigeria and provide recommendations that will be relevant for the ongoing response and recovery efforts and promote the inclusion of women with disabilities. It also shares recommendations that are applicable far beyond the COVID-19 crisis. The experiences of the women involved in the consultations were in many cases not unique to the context of COVID-19 but rather an amplification of existing experiences resulting from historical and systemic marginalisation and are likely to be experienced in other crises, such the climate crisis.

This paper shows how women with disabilities in Nigeria face challenges meeting their basic needs during the pandemic. These needs include buying enough food for their families, keeping an economic activity, managing an increased burden of unpaid care and accessing support and services during the pandemic.

Lessons must be learnt from this pandemic so that future responses apply an intersectional approach to identify the most marginalised people and consider how multiple and intersecting forms of discrimination lead to increased exclusion. This is essential to effectively remove barriers to services and to end all forms of discrimination for people with disabilities. Political and policy responses must ensure that the human rights, perspectives and leadership of women and girls with disabilities are included in all COVID-19 response and recovery efforts and beyond.

The experiences of women with disabilities during the COVID-19 pandemic

Poverty and economic impacts

Participants consistently stated the lack of food was the main challenge they experienced during the COVID-19 pandemic. Many women cut down their food intake to one or two meals a day or prioritised feeding their children first. Some women explained that they and their children had tried to beg for food and money, which they felt ashamed about. However, they found that other community members either did not have enough themselves to share or weren't leaving the house owing to COVID-19 restrictions, so as a consequence there was little food or money available. Some participants felt that men had more opportunities to find food outside of the home as they were more likely to go out, but this was not always brought back to share with the family. The lack of food was driven by decreases in income, rising prices and the fact that

many families did not have enough money to buy food in advance which became essential when leaving the house was restricted. One woman explained that they were reliant on leftovers from neighbours, "We had to eat the burnt part underneath the pot that the neighbour gave us. The day we got the burnt part underneath the pot of rice, the joy on my children's faces knew no bounds and it broke my heart." Despite lockdowns easing, food prices have continued to rise.

Beyond food, increased levels of poverty and financial insecurity were evident. One participant explained that some women had taken up sex work. Other women had sold valuable possessions or lost their homes due to not paying rent.

Borrowing money was consistently raised as a coping strategy and there were often concerns about people's ability to pay back the money due to the ongoing uncertainty and their reduced ability to "bounce back" from the pandemic. One woman described having to sell her home and land for less than it was worth to repay debt.

Health

Some women highlighted that they knew people who had contracted COVID-19 and become extremely ill or died. However, most concerns around health focused on broader issues and how it became more challenging to access routine health services during the pandemic. Financial barriers made up a significant proportion of the women's worries about accessing health care. Some participants explained that due to a lack of money, they reverted to traditional herbs to treat themselves and their children. Women explained how this impacted access to maternal health care, as one woman explained, "I couldn't go to the hospital during pregnancy until the eighth month. I was at home. When it was eight months, my mother-in-law complained that won't I go and register? I then told her that the hospital expense is much, and I don't have money to pay."

People were also scared to go to the hospital as they may contract the virus or be refused treatment as COVID-19 patients were being prioritised. The lack of accessible and affordable transport to services was also a barrier.

The discussions rarely mentioned mental health specifically, although some of the younger women discussed feelings of hopelessness and isolation due to remaining inside or missing out on their education. Some women shared that people had died of "unhappiness" or because they were not used to being indoors.

Family dynamics and support

For some women with disabilities, physical distancing rules were particularly challenging. For example, women who needed support to get into their wheelchairs, or who had no access to mobility aids, sometimes had to crawl or use the floor to move around. People in the broader community were also less able or willing to support with mobility or guidance due to the fear of catching COVID-19. Together, this increased the feeling of isolation.

Education

The impact on access to education during COVID-19 was significant. Some online provision was available while schools were closed but this was often via radio or TV and was not accessible to all children with disabilities. In other cases, a lack of access to the internet or a mobile phone prevented engagement.

In some communities, richer parents paid privately for their children to continue being educated while government schools were closed. But this was not available to poorer families, who were understood to be more likely to have children with disabilities. This not only impacted equitable access to education but caused tensions within broader communities. One parent paid for online education for her child with a disability but the impact on the family finances was substantial. In addition to the impact on formal education, the lack of access to schools resulted in reduced access to health and rehabilitation services which are particularly essential for children with disabilities.

Now that schools have reopened in Nigeria, participants shared their concerns about teachers rushing children through the curriculum. This is particularly challenging for children who had less access to online learning or who were already behind due to previous exclusion. If children were due to sit external exams, these have been postponed and they are expected to catch up in the next year.

Employment

Many women in the study were self-employed and had small businesses before the pandemic. Some of them explained that due to lockdown, most of the money need to sustain their business had gone on their survival and reestablishing their businesses was difficult. High levels of inflation were an ongoing challenge. There was a feeling that many elements of society had not

returned to 'normal', which meant that some businesses, such as those linked to tourism or travel, were no longer viable or wouldn't be for a long time. Women felt there was very little support to change industries or understand what options they had. Loans were also seen as harder to get for women with disabilities.

Gender dynamics

Participants were very divided on whether they thought the pandemic had been more difficult for men or women with disabilities. However, it was clear that gender dynamics were in play when they discussed the differential impacts. The main issue raised in relation to men was that due to lockdown and the economic situation, men were not able to fulfil their perceived household role as breadwinners, which many women thought had a significant psychological and social impact on them. As one woman put it, "[the lockdown was a] big blow to men who were used to going out each day and providing for their family."

For women with disabilities, the dynamics were more varied and intersecting with age and marital status. Some explained that women were more likely to have businesses that were affected by the pandemic, due to the types of work they usually engage in. Women also felt they were less able to ask for external help because their husbands would not want them to, but seeking support was seen as more socially acceptable for men.

Women had set responsibilities and expectations in the home and were expected to take care of the household which placed a significant burden on them. Several women explained that it was men's responsibility to earn money but everything else sits with the women. However when men cannot earn money then this expectation also falls to the woman. Women also described the dynamic of money in the household as a woman's salary is supposed to be shared but men will often keep some for themselves. As one participant explained, the "mother is the one that takes all the heaviness of the family."

Even when women believed that men had a harder time during COVID-19, due to the reasons outlined above, there was a strong agreement that women's voices and perspectives were not listened to by all levels of leadership and society. As a result, this impacted the support and opportunities that they were given. For some women, the consultations were the first time they'd been asked about their opinions. They consistently raised the point that men from within OPDs, and more broadly, were often not willing to give space for

their opinions. One woman asked, "there are lots of women that have good ideas up their sleeves but are the men ready to give us a fair chance?"

There were also gender dynamics around children. One mother explained that she prioritised her sons because they are more likely to care for the family in the future. She said, "if we are asked to choose who will be empowered, I will choose the boys because they become the fathers, breadwinners in the home."

Violence

Some participants shared how COVID-19 and the lockdowns had caused changes in family dynamics and introduced new tensions. As one woman put it "every day is from one fight to another and is over little things."

Not all women reported that there had been an increase in violence. Many women from different contexts did say that they had heard of specific cases of violence during COVID-19. One participant explained that, "domestic violence was just too much. The husband that does not have money to give his wife and wants to eat and have sexual pleasure, which causes quarrel and violence in the home, and it is the disabled person who is at a disadvantage because she will not be able to run."

Some participants also mentioned that changing household dynamics led to men becoming increasingly violent. Others flagged that gender dynamics between men and women resulted in men feeling threatened or undermined by women and as a result "they will just hit her." Some women reported psychosocial abuse.

For example, one blind participant described how her husband would say there was no money for food but would then go outside and drink because he knew she couldn't see him, although others could. Other participants explained that they knew about cases of rape, including rape and sexual abuse of girls with disabilities. Specific dynamics relating to disability were raised, including the perception that women with disabilities do not have the power to leave, resist abuse or will not be believed. As one woman framed it,

There were also cases of violence that had been normalised as being the 'fault' of the woman, as she had gone against her husband's wishes. This demonstrates the complex gender and cultural dynamics at play and even among women with disabilities themselves. An example was given of a Deaf woman who was visited by other Deaf people during the day with who she

would communicate. When her husband found out that she was seeing other men without him present, he would be violent towards her.

Women also spoke of violence being inflicted outside of the home and particularly relating to the enforcement of COVID-19 rules by authorities. This presented unique challenges for people with disabilities who were not always able to fully understand or comply with these rules due to inaccessible information or specific access requirements.

Responses to COVID-19

Access to government support during COVID-19 varied significantly but was generally seen as insufficient and inequitable for people with disabilities. Many women received some limited food supplies and a smaller number were given money. However, this was often received quite late into the pandemic. There were also examples of free face masks being handed out.

Most participants were highly critical of the government's response to the pandemic, with many believing that they should not have put restrictions in place without first establishing appropriate support. As one woman put it, "truly the government did not try at all, especially to people living with disabilities."

While the overwhelming view was that the government had not done enough, some felt that they had tried but the challenges in distributing assistance were more significant at a local level.

One major issue raised was the prioritisation of people with disabilities in the response. Many women explained that they had not been on the list of people due to receive support. In some cases, this was seen to be a political decision because those in power did not view people with disabilities as important and saw them as having very little voice. As one participant put it, "it is only when it comes to [an] election that they will remember we exist."

In other cases, the lack of inclusion was seen to be an administrative challenge as there was a lack of systems in place to register people with disabilities. In some cases, women with disabilities who were not initially eligible for support got the help they needed when they brought it to the attention of the authorities.

Some women with disabilities were aware that support was available but the communication about the available resources was also not always accessible or clear. Women explained that they had been told where to go to collect

food, but when they arrived, they found that the distribution had already finished. Others had heard about provisions on the radio but had not been able to access them. In other cases, support had been promised but never arrived.

A few participants reported that they had been actively discriminated against during food distribution, "they gave the good ones to other people and gave us, people with disabilities, the expired ones."

People with disabilities were also reported to have received less food and money than other people in their community. Women without husbands also experienced discrimination and were told that they would only receive distribution if they came with their husbands. Women highlighted that men were more likely to leave women with disabilities or not marry them at all, due to stigma and misconceptions about the causes of disability.

Corruption, at multiple levels, was seen as an additional problem that prevented an effective and equitable response to COVID-19. Many participants suggested that local distribution was one way of ensuring that all people were given the necessary support as traditional leaders know how many people with disabilities live in their communities. However, others expressed concern that village heads and grassroots leaders had not been distributing food evenly or according to need. In one case, it was felt that "leaders in the grassroots held onto it, all, of us in our area nobody got any."

Similarly, there was a consistent call for organisations of people with disabilities (OPDs) to be more involved in the distribution of support, especially as they understand the people in their communities. However participants did also give examples of OPD leaders who had not fairly distributed resources among people with disabilities. Participants trusted other women with disabilities and felt that if they were responsible or involved in the response then they would be more likely to hear about the support needed and it would be more fairly distributed. Talking about another woman in the group, one participant explained "even if it was given to her no matter how small, she would have made sure one or two persons get [it]." The women flagged that OPDs should have more women in leadership, "every group of disability should have a woman leader and a man leader."

As with other services, the lack of accessible and affordable transport meant that some women with disabilities were unable to travel to receive support or felt that the support offered was not worth the cost of transportation. Women with disabilities consistently agreed that their voices were not listened to and not heard in policymaking. Participants felt they were not seen to "have any value" and that "a lot of us have things to say but we cannot because no one is listening."

Some examples of local non-governmental organisations providing support were given. It was not clear whether these provided specific assistance to women with disabilities, but one participant explained that an organisation had gone street to street to ensure no one was missed.

While women felt that they should have been given more immediate food support during the pandemic, they highlighted the long-term importance of being supported to live independently as many preferred receiving cash over food or other items. The ability to choose how to spend the money and become self-reliant through using it to establish businesses was seen as critical.

There was also a call for greater accountability in the response and for the government to ensure that all planned distributions were made. There was also a recognition that if OPDs were strengthened then they could also play a role in accountability.

Recommendations

The experiences of women with disabilities during COVID-19 has demonstrated that governments and development actors must ensure that their crisis response and interventions are disability-inclusive. The experiences outlined in this paper were not new but were existing forms of discrimination that were amplified and exacerbated. The Nigerian federal and state government and development actors must use this moment to consider what future emergency responses should include but also how to address the long-term and systemic forms of inequality.

Short-term

Multiple factors contributed to participants being unable to meet their basic needs during the COVID-19 lockdowns. Emergency responses must recognise the intersecting and contextual forms of discrimination that people experience and how these impact their resilience to crises, the support they require and the barriers they face in accessing support. Younger and older women faced different and significant barriers.

Meaningful consultation with people with disabilities, including women with disabilities of all ages, is an essential part of understanding intersecting forms of discrimination and must form a key part of designing emergency responses. COVID-19 has demonstrated the importance of accessible and inclusive information during emergencies and beyond. To ensure that services and responses are accessible, communications should be clear, consistent and available in multiple formats.

The emergency distribution of food or cash should account for the greater level of need among people with disabilities due to the higher levels of poverty. They should also be provided through alternative distribution mechanisms.

It is critical that remote education is provided in multiple formats and is inclusive. It must also recognise that children with disabilities are often among the poorest in any community and are less likely to have access to the internet or other services.

Inclusive and accessible responses to gender-based violence should be considered as part of any emergency response.

Medium and long-term

The registration and identification of people with disabilities ahead of crises must be improved to ensure systemic access to support them during the crisis and then in the longer term. This should build on the knowledge of communities and OPDs but must not be reliant on individuals' decision-making as this may perpetuate existing inequalities. Registration must be grounded in a rights-based approach to ensure that it does not risk further exclusion of particularly marginalised communities. This should account for not all people experiencing barriers identifying as people with disabilities, such as some older people or people with albinism.

Enabling women with disabilities to access income security will be key to their recovery from the pandemic. This should include recognising that women with disabilities are often undertaking informal forms of self-employment and they should be supported to strengthen their businesses post COVID-19. This should include access to training and safely ensuring equitable access to capital. Women with disabilities should be supported to establish businesses that will be sustainable and resilient to future economic changes or crises and provide opportunities beyond subsistence.

Comprehensive disability-inclusive social protection systems must be put in place to support people's income security and facilitate active and meaningful participation in society. Social protection entitlements should recognise the higher costs that people with disabilities have in accessing services and participating fully, alongside the barriers they face to enrolling in existing schemes. Disability-inclusive social protection systems should allow the government to be responsive during crises, as systems developed during crisis periods are likely to exclude the most marginalised and the most at risk.

The availability of accessible and affordable transport should be improved and seen as a critical enabler for people with disabilities to access other services as well as an important service itself.

Women with disabilities must be supported so they can progress into leadership positions with community mechanisms, OPDs and more broadly. This will require an approach that eliminates the multiple barriers that currently exist. It is critical that practical barriers, such as the burden of unpaid care, are tackled alongside more entrenched societal barriers, such as the perception that women with disabilities do not have a valuable contribution.

Where they do not exist, women with disabilities should be supported to establish women specific OPDs or sections of OPDs. Where these groups do occur, they should be supported to ensure that they can raise their voices in mainstream policy discussions. This is critical to give a safe and supportive space and to ensure that advocacy is targeted on the issues that most affect women with disabilities but also fosters emerging leadership in the sector.

Responses to gender-based violence must be accessible and inclusive. They need to recognise the complex dynamics around violence that exist for women with disabilities which are due to high levels of stigma and discrimination. These may include the barriers around violence being internalised as 'right' or understandable in certain circumstances.

Women with disabilities should be involved in the design and delivery of responses.

As schools return, it is important that children with disabilities are supported to come back and are provided with adequate support. 'Catching up' should not just focus on lost learning but also on the impact that the pandemic has had on children's wellbeing.

Efforts should be made to ensure that access to rehabilitation and health services are not lost. Existing barriers to health care must be removed. This includes the high out-of-pocket costs which impact health-seeking behaviour.

Sexual and reproductive health services, including maternal care, must be prioritised for women and girls with disabilities.

It is vital that disability inclusion is budgeted for at multiple levels. There is a need to ensure that state and federal budget processes as well as outcomes are disability inclusive.

Efforts to implement legislative agendas including Nigeria's Disability Bill and state-level disability laws must be increased. Part of this should include efforts to improve accountability to ensure that the intentions of government policy and programmes are realised at the local level. The outstanding Gender and Equal Opportunity Bill must also be passed.

Women with disabilities and OPDs should play a key role in accountability mechanisms and consultation with women with disabilities should be required.

There is a need to increase the capacity of government to improve the quality and availability of disability disaggregated data to help inform policy making and guide the allocation of resources.

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