EXPERIENCES OF PERSONS WITH DISABILITIES IN INFORMAL SETTLEMENTS IN NAIROBI, KENYA

This brief examines the experiences and challenges faced by people with disabilities in the Korogocho and Viwandani informal settlements in Nairobi, Kenya. The information was collected using Photovoice, a participatory research approach, as a part of work undertaken by the ARISE consortium.

Photovoice participants were identified with the support of Community Health Volunteers (CHVs) who had a deep understanding of the Korogocho and Viwandani communities.

With the expertise of the co-researchers in both Korogocho and Viwandani informal settlements, three categories of people were identified as the most vulnerable and marginalised: People With Disability (PWD); elderly persons over the age of 65 and leading a vulnerable life; and children heading households.

This brief will focus on the journeys of people with disabilties, giving special attention to specifically the challenges they face. This includes the burden of caring for themselves and their dependents such as their children, access to and affordability of health care services, as well as the experiences of discrimination and social stigma.

PHOTOVOICE: AN APPROACH TO CONFRONT THE EXISTING INEQUITIES

Photovoice is a community based participatory qualitative research method that utilises photographs taken and selected by study participants depicting lived experiences of communities. Respondents subsequently reflect upon data gathered through their photos. In the photovoice approach, participants are co-researchers because they take the photographs and interpret their meaning for the researchers. This method differs fundamentally from traditional research where the power often lies solely with the researcher.

AXIS OF DISABILITY

In Korogocho, the main forms of disability identified among the participants included: deafness, blindness and other physical disabilities such as the use of only one hand, use of crutches, and use of a wheelchair. In Viwandani, we interviewed blind participants, and a participant who was physically disabled and using a prosthetic limb.

The vulnerability and marginalisation experiences of this sub group were centred around three areas:

- Burden of care for self and children
- Challenge with access and affordability of health care services
- Experiences of discrimination and social stigma.

BURDEN OF CARE FOR SELF AND CHILDREN AND ITS IMPACT ON **HEALTH AND WELL-BEING**

The nature of disability shaped participants' vulnerability and marginalisation. Poverty and financial constraints that resulted from lack of employment, manifested in the form of burden of care for self and the children. This is as a consequence of their inability to provide the household with nutritious food, as well as catering for children's school needs. Participants pointed out to their struggles in doing house chores such as laundry, cleaning and cooking.

CHALLENGE WITH ACCESS TO AND AFFORDABILITY OF HEALTH SERVICES

The study revealed that access to health services by PWD was a challenge due to various factors which included a lack of the right skills, tools and infrastructure to meet their needs. The study participants reported a lack of sign language interpreters for the deaf in one of the health facilities. The lack of income and poverty for many of these people exacerbated their challenges in accessing health services. In many instances, many could not afford prescribed drugs. A total of 18 participants including a health care provider from the Korogocho health facility mentioned lack of medicine at health facilities as a key challenge.





"When I think too much, some thoughts sometimes come to my head that I just feel like there is no point being alive in this world if that is the life we are living. I can't help my mother, my sisters. My wife is telling me I should go for my child because he is crying for me."

MARTIN IS BLIND AND LIVES IN VIWANDANI INFORMAL SETTLEMENT



"The children become sick and when you take them to the government hospital there are no medicines so you are forced to buy medicine outside. It is better to go to a private one where they get treated and are given medicine... I prefer the private hospital because when I go to the public one sometimes you can find they are not there, or they tell you to come the following day."

PAULINE IS A PERSON WITH DISABILITIES LIVING IN VIWANDANI INFORMAL SETTLEMENT



KOROGOCHO AND VIWANDANI INFORMAL SETTLEMENTS

Korogocho, the fourth largest slum in Nairobi, hosts over 250 dwelling units/ households with an average of three persons per household. Korogocho is characterised by generational poverty depicted by poor housing, with most houses made of semi-permanent materials such as mud, tin and timber walls. The environment is highly polluted due to its proximity to the Dandora dumpsite that serves the entire Nairobi County. Poor or lack of basic infrastructure such as roads and sanitation, as well as low education levels, extensive violence, insecurity, lack of clean and affordable water for domestic use is characteristic of Korogocho.

Viwandani is one of the largest slums in Nairobi, located about 7 kilometres from the Nairobi central business district (CBD). It is situated within the industrial area of Nairobi. Many of its residents are youthful and highly mobile, working or seeking jobs within the nearby industrial area. The Ngong River, which is heavily polluted by industrial waste from neighbouring industries, is situated to the south of the settlement. Structures in Viwandani on the most part are made of iron sheets and tin walls with iron sheet roofs.

STIGMA AND DISCRIMINATION: DIFFERENTIAL TREATMENT

Discrimination and social stigma affected the ability of persons with disabilities to secure job opportunities. Many of the participants also relayed feelings of being looked down upon by the rest of the community. This has had negative impacts because they are often left out of initiatives and locked out from opportunities of having their voices heard as well as tabling their issues.

"There are those who discriminate against us... it is happening. There are those who just look at us deaf people and they don't understand our situation well. Even at the family level there are those with an attitude towards us and stigmatise us... it is a challenge because for example when you want to tell them [people in neighbourhood] about a challenge that you are having for example if it is an allergy that you are experiencing or coughing and I request them to stop smoking bhang, they will stigmatise you instead of helping you so that also is a challenge."- Miriam is a person with disabilities living in Korogocho Informal Settlement.

THE NATURE AND IMPACT OF THE ENVIRONMENT ON THE HEALTH AND WELLBEING OF PWDS

Participants living with disabilities gave an account of their challenges with their environment. Common health issues were attributed to lack of decent infrastructure, poor and precarious housing conditions including leaking roofs.

Poor sanitation and hazardous waste disposal including open sewerage, blocked/ stagnant drainage systems, and mountains of garbage were captured in photos and described as detrimental to health and wellbeing of the participants. Poor sanitation and waste disposal hindered free movement and mobility; and increased accident risks among PWDs due to abstracted road/pathways.

Poorly built environments and infrastructure as a result of low social economic status exposed the populace and particularly PWDs to health risks including electrocutions and accidents. Wide roads without restricted foot paths posed the risk of road traffic injuries and heightened their anxiety.

RECOMMENDATIONS

In conclusion, it was noted that vulnerability and marginalisation were driven by individuality and other factors that affected individuals in all categories generally. The co researchers and researchers collectively came up with some recommendations.

- It is vital to disseminate and implement Kenya's Persons with Disability Act of 2003. This will help to reduce social stigma, increase participation in economic activities for PWDs and fully enforce their rights; particularly in regard to the right of participation in decision making.
- Urban planning and the development of infrastructure needs to be sensitive to the needs of persons with disabilities. Attention should be paid to the construction of disability-friendly roads with restricted pedestrian paths for them. Most persons with disability; particularly those born with disabilities historically face multiple discrimination and subsequent denial of education and other opportunities. This aggravates their marginalisation and vulnerability. To this end, there is need for special consideration for children born to persons with disability in the issue of bursaries and other interventions implemented at the local level.
- · Social protection interventions such as cash transfer for disability needs to reach all deserving PWDs to as a measure of alleviating vulnerability.

SUGGESTED CITATION:

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"When my prosthetic is spoiled I have problems walking. This means I won't get to where I was going to be able to provide for my family. When I see people walking well and are able to make their income while I am forced to rely on my broken artificial legs. I pity myself because my children depend on me, yet my artificial leg is at times broken... and I am unable to provide for them so I end up feeling worthless. Also, sometimes when walking, people expect me to walk at their pace, yet I am unable. I have to walk at a pace I can manage."

PAULINE IS A PERSON WITH DISABILITIES LIVING IN VIWANDANI INFORMAL SETTLEMENT

The ARISE Hub - Accountability and Responsiveness in Informal **Settlementsfor Equity** – is a research consortium, instituted to enhance accountability and improve the health and wellbeing of marginalised populations living in informal urban settlements in low-and middleincome countries.

The ARISE vision is to catalyse change in approaches to enhancing accountability and improving the health and wellbeing of poor, marginalised people living in informal urban settlements.

ARISE is guided by a process of data collection, building capacity, and supporting people to exercise their right to health. ARISE works closely with the communities themselves; with a particular focus on vulnerable people living in the informal settlements; often overlooked in many projects and initiatives.

ARISE was launched in 2019 and is a 5-year project. It is implemented in four countries: Bangladesh, Kenya, India and Sierra Leone.



