

# Existing but totally forgotten: Challenges faced by people with disabilities in sustaining health equity in urban environments

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## Abstract

This study seeks to explore the challenges that are faced by people with disabilities to live a sustainable life in urban environments. The study was qualitative and employed case study design. It employed observation and semi-structured interviews for data generation. Purposive sampling was used to select the participants who were information rich. The study found out that people with disabilities are homeless and live close to public toilets with their bags of clothes close by. The toilets are not adjusted to suit the needs of people with physical disabilities and they end up messing themselves. This has severe negative impact to people with disabilities since they become associated with dirt all the time. Some users including people with physical disabilities and the blind end up crawling into the public toilets and such practices are leading to disease spread. They drink water from public tapes and sometimes go without it due to water shortages experienced in urban environments. Due to lack of decent shelter, their children engage in early marriages and this is causing high rate of infant mortality, the spread of infectious diseases including the spread of HIV and AIDS. The study recommends that urban councils should craft policies that redeem people with disabilities from the bondages of poor sanitary facilities and upgrade their status.

**Key terms:** sustainable urban environment, people with disabilities, sanitary facilities, health living conditions, forgotten tribe

## 1. Background to the study

The target of providing health for all by 2015 might remain a dream if municipalities are not caring for the health of people with disabilities who live in urban environments. People with disabilities are a forgotten tribe in most urban environments as most urban councils are silent about providing a sustainable life for these people. While it is important for urban councils to make life sustainable for individuals and societal members, there seems to be very little attention paid to improve the health living conditions for people with disabilities. The focus by most governments to ensure sustainable living for the most excluded and marginalized populations will not be achieved to meet the Millennium Development Goals if Urban councils do not step up to meet these people's needs.

There is little doubt that during the latter half of the 20th century, our understanding of health for all including people with disability been transformed. Since the emergence of the international disabled people's movement in the late 1960s, it is hoped that attitudes towards the provision of sustainable health conditions has cleared deprivations encountered by people with disabilities. This seems to a dream in most urban centres. People with disabilities are still neglected and their health is in jeopardy. It is argued that:

The particular form of poverty principally associated with physical impairment is caused by our exclusion from the ability to earn a living on a par with our able bodied peers due to the way employment is organised. This exclusion is linked with our exclusion from participation in the social activities and provisions (UPIAS, 1976: 14).

The World Health Organisation calls for the removal of unfair health differences among all segments of society in order to meet the Millennium Development Goal of Health for All but reality on the ground seems to point to inattention to the provision of sustainable health living standards for people with disabilities. It is important to realize that attention must be focused on the needs of the most vulnerable particularly those with disability in order to achieve the Millennium Development Goals (MDGs). On that note, it is argued that there is need to fight against the oppression of people living with disabilities (Joseph, 2007).

Results from the Zimbabwean population census (CSO, 2012), highlights that approximately 350 000 people with disability were identified which equates to 2,9% of the population. Wilbur (2010), points that people with disabilities (PWDS) are sometimes a forgotten tribe in terms of provision of appropriate sanitation facilities. This reality has severe and widespread consequences for the health and dignity of people with disabilities. Disabled people live without access to basic sanitation services which can exacerbate impairment and poverty. They are often excluded from development interventions.

Studies indicate that PWDS are excluded from accessing sanitary infrastructure and participating in planning and implementation of environmental sustainability programmes. They have relatively poor access to basic services and these include accessibility to safe water and toilets. UNICEF (NYHQ (2008) points out that disabled people have the same needs and rights as everyone else, including access to adequate living conditions, sanitation facilities, safe water education and health services.

Disabled people exist in every community of the world. It is estimated that of 58 million disabled people, two thirds live in low income countries of the south (Miles, 1999). Disabled people are among the most marginalised, socially excluded and poorest groups in Zimbabwe. It is estimated that there are 1.4 million disabled in the country. As in other countries, people with disabilities encounter multiple environmental barriers that militate against effective inclusion in the society (Chidowa, 2007).

## **2. Statement of the Problem**

People with disabilities do not easily access sanitary facilities in urban environments. The blind are seen with a sight guide into the toilets at bus terminuses and they hardly step on neat points in publicly used toilets. People with physical disabilities crawl into toilets some without gloves in order to use the toilet facilities. It is very difficult if not impossible for persons with disabilities to access most facilities. The fact that there are no guiding rails, no recorded voices for persons with visual impairments and toilet pathways are too narrow to accommodate wheelchairs. The toilets cubicles are too high for persons with physical disabilities. People with disabilities face multiple difficulties in accessing toilets. The toilets are not adjusted to suit the needs of people with physical disability and they end up messing themselves, the blind end up crawling into the public toilets predisposing them to all sorts of diseases. They experience all kinds of pollution because they cannot easily lift themselves from one point to another. Against all this background, urban councils seem to be looking aside and do not consider improving the lives of this marginalized group. Due to the fact that people with disabilities are also people who need care and healthy living standards, there is need to investigate challenges they face in sustaining health equity in urban environments. This study fills the void.

## **3. Main Research Question**

What are the main challenges faced by people with disabilities with regards to sustaining health equity in Masvingo urban?

## **4. Purpose of the Study**

This study seeks to explore the challenges that are faced by people with disabilities to live a sustainable life in urban environment.

## **5. Research Questions**

- To what extent do people with disabilities face challenges to live sustainable health lives in urban environments?
- How far do people with disabilities experience sanitation challenges?
- How do people with disabilities encounter barriers in relation to health living conditions?

## **6. Conceptual framework: The concept disability**

According to World Health Organisation (2013) disability is an umbrella term, covering impairments, activity, limitations and participation restrictions. Disability is thus not just a health problem, it is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. To that end overcoming the difficulties faced by people with disabilities requires societal interventions to remove environmental and social barriers. WHO (2006) defines disability as any restriction or lack of ability to perform an activity in a manner or with a range considered normal for a human being. UN (2006) noted that disability is an evolving concept and results from interaction between persons with empowerments and attitudinal barriers that hinders their full and effective participation in society on an equal basis.

## **7. Theoretical framework: The Social Model of disability**

The social theory of disability is premised on the concept of oppression (Abberley as cited in Anastasiou and Kauffman, 2013). It is society which disables people. Disability is something imposed on top of the disabled. They are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. Accordingly, it is argued that it is not individual limitations, of whatever kind, which

are the cause of the problems but society's failure to provide appropriate services and adequately ensure that the needs of people with disabilities are fully taken into account in its social organisation (Oliver, 1996a, 32). People with disabilities are not provided with facilities and resources for sustainable living because they are oppressed by societies.

## 8. Literature

According to World Health Organization (2011) during a world report on disability, it was noted that the lack of inclusive facilities means disabled people often engage in unhygienic and dangerous practices. Wheelchair users are forced to crawl on the floor of latrines; others defecate in the open to avoid the discrimination associated with using public toilets. People with disabilities may also restrict themselves from intake of food and water to avoid the rate at which they might need to go to the toilet. To that end, delayed urination might affect most men's pancreatic glands and end up having urination problems. Disabled people are likely to experience increased health risks because of lack of access to sanitation and hygiene services.

In a study by Chigunwe, it was found out that people with disabilities are excluded from accessing sanitary infrastructure and participating in planning and implementation of environmental sustainability programmes. They have relatively poor access to basic services and these include accessibility to safe water and toilets (Chigunwe, 2014).

Water Aid (2013) notes that it is vital that sanitation facilities are appropriate for specific design. Features such as ramps, wide doorways and hand rails can have a life changing impact. People that once had a choice but suffer the indignity of defecating in the open can share benefits of having a safe and private place to go to toilet. A shallow ramp and wide doorway allow easy access of wheelchair users. People with disabilities are often left out due to lack of adequate proper infrastructure and support system (Zimbabwe Herald, 2013).

Results in a study done in Uganda revealed that toilet access was problematic for children using wheelchairs in primary schools. It was observed that some latrines are a long distance from their hostels or home or class and many do not have ramps. Some children have difficulties in opening the doors to enter closing while inside the door locks are sometimes too high for them. Space inside is limited to freely turn and transfer. Cleaning after use and washing hands is also hard (Kiwanuka 2002).

Mulholland et al (1998) cited that for those people with disabilities who were crawling they find the floor too dirty, yet they used bare hands at times when crawling, where a water source is not closely by the user may face the problem of how to carry water to the toilet for washing. Inaccessibility can force disabled people into unhygienic and inappropriate practices (Ahsam, 2002; Sachelo 2000). Disabled people risk being stigmatized and isolated both within the household and community if they cannot keep themselves clean up to community standards. (Vander Kneft 2002).

According to CRP (2002), in Bangladesh many community members believe that impairments are courageous or a punishment, disabled people may be prevented from sharing latrine facilities which forces families to use unhygienic sanitary practices. Lack of inclusive facilities means disabled people often engage in unhygienic and dangerous practices for example wheelchair users are forced to crawl on the floor of latrines and others defecate in the open to avoid the discrimination (UN 2006).

People with disabilities face particular differences accessing to toilets. The main challenge is with the design of facilities. Most toilets are always crowded because they are public and because they are the ones close to their habitats and the disabled find a lot of challenges to meet the high health living standards. Where a toilet is being built to suit an individual disabled person the seat should be positioned such that people with disabilities person's strongest arm is next to the seat when they come alongside in the wheel chair.

A study by Chigunwe (2014) argues that disabled people are likely to experience increased health risks because of lack of access to sanitation and hygiene services. According to (Herald Dec 19, 2013), three women with disabilities were called for a cervical cancer screening during a workshop three women had varied disabilities ranging from visual impairment, physical challenges and hearing and speech impairment and the nurse was providing information on cancer women with hearing and speech impairment were totally left out as there was no sign language interpreter. At a cervical cancer screening the wheelchair bound woman struggled to get into the screening room because of the infrastructure. People with disabilities are often left out due to lack of adequate proper infrastructure and support system.

The Zimbabwean parents of handicapped children association in its 2003 partial study revealed that most people with disabilities are more vulnerable to infections as they are not targeted in most programmes. Testing and counseling services have not engaged specialized counselors to deal with special kinds of disabilities such as deafness more often than not as we pass by visually impaired beggars in the streets, we often comment on them as having too many children. Do we ever think of who gives these people information and to what extent is it of

help to them?

A country should be judged by how it treats vulnerable members of society and in this case the disabled (Zimbabwe Herald 2013). It is argued that accessibility to infrastructure and buildings such as toilets, tubs, among others, poses great challenges to people who are physically challenged.

### 9. Research Methodology

This study employed a qualitative case study design. Qualitative research takes place in natural settings. It employed semi-structured interviews for data generation which encourage participants to describe their experience in their own language. This allowed them to freely recount challenges that affected them without being influenced by a chain of questions. Richness of participants who live with disabilities and willingness to participate in a series of personal in-depth interviews were the primary considerations in identifying participants for this study. Purposive sampling was used to select participants. Patton, (1990 p 169) argues that the logic and power of purposive sampling lies in selecting information – rich cases for in-depth study. This study focused on participants living with disabilities who were willing to participate in the study (Flick, Kardorff and Steinke, 2004).

### 10. Data Analysis

This study used the thematic approach to generate emerging themes from data generated by participants. This involves “working with data, organizing it, breaking it into manageable units, synthesizing it, searching for patterns, discovering what is important and what is to be learned and deciding what you will tell others” (Borgdan and Biklein, 1982, p. 145). It allows research findings to be drawn from significant themes from the raw data without the constraints of more structured methodologies (Thomas; 2003). The primary goal is to generate understanding of the respondents’ sense making in the situation. The researcher identified the emergent categories and generated themes from these to ease presentation of findings and discussion.

### 11. Findings and Discussion

#### Toilets are too dirty

*P1: As a wheelchair user, I find that the doors to the toilets are too narrow. I cannot maneuver my wheelchair and end up using some corner to help myself. It is very stressful and an embarrassing experience for us who are disabled.*

*P2: The toilets are often dirty. I use my hands to crawl as there are no ramps to assist me and this predisposes us to many diseases.*

*P3: Toilets are too small, and are dark inside and no rail bands for support. I sometimes end up trying not to eat or drink much to avoid using the toilet (wheelchair user woman).*

*P4: With my crutches, I find it difficult to access some offices because of the steps in some buildings. This is really very stressful.*

*P5: Most of the toilets here in town were designed for able bodied people and not for us the blind people. There are no rails or any sign post to guide us, then we end up touching everywhere to find the hole, and this gives us diseases.*

The main challenge is with the design of facilities that toilets are too small and without rails. Ahsan (2002), Sachelo (2000) stated that inaccessibility can force disabled people into unhygienic and inappropriate practices. Literature points that for those crawling, they find the floor too dirty, yet they use bare hands (Mulholland et al, 1998). Disabled people are likely to experience increased health risks because of lack of access to sanitation and hygienic services (UN 2006). WHO (2011), pointed out that disabled people may also restrict their intake of food and water to avoid needing to go to the toilet. In a study in Z.W.G. Chigunwe findings were that inaccessibility of buildings such as lecture theaters or rooms of residence, toilets, disadvantaged greatly those students who are physically disabled.

#### Lack of health information

Participants had this to say:

*P1: Health personnel forget about us that we need information like anybody else. If only they could have someone to use braille for us.*

*P2: We are being overlooked on issues of HIV and AIDS.*

A study in Zimbabwe revealed that most people with disability are more vulnerable to infections as they are not targeted in most programmes. Testing and counseling services have not engaged specialized counselors to deal with special kinds of disabilities such as deafness and visual impairments (Zimbabwe Herald 2013).

### **Lack of assistance**

*At times I feel that I need someone to help me into the toilet, but fail to get one, it is really embarrassing. I get nobody to assist. People just look at you and they go away. Some told me to go to the villages and questioned why I stayed in town.*

### **Hygiene problems**

*P1: One visual impaired woman had this to say: Scarcity of water sometimes make it difficult to use the toilet or even to wash myself. Have difficulties to go to the boreholes. I end up not bathing at all and it is not good for my health.*

*P2: One using a wheelchair expressed that, there is a big problem of water. I can't fetch water. I am using a wheelchair – sometimes I am unable to bath – no one helps me to collect water from the boreholes. At times I feel uncomfortable to be near other people.*

Literature points that disabled people have relatively poor access to basic services and these include accessibility to safe water and toilets.

## **12. Conclusions**

The study concludes that people living with disabilities experience a lot of challenges in terms of accessibility to infrastructures, use of toilet facilities. They seem to be a forgotten people. Findings also showed that disabled people are not catered for when it comes to health programmes like HIV and AIDS. They do not benefit from health education as no special language is used for such individuals. They have challenges in getting drinking water, water for toilets and bathing. Buildings are not user friendly.

## **13. Recommendations**

The study recommends that:-

- Municipalities should address the issue of Sanitation facilities in public infrastructures, making changes in the physical structure where possible.
- There is need for city councils to put rails or grab bars to facilitate transfers to toilet bowls for easy transfer
- Town planners have to take into account the needs of people with disabilities, in approving building plans engaging architectures Ministry of Local Government and Public to work together in making the infrastructure accessible to people with disabilities
- There is need for some health personnel to learn sign language so as to be effective when giving health education
- Health personnel and the society to be sensitive to the needs of PWDS
- People with disabilities to be involved in all programmes such as Cervical Cancer screening, HIV and AIDS issue.
- Health personnel to ensure that, health issues reach all sectors of the community.

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