“Tuna Haki Pia”

Disability Justice for Nairobi’s Informal Settlements
Disability Justice

This report focuses on the fight for justice for those living with disabilities in the informal settlements in Nairobi, with a particular focus on Mathare. Through the use of quantitative and qualitative research, the report aims to:

• Set out the legal responsibilities of the government with regards to disabled citizens and identify current government programmes;
• Assess the current situation faced by disabled residents of Mathare, including the challenges they face;
• Provide the results of the Disability Justice Survey undertaken by MSJC;
• Set out the Public Buildings Accessibility Audit results;
• Show the personal stories of disabled residents living in Mathare;
• Interview authorities to discuss Disability Justice; and
• Set out tangible actions that should be taken to address the issues identified throughout the report.
About MSJC

Mathare Social Justice Centre (MSJC) is an initiative by young members of the community to promote social justice in Mathare. For years Mathare has been a place where much violence has been allowed to go on without any redress for its residents. In response, a collective of young community activists in Mathare came together in 2015 to envision a centre that would promote more participatory forms of justice. We work in all wards of this constituency to fulfil our core mandates: social justice advocacy and the documentation of human rights violations. These objectives are captured in both our vision and mission which are:

Our Vision: To have a Mathare free of human rights violations.

Our Mission: To promote social justice through engaged community and social movement platforms.

Currently our ongoing campaigns, all anchored in participatory action research, are:

- Art for Social Change
- Reproductive justice
- Maji ni Haki
- Political Accountability and Political Education
- The Mathare Green Movement
- The MSJC Kids Social Justice Club
- Disability Justice
- Arbitrary arrests, Enforced Disappearances & Extrajudicial Killings

While a majority of our members are between the ages of 18-45, we work with and for all generations, genders, religions and ethnicities in Mathare and beyond.
Those who know Mathare know the many challenges already faced by the people who call this place home. A lack of basic services, proper housing and access to sanitation, are just a few of these challenges. Our social justice centre has compiled two reports detailing local experiences of extrajudicial executions and unequal water access that residents live through every day. And these are just two examples of the gross human rights violations that occur here, and in other poor areas, impacting extensively on residents’ lives. While we know we need to do a lot to heal our communities to reduce internal violence, much of what residents with disabilities go through is a result of government negligence, and their life conditions as Mathare residents are made worse because of their disabilities.

Despite all that this government is mandated to do, and has indeed said it will do, people with disabilities in informal settlements have seen little improvement or support. Why do so many people with disabilities in informal settlements lack access to vital support services? Why is their quality of life not taken seriously? Why are their human rights not protected? Why do they have to bribe to get crutches, wheelchairs, cash transfer services and even education bursaries?

This participatory action research process was undertaken to better understand and document the lives, experiences, challenges, and needs of people with disabilities who live in informal settlements, and in particular Mathare which is our community. The experiences of their families and carers are also considered. The power of this participatory research is in the collective storytelling; of pain, possibility and triumph.

From the very start, we would like to acknowledge that people’s relationship to their disability is very personal. Some live with a disability which they would like to fix or change, whereas others are empowered and happy with their differing abilities and simply want to be supported to live their fullest and best life.

Most of this research was conducted within the informal settlement of Mathare, and this report is the result of ongoing conversations, a community dialogue, one awareness creation event, a survey of 82 persons with disabilities and in-depth interviews with six others. We also interviewed other relevant authorities and collaborators, and carried out an assessment of key public buildings to better understand the gravity of the accessibility challenges faced by people with disabilities in Nairobi.
We have compiled this report to express and document those findings, to highlight where there are gaps and gross violations, and to demand what is mandated for people with disabilities to survive and thrive. Wakona haki pia. We would like to amplify their voices, to recognise their resilience and fortitude in the face of being left behind.

It is impossible to separate their experiences from the challenges and injustices of poverty. Poor access to water and electricity, struggles to access adequate sanitation facilities, a difficult terrain and a lack of access to support services or medical care are all compounded by the experience of having a disability.

We also hope that with this report, all can better understand the experiences of those among us with disabilities, and that as an organization and individuals we can do and demand better. Equipped with this knowledge, we can then support one another to live full and meaningful lives.

In this report, we continue to ask the following questions:

- Why has the government not fulfilled its legal obligation to the people living in informal settlements who have disabilities?
- Why are they not provided with the services, support and financial support they need?
- Who is actually receiving any of these services?
- Where is all the funding going?
- Who is benefiting from the allocated money, since it is apparently not the residents of Mathare who have disabilities?
What is disability?

“disability” means a physical, sensory, mental or other impairment, including any visual, hearing, learning or physical incapability, whether arising from natural or artificial causes, which is irreversible and long term and which impacts adversely on a person’s capacity to participate in social, economic, cultural or political activities;”

In the past, disability has been framed as the fault of the individual, in some cases believed to be the result of a curse or witchcraft. In reality, the problem is not with individuals, their bodies or their minds. There is a diversity of human experience which makes us human and disability is a natural part of being human. The problem is the physical and social barriers which prevent people with disabilities from ‘full and effective participation in society on an equal basis with others’.

We also recognise that people have a huge diversity of disabilities, which impact their lives in many different ways and some have had their disability since birth or childhood, while others develop it later in life. Of those who developed a disability later in life, this was a result of illness, an accident, mob violence and even police violations.
Current Government Policy

The following is a list of legislation that is in place to support, protect and provide for the rights of people with disabilities in Kenya.

- The Constitution of Kenya, 2010
- Basic Education Act, 2013
- The Teachers Service Commission Act, 2012
- The Kenya Institute of Curriculum Development Act, 2013
- The Kenya National Examinations Council Act, 2012
- The Children Act, 2001
- Persons with Disability Act, 2003
- National Children Policy Kenya, 2010
- Special Needs Education Policy, 2009
- The Universal Declaration of Human Rights 1948
- Convention on the Rights of Persons with Disabilities 2006

Who is responsible for delivering this Constitutional mandate?

The National Council for Persons with Disabilities (NCPWD) is the peak oversight and support body for people with disabilities in Kenya. The Persons with Disabilities Act (2003) established this council, thereby giving it its mandate. Its core functions were outlined as follows:

- Formulating and developing measures and policies designed to achieve equal opportunities for PWDs;
- Cooperating with the government during the National Census to ensure that accurate figures of PWDs are obtained;
- Issuing orders requiring the adjustment of buildings that are unfriendly for use by PWDs;
- Recommending measures to prevent discrimination against PWDs;
- Encouraging and securing the rehabilitation of PWDs within their own communities and social environment;
- Registering persons with disabilities and institutions and organizations giving services to PWDs; and
- Raising public awareness on disability.
Applications to the National Development Fund for Persons with Disabilities are open throughout the year.

In this context, persons with disabilities refers to those who need permanent care including feeding, toilet assistance, protection from danger by other persons. Full time support has to be offered by a caregiver to ensure their needs are attended to.

The Council has been implementing the National Persons with Albinism Sunscreen Support Programme that is providing sunscreen lotions to over 3,026 persons with albinism.

An established department at NCPWD. Its sole mandate is to facilitate Disability Mainstreaming Programmes in public and private sectors.

This department analyses market information trends in order to provide relevant data to PWDs.
The current situation

Mathare is the second largest informal settlement within Nairobi, with a population of around 350,000 people.

Since ten percent of the population of Kenya have a disability, and more than half of Nairobi residents live in informal settlements, we can therefore assume that the vast majority of people in Nairobi with disabilities are living in these poor urban areas. In this context, why is there a lack of local support services for these people? Where is the funding going? Why is the NCPWD head office located in Westlands, so far from Eastlands, a district in which highly populated informal settlements such as Mathare are situated?

By the very nature of the informal settlements, there are very many challenges related to housing, water access, poverty, employment, criminalization, terrain (see image), environmental degradation, pollution, flooding, discrimination and police violence. A combination of these challenges is experienced by residents who have disabilities which then compounds their situation. The intersection of disability with these conditions was very prominent in the interviews we had and the survey we conducted. These results are explored below.
A profile of participants

We surveyed a cross section of people with disabilities in Mathare - our results reflect a variety of ages and experiences of disability. **43% of participants were under 18 years old, 46% were aged 18-55, with 8% over 55.** One participant declined to give her age. This spectrum gave us a concise picture of the different but shared experiences and challenges facing children, young people, and adults. All six wards in Mathare were surveyed.

*Age demographics of Participants*
## What forms of disability where documented?

<table>
<thead>
<tr>
<th>Physical relates to</th>
<th>People who have disabilities that include rickets, missing or amputated limbs, inability to move about without supportive equipment. The impacts and experiences of these physical disabilities differ widely.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental relates to</td>
<td>people with intellectual disabilities or those who have a mental illness.</td>
</tr>
<tr>
<td>Mute refers to</td>
<td>those who do not or cannot speak. While undertaking this research we learned that mute is not a term that is used anymore and some find it offensive. Instead, it is preferable to refer to the person’s actual experience, for example - does not speak, hard of hearing, deaf etc.</td>
</tr>
<tr>
<td>Hydrocephalus refers to</td>
<td>a condition associated with a build up of fluid in the brain. When treated properly in infants, the long term impacts can be significantly reduced. If not treated it can be fatal. Symptoms include headaches; nausea; vomiting; fever; blurred or double vision; unstable balance; irritability; sleepiness; More than 40% of those affected have normal intelligence.</td>
</tr>
</tbody>
</table>

---

This graph gives the impression that the majority of participants had full access to many basic services such as water, transport, education and healthcare. However, upon further inquiry, we found that almost all of those who had indicated that they accessed these services in fact had very limited access. For example:

- Virtually all participants who suggested they had access to water later made clear that they purchased it inconsistently, and often were subject to high prices.
- Many participants who responded that they had access to services later explained that they were forced to illegally access water and electricity as it was not accessible to them through legal means.
- Participants’ access to shops was usually only possible with the assistance of neighbours.
- Many participants who had access to education went on to suggest that this education was not suitable for their or their child’s needs.

This lack of understanding of the full meaning of accessibility suggests that many people living with disabilities in informal settlements are unaware of their human rights and rights as Kenyan citizens.
The Stark Reality

It is clear from our research that residents in Mathare who have disabilities do not have their most basic needs and human rights met and protected. When it comes to specific needs that people have due to their disabilities, the statistics are even more shocking:

- From May to July 2019, we conducted a survey of 82 people with disabilities living in Mathare (one resident was from Kariobangi South);
- The majority of respondents live in poverty, but only one respondent was receiving financial support from the government;
- 90% of respondents who require sign language and braille training did not have access to it;
- Despite many respondents living with physical disabilities, none had access to a disabled toilet;
- Of the 82 people surveyed, 78% required some form of supportive equipment - of these:
  - 96% did not have all the equipment they require;
  - 59% need mobility equipment (e.g. wheelchair) which they do not have;
- For those of working age, 53% were unemployed and 13% relied on begging for an income;
- 54% were aware of the PWD card, yet only 40% had one. Of those who had a card, very few received any benefit from it.

From these findings and our interviews, the fundamental challenges people are facing can be grouped into the following interconnected challenges: money; education; employment; support services; mobility; transport; stigmatization.
Key challenges faced by residents with disabilities

**Education**

Article 54 - Constitution of Kenya
(1) A person with any disability is entitled--
(b) to access educational institutions and facilities for persons with disabilities that are integrated into society to the extent compatible with the interests of the person;

The challenges regarding education are many, including a lack of finances, medical care, a lack of equipment within the institution and stigma. The general population also needs to be educated about disabilities - how they occur, what they mean and what support options exist. Many people do not have a full understanding of their own disability or that of their children.

*I think the government is not doing enough... because our school down here has a disability class, but you see the parents are paying for that class, they are paying for their student to be there and it's a government institution. They're paying more than other parents with able children.*

Joseph Shiundu, Baraka Hospital

*When going to apply for PWD card they want to see an obvious physical disability (like being in a wheelchair) or else they don't believe you are genuinely disabled.*

Summary of one survey participant’s comments on disability awareness

**Employment**

Article 23. UDHR 1948
(1) Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.

A frequent theme was that people are discriminated against because they have a disability and feel that this is the reason they are not given jobs they apply for. Many people want to start small businesses so they can support themselves and their families, but without financial support they are unable to do this. Additionally, if people do not have access to vital support equipment and medical care they are unable to work. Adults with disabilities are overwhelmingly unemployed or underemployed, with the majority wanting to work but facing many hurdles.

*PWDS have good minds [are very capable] but are discriminated against when looking for employment.*

Survey participant
Key challenges faced by residents with disabilities

Financial difficulties include - not being able to financially support the basic needs of feeding and housing a family; sending a child to school; buying medication; purchasing vital equipment; accessing medical care, including physical therapy; psychological support or vital doctors visits. Overwhelmingly, research participants faced money related challenges on a daily basis.

I cannot support myself. I had to move out due to cost of rent and because I could not pay school fees. Sometimes I cannot afford dressing for the amputation wound.

Summary of one survey participant’s comments

A frequent theme was that people are discriminated against because they have a disability and feel that this is the reason they are not given jobs they apply for. Many people want to start small businesses so they can support themselves and their families, but without financial support they are unable to do this. Additionally, if people do not have access to vital support equipment and medical care they are unable to work. Adults with disabilities are overwhelmingly unemployed or underemployed, with the majority wanting to work but facing many hurdles.

PWDs have good minds [are very capable] but are discriminated against when looking for employment.

Survey participant

Article 25. UDHR 1948
(1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

Article 23. UDHR 1948
(1) Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.
Key challenges faced by residents with disabilities

Article 25. UDHR 1948
(1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

Adequate local support services do not exist; support services that do exist are far away, with travel being a challenge for many people with disabilities for physical and financial reasons. Many people with physical disabilities need access to regular physiotherapy but can’t afford it. Most cannot access or afford vital medical care or medication. There is also an urgent need for greater access to sign language and braille training for those living in informal settlements.

Moving forward, the same way we have police stations everywhere, we should have centres for people with disabilities

Billian Community Organiser, Billian Music Family

PWD registration is useless - they were promised that the card would give them access to services but two years on it hasn’t helped at all. The government needs to be serious in engaging with PWDs.

Summary of one survey participant’s comments

Article 54 - Constitution of Kenya
(1) A person with any disability is entitled--
(e) to access materials and devices to overcome constraints arising from the person’s disability.

An overwhelming number of people with disabilities do not have access to vital supportive equipment, such as wheelchairs. This means people cannot move around freely, and many not at all. It means it is difficult for people to attend school or seek employment. Many children including heavy teenagers are carried on the backs of family members to and from school and health centres. This work is often done by elderly relatives.

Many participants expressed a need for access to necessary mobility equipment. For those few who do have supportive equipment, they still face mobility challenges throughout Mathare. Most of the pathways are unsealed making them difficult to navigate for anyone who has mobility difficulties. The terrain is steep in parts, rocky and scattered with open drains and narrow paths.

Getting up hills or over sewage trenches is difficult.

Summary of one survey participant’s challenges
**Key challenges faced by residents with disabilities**

**MONEY**

Article 22. UDHR 1948

Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Financial difficulties include - not being able to financially support the basic needs of feeding and housing a family; sending a child to school; buying medication; purchasing vital equipment; accessing medical care, including physical therapy; psychological support or vital doctors visits. Overwhelmingly, research participants faced money related challenges on a daily basis.

*I cannot support myself. I had to move out due to cost of rent and because I could not pay school fees. Sometimes I cannot afford dressing for the amputation wound.*

**Summary of one survey participant’s comments**

**TRANSPORT**

Article 54 - Constitution of Kenya

(1) A person with any disability is entitled--

(c) to reasonable access to all places, public transport and information;

Most affordable transport in inaccessible for people who have disabilities that affect mobility. Transport that people may be able to access is also prohibitively expensive. The impacts of this are far reaching: employment prospects are drastically reduced, as is access to education, government offices and support services. This lack of access to transport therefore not only contributes to practical barriers but can also have negative implications on major life opportunities.

*Public transport should be made accessible to persons with disabilities.*

**Summary of survey participants’ suggestions.**
Key challenges faced by residents with disabilities

<table>
<thead>
<tr>
<th>STIGMATIZATION</th>
<th>MENTAL WELLBEING</th>
</tr>
</thead>
</table>
| Article 54 - Constitution of Kenya  
(1) A person with any disability is entitled--  
(a) to be treated with dignity and respect and to be addressed and referred to in a manner that is not demeaning;  
Ideas still exist within the community that certain disabilities are the product of witchcraft or a curse. Some people with disabilities face stigmatization because their disability is simply not understood. Assumptions are also made about their capabilities.  
For instance, some believe people with intellectual disabilities cannot learn to read, yet this is often not the case. It may take such students longer, or require specific interventions, but reading skills are often attainable. Sometimes simply introducing alternative teaching methods can help reach this goal. The impact of all this is exacerbated by the stigmatization of poverty, as the two often co-exist. Society blames people for being poor. However, systems of economic exploitation, imbalance and corruption are in fact to blame.  
*The mentally disabled need to be assessed and respected equally. Education for disabled people is important.*  
Summary of one survey participant’s comments | Article 19 – UN CRPD  
(b) Persons with disabilities have access to [...] assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;  
Mental health and wellbeing was not a focus of our research process, but we were left with the impression that it is a major issue amongst persons with disability in informal settlements. As an issue, it is massively overlooked and not treated as a serious concern. Many people who have disabilities also faced significant mental health challenges such as depression. Many experience isolation, loneliness, bitterness and hopelessness. Mental health support for people with disabilities and their families has the capacity to massively improve wellbeing for all. It is essential in order for a community to thrive, rather than just survive. This view is also echoed by the UN General Assembly, which has specifically set out that it considers obligations related to mental health of equal importance to those related to physical health. |
In summary

All of these challenges and vulnerabilities adversely interact with one another. Mobility, finance, parental employment, healthcare and support services, stigma, mental wellbeing and transport could all affect whether a child can attend school.

The government is mandated and obliged to provide support and protect people’s basic human rights. It is apparent that they are failing miserably when it comes to people with disabilities who live in communities such as Mathare. The government has a duty to all its citizens, yet the most vulnerable are left struggling to survive.
Overview

We also undertook a public buildings accessibility audit. The idea was that key public buildings were audited to better understand how accommodating and accessible they are for people with disabilities -- as they should be in law. The four public buildings visited were selected due to their relevance to people with disabilities in terms of accessing healthcare, basic government services and higher education. As some of the most significant and often visited public buildings in Nairobi, we hoped that great consideration had been put into making them accessible. Public buildings visited:

<table>
<thead>
<tr>
<th>Public Building</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>KENYATTA HOSPITAL</td>
<td>This hospital is large. For someone with mobility challenges, it could be very difficult to get around. The access ramp to the second story is very long, steep &amp; slippery. The only accessible toilet is in the specialist doctors’ area of the hospital. Much of the ground is too uneven for people who have mobility challenges, and seemed likely to challenge the visually impaired.</td>
</tr>
<tr>
<td>NYAYO HOUSE</td>
<td>To enter the security area which surrounds Nyayo house, those who use a wheelchair must use the road as a special entrance. This is unsafe due to other road users. The only ramp from road to pavement is inadequate, small and bumpy &amp; the ramp to enter the main building is prohibitively steep, even when someone is being pushed up in their wheelchair.</td>
</tr>
<tr>
<td>HUDUMA CENTRE</td>
<td>To enter the Huduma Centre a person who uses a wheelchair must use a special entrance. The crossing from the pavement to the road outside the building is a significant challenge for someone who uses a wheelchair. There is a public washroom outside and around the corner, however there is no accessible toilet present in this complex.</td>
</tr>
<tr>
<td>THE UNIVERSITY OF NAIROBI</td>
<td>Much of the ramp access to buildings were prohibitively steep and to the rear of buildings. People who use a wheelchair would need support from to use the ramps. There is only one wheelchair accessible toilet on the entire campus. The door to enter the washroom is heavy that impossible to open unassisted. The doorways are not wide enough and the cubicle is not spacious enough.</td>
</tr>
</tbody>
</table>

The largest public hospital in Kenya & is especially important to residents who have disabilities throughout the city as it is the largest referral hospital in the country.

It houses various government departments, such as the Ministry of Immigration.

One of a number of centres that provide various national government services. As part of Vision 2030, the Huduma Kenya initiative claims to aim to enhance easy accessibility for all.

A public university with 84 000 students, located in central Nairobi. The university’s stated mission is to provide an enabling environment for students with disabilities.
Public Buildings Accessibility Audit

Audit summary

Our built environments must provide for the free movement of people with disabilities so that they are able to move about independently and as freely as those people without disabilities.

In all of the four public buildings visited, we discovered areas where improvements could be made to make them more accessible to PWDs.

What stood out during this survey was how difficult it can be for people with any mobility challenges to safely use and manoeuvre the roads and pathways that join all these buildings. Many of the paths do not have appropriate ramps for people to move from the path to the road or vice-versa. Many of the pavements were cracked and broken. At times this was in such a way that it would be completely impossible to navigate with a wheelchair. These few, small, narrow, cracked and broken pavements are already inadequate for those who can walk, and so pose significant safety threats to those who use supportive equipment to physically move around. They would also be a hazard to those who are blind. This was all in developed areas that have some level of investment in public infrastructure. We know that the situation in informal settlements is even more dire than in the areas visited and audited.

We thank staff members and members of the public who were helpful and stepped in to support Jonte when moving about the different spaces.

However, the concern is - what happens when there is no one around to do this?
A profile of John Ngugi (Jonte)

John is currently the coordinator at MSJC for the disability justice campaign - he is affectionately known as Uncle Jonte. He has a physical disability from childhood which limits his ability to move about unassisted. Consequently, he uses a wheelchair to get around. Jonte went to Masaku School for the handicapped in Machakos County and then attended Joy Town Secondary School (both are specialist schools for people with disabilities). Jonte has two children who are both healthy and in school. He has always been a hard working man who believes his disability is not inability. He believes it should not deter him from achieving his goals.

Completing secondary school, he went to college and studied computer studies. He then went into business. He started a company for purifying water in Mathare. Unfortunately a fire broke out and all the machinery was burnt and all was lost, but he did not give up. Jonte is now a small business owner: he operates an Mpesa shop.

In terms of his advocacy for people living with disability, it started after he was denied admission to a reggae event. He felt he was discriminated against because of his disability. This angered him greatly and he doesn’t want others to go through similar experiences. His organizing started with community dialogues and raising awareness about the rights of people with disabilities. He participated in a documentary titled: The Plight of Persons Living with Disability: ACCESS DENIED. He has also been at the forefront of this research.
John Chege

I have had a lot of challenges because I have tried to look for employment through interviews. They always disqualify me saying that I cannot perform since I’m disabled and that is why I decided to come and start a micro business. I sell electrical and mobile accessories. We have plans to expand our business, but we have financial problems since we have no other sources of income, and because of my disability, it limits me from doing some jobs, so I have to stay here, save and expand the business. And I’m also planning that after 10 or 15 years I should have my own house.

I’m usually not involved in the community groups, most of them do not accept me being part of them... at times it makes me feel lonely and I choose to be alone so that I do not meet other challenges.

I have been trying to reach out to the government but I have not been able to. I started by filling [in] many forms from the government when I was in my rural area, then I came to Nairobi. I tried again but I have never received any kind of help or services from them, let alone a response to my many applications.

The government should help us with some financial assistance to start businesses so that we can raise our kids and enable them to attend school just like other people do.
Kelvin Omondi

My disability came about in July 2018, through a scandal of mob justice. My life changed then because my leg was broken and working is now an issue, so I’m just idle. My biggest challenge is poverty, since I can’t work, survival is a problem. I’m staying with my friend who helps me a lot. I don’t get access to any services, I don’t go to any hospital I just stay at home. I feel the government is not fair. People like us, who have disabilities, are not seen. The government doesn’t look at people like us, they should help us get jobs that will enable us to support ourselves. People in our community respect us. I wish to start a business of any kind. People like us need to be supported because we are disabled.
Everline Anyango

My son Shadrack, is one year and ten months old. It takes a lot of time to take care of him because he cannot walk on his own, so I have to carry him everywhere. If it is not taken care of at this age, then it will disturb him in the future. He is suffering from hydrocephalus. I have three children plus their father. I hope for Shadrack, that he will be OK - I would just like him to be like others who are not disabled, that he will study well, get further education and have a good life. Mostly, people with disabilities are not respected in the community. I think the government should support the disabled. They have tried but not enough. I would like to maybe see the government offer some funds for them to start their businesses.
Florence Aloda

My arm was cut during the 2007 post election violence, while we were sat in the car. My biggest challenges are in washing clothes and not being able to work. Survival is a problem. Now I’m forced to stay here without doing work. I have to work with one hand, that’s my problem. Ever since then, my life has been hard because I used to work – but now I don’t. I was receiving a salary – but now I don’t. I just have to stay without a job. Survival is hard. The people in my community don’t disrespect me. They take me as a disabled person but the problem is that they can’t help me. They only understand me and then go about their business. I live with two of my children. One is in standard five, that’s the last born. The other one is a construction worker and breadwinner. He helps me pay rent. But then again it is a struggle. There’s no water; there’s no electricity. I pay for water.

I hear that the government has money for the disabled. When we follow up, they say we must have an identification card. When we go and get the card, they say the money’s gone. The money goes to the rich, honestly. Those of us down here, we don’t see the money. What I want to see is for the government to help us here, at least so that we have enough. I would also like an artificial hand through donations.
Reagan Onyango

You see this area is about struggling. The area is tough so you just try the hardest you can to survive. Let me put it this way, people with disabilities are very affected in this country; during the election period adversity came among the people so you saw people run and I can’t run. So that was a big challenge.

My living situation is still hard but I can handle hardship. I sell shoes to people. I go purchase some shoes, some clothes and sell them so that I can get some living. My ambitions are big. I want to inspire young people. You see the kids have a lot of problems and it is our work as grown people to show them that even if there’s hardship in life you can still tackle them and do whatever you want with what you’ve got. Almost everyone in this area is my friend. I feel valued.

Growing up as a child there were some things I wanted to do as a kid and I could not do them because of my situation and how I viewed myself. I was playing football when I was young, but I had some beliefs that started taking control of my life. So the things that I wanted to do just vanished away.

In my point of view, there are some disabled people who are treated very well, they have come from privileged families. If your family has something, you have an advantage and are being treated well and the ones like us who have come from hardship - we need to work very hard to do what we can. I would like to see government come up with some good policies which can help our disabled people be included in the government... [so that] what we say can be taken seriously... it would be nice.
Yunis Moraa

My daughter, Kwamboka, was playing football in school. While she was in Form 2, she left school one day with her uniform and came home to sleep. So I asked her, “Why have you left school to come sleep?” She didn’t answer me. She just kept quiet and slept with her uniform on the bed. A few minutes later the child wakes up, she doesn’t talk, she defecated and urinated there. She then took off her clothes and ran out.

So I asked myself what could be the problem? I took her to a mental hospital. She was given medicine but there were no changes. She still didn’t talk. She just cries, sometimes she cries, sometimes she defecates at the door and urinates in the house. She doesn’t talk, she just stays there. She is now 23. My biggest challenge is looking after my daughter.

I have to take care of her all the time so that she doesn’t run away. I also have financial problems because selling groceries does not bring in enough to support my family.

Some of my neighbours I don’t talk to, some just stare at us and others laugh at us. I just want my daughter to be well. I am registered with the government but they don’t give me any support. There is so much poverty in the slum and the government is not doing enough, they don’t even supply us with enough water. I need help at home.
Q. What do you believe are the main challenges faced by PWDs in informal settlements like Mathare?

The challenges are many but I think poverty is a big challenge because people are not able to get food, supply shelter, clothing, and above all, medical attention. The environment in the slums is a bit inaccessible. So sometimes when meetings are called, they can’t go to those meetings because of the inaccessibility of the meeting places, so some of them resort to keeping indoors and to themselves – that is a big challenge, you are not even discussed because you are not there. If you are present in a meeting maybe people can recognize your presence and look into your needs. Persons with disabilities in the slums also have challenges with social amenities. Some of the NGOs are so vibrant in the slum areas but they may not be focusing on disabilities so much, but they are there.

Q. What strategies does NCPWD employ to reach out to PWDs in informal settlements?

One of the ways we reach them [PWDs] is through social workers - we use social workers that are on the ground. We also use NGOs [and] community based organizations that are already there, [and] we use faith based organisations.

We also use persons with disabilities themselves. And then some are reached through their parents – as the main caregivers, they have the information. We have also encouraged them to form support groups. We call them the beneficiary welfare committees – especially those who get some cash transfer programmes. This is where those groups share the challenges they face when they are, or care for, persons with disabilities. So those are the strategies we use and to a limited extent, sometimes the media – the local radio stations.

Q. What challenges does NCPWD face?

Funding is the main problem; we are not getting enough funding even to employ staff at the grassroot levels. We have a lot of demands that we cannot meet: we have 3000 applications for education bursaries, but we can only give 100 in a financial year. Then, we have another challenge of convincing other institutions to take on-board persons with disabilities. Like financial institutions – they’re sometimes hesitant because they say “now that the government came up with a national council, let it fund it.” So whenever we get some support from these organisations, it is like charity; this charitable attitude is a challenge for us because now concrete policies cannot be made by those organisations to help persons with disabilities. We are also having a challenge of capacity in terms of us being trained, specifically to be able to handle disability issues – very few of us have some idea of how to manage disability matters. Most of us may not have that experience. We are still very basic.
Another challenge is political - I think this is my personal opinion – because our directors and board members are chosen on political grounds, that maybe someone who lost in an election has to be rewarded or given some token in the form of an appointment. Maybe through this you may not hire someone who can handle disability matters. That is a challenge to us because we do not have the best people to lead this organisation.

Q. Why do you think many PWDs feel ignored by the government and that PWD registration is of no use to them?

People feel this because we are not providing what they want. We are not giving them food, paying rent for them; we are not paying medical assistance to them. Having the disability card means nothing to them because having the disability card without applying for a service, you virtually benefit from nothing.

Q. Do you believe the state does enough to accommodate PWDs, since some feel they are indirectly discriminated against in various ways?

We can always do more, we can always do better. I think the discrimination you mention may not be intentional but may be circumstantial -- it is not the purpose of the government to discriminate against its citizens but they have prioritized other things at the expense of disability.

If we had had inclusion working well, we may not have needed National Council for Persons With Disabilities to do what it is doing now.

Q. What would you say are the basic rights and services which PWDs are entitled to, and do you believe they currently have access to these services?

Of course - right to life, right to education, they have rights to access medical care; those rights are there but we do not have specific programmes targeting them, no. Medical care -- there is no government programme offering physiotherapy to persons with disabilities yet it is important. Education -- we are doing it, but just the tip of the iceberg. We could do better. I’m not sure we are doing the best.

Q. What upcoming plans or improvements does NCPWD have in mind for current or future services, especially those related to informal settlements?

Maybe the programme they have in mind is the increase of cash transfer programmes for persons with severe disabilities, whereby the number should increase. But I don’t know by how much – they are saying they should increase the number of beneficiaries and this increase is subject to government finances. I’m not sure this future programme is going to happen without funding; if the Ministry does not provide for funds then it will remain in the archives.
Q. If you had a significant increase in funding, what changes, improvements or new services would you wish to introduce?

Personally, I would be very, very happy to see persons with disabilities getting better medical care. So many people are crying out for physiotherapy, so many people are crying out for continence material. So, if I had money, I would increase or I would bring in a programme for healthcare for persons with disabilities. Another thing I would do is to improve the level of technology so as to pass information faster and to improve our services to the public.

Q. How can NCPWD and Mathare Social Justice Centre or other community organisations work together towards the goal of justice, equality and improved standard of living for people with disabilities?

We can partner in various ways. If there are any institutions taking care of persons with disabilities, especially learning, we could give them some education assistance or infrastructure development.

Further comments:

My dream is that the national council should have a fully-fledged office: we should have our own physiotherapy, our own workshop for making wheelchairs and all that. For the hearing impaired we should have like a centre for testing, for assessing the persons with disabilities, fitting the hearing aids -- fully-fledged departments making an impact. I wish we could reach the community more. It is not sensible for someone to come from Mathare to come to seek the services here. It is better for us to take the services to them.
Our Interpretation of the Interviews

We feel that the views expressed by the spokesperson for Baraka Medical Centre show a clear understanding of the challenges faced by PWDs in Mathare. However, the magnitude of unmet need within the community, combined with limited resources, means the overall impact of the hospital’s activities is expected to remain somewhat restricted. Both interviewees gave clear insights into the major challenges they face as organizations, however we are especially concerned by the opinion expressed by the Nairobi County Disability Service Officer, namely that “directors and board members are chosen on political grounds.” Similarly, the suggestion that not all NCPWD staff are adequately trained is worrying.

Both interviewees expressed positive visions for the future, indicating their desire to engage with the necessary processes required to improve the lives of those under their care. However, much more needs to be done. And immediately.
We set up a space to provide for the needs of the community and started running a child care centre for children with disabilities. The centre also runs free physio sessions once a week. We also realised there was a need for education, to reduce stigma and for parents to understand their child’s disability.

Children from the other side of the town are able to access more equipped facilities - you get the pathways where you can have wheelchairs, you have special parking for PWDs. So there are areas where they really, really try to give the services. But in Mathare, here, the parents are left to struggle to look for those facilities.

Some of these children are heavy, the parents cannot carry them physically from their homes to the centre every day. If you look at our roads, if you look at our paths, if you look at our houses, almost all facilities are not friendly to PWDs. It is a real struggle for the parents of children with disabilities, to connect to those centres, even getting to those centres is a challenge.

Given the lack of official government support options, the community has had to step in to support the residents of Mathare who have disabilities. They seem to have far more impact than government initiatives.

One of the services that I would like to see is these kids going to school, we need to have schools for them, we need to have opportunities for them, that can take them to the next level.

We have even been encouraging the fathers, because most of the time it is left to the mothers, so we have been trying to see how we can have a conversation with the fathers and try to encourage them, to bring the fathers into the system, and start appreciating and loving these children.

One of the challenges that we face is as an organisation we don’t really have the facilities. We have zero support from the government. If we partner with the government we are able to do more.

Moving forward, the same way we have police stations everywhere, we should have centres for people with disabilities

Billian Ojiwa - Founder
Eleven Disabled Self-Help Group
Mathare Area 3

This group was formed in February 2018 by Samuel Kavo, a local amputee and construction director. It is named after the initial 11 members. They meet every Saturday at 4 pm in the street, because they do not have an office and have various disabilities. The main agenda has been to seek funds to begin a project which involves acquiring a water tank to fulfil various local needs, and to begin a shared financial venture of opening a car-wash. This will become a self-help project. The group is officially registered as a self-help group and now has 14 members.

The group’s goal - “To enable independence for individual members so that no one must rely upon well-wishers to survive.” - S. Kavo

Challenges:

• Lack of financial support and general funds is their main challenge (a member recently died and they were unable to gather a significant amount of money amongst themselves and did not receive any donations/help).

• The group receives no support and has not been able to meaningfully collaborate with other groups/organisations.

• Other wards and neighbourhoods seem to receive more government money and attention.

• The local authority have so far been unwilling to supply the group with a water tank, despite there currently being a scheme of giving away free tanks to group projects.

• Reports of discrimination, e.g. that PWDs are being denied their national ID cards in Kariokor. We heard an account of someone taking their documents to be signed by the chief but the documents being ripped up simply because he was disabled.
It is clear that the government is failing to fulfil its duties to Kenyan citizens, and this is made worse for those with disabilities. Those left behind the most are those who live in informal settlements.

A prominent theme that came out in our research was the lack of access and stigma. People with disabilities lack access to all manner of things that they should be granted under Kenyan law, and protected as their most fundamental human rights. The challenges facing children with disabilities and their families differed slightly from those faced by adults, however many were still issues of accessibility.

In some cases people are not aware of the small support services that do exist. It is also clear that the NCPWD is underfunded and unable to do the work that it is mandated to do. Its offices are also located in areas which are inaccessible for the many people with disabilities who live in Eastlands, such as residents of Mathare.

While carrying out our research, we saw how women and mothers took up most of the work as caregivers. We also witnessed the determination, resilience, strength and creativity of people with disabilities living in informal settlements, and all the ways they have found to survive in the face of so many injustices and challenges.
## OUR DEMANDS

1. The government provide the services they are mandated and obliged to provide for PWDs
2. That all children with disabilities have access to free education that suits their specific needs
3. That all people who require medical care are able to access it free of charge
4. Therapy and mental health services are made accessible to all
5. Local support groups within informal settlements are better funded and supported
6. Support services, relevant government offices and PWD centres are within or closer to informal settlements
7. Qualified and committed people are appointed to the bodies responsible for providing support to PWDs
8. Awareness to create understanding about the specific needs related to one’s or a family member’s disability
9. Vital supportive equipment is provided to all those in need of it
10. PWDs are supported in finding employment and developing their employability
11. Financial support for PWDs looking to start their own businesses (in order to combat employment discrimination)
12. The accessibility of public buildings is drastically improved and maintained
13. Roads and pavements are improved in Mathare and Nairobi’s other informal settlements.
14. Financial support is offered to those who are unable to work, or need to care for someone full-time
15. Accessible toilets are made available to everyone living in informal settlements
16. Clean, safe, adequate, affordable, accessible and consistent water is provided for all residents of informal settlements
17. Sign language and braille training are made accessible to people living in informal settlements
18. A national campaign is launched to combat the stigmatisation of people with disabilities
Special thanks to those who did so much to make this research and report possible, and especially John Ngugi (MSJC’s Disability Justice Campaign Coordinator), Thomas Chakrabarti (Research Team Leader, Report Co-Author), Matilda Stevens (Report Co-Author, Research). We also thank Juliet Wanjira, Mary Njeri, Rahma Wako, Jennifer Omae, Kennedy Chindi, Wangu Kimari, Open Society Initiative for East Africa (OSIEA), German Doctors/Baraka Medical Centre in Mathare, Mama Victor, Mama Njeri, Joanne, Ekal, Jill and Yash Ghai.

Also very many thanks to Alicia Kedzierski and Coltrane McDowell for the design and layout solidarity.

We would like to acknowledge and pay our utmost respect to all the people living with disabilities in Mathare who shared their life stories and time with us, and contributed to both our participatory research on disability and this report. We are also grateful to their families and carers. We would like to honour their strength, resilience and tenacity. Tunasema viva. Tupo pamoja.

With this report we hope that their lives, humanity and freedom are celebrated and fought for.

Together we continue to fight for disability justice and dignity.
“To us, disability is not a point of individual or social tragedy but a natural and necessary part of human diversity. The tragedy of disability is not our minds and bodies but oppression, exclusion and marginalization. We do not need to be cured. We do not need charity. We need respect, equality and access.”

“Moving forward, the same way we have police stations everywhere, we should have centres for people with disabilities”