

SHUJAAZ

INC.

**GROUNDTRUTH
REPORT**

Executive Summary

Contrary to the general belief that youth in Kenya know little about disability and people with disabilities, we found that the level of awareness about disability among young people in Kenya is high; moreover, they are able to clearly distinguish between physical and mental disabilities, their causes and manifestations.

The attitude and behaviors that youth exercise around Persons with Disability (PWDs) depend on the visibility of PWDs to youth and the context in which youth see them; i.e., it is important how often and under which circumstances youth interact with PWDs. For example, in areas where youth with and without PWDs have grown and been schooled together, young people are more positive towards PWDs and there is little to no discrimination.

The attitude and behavior of youth towards PWDs also depend on the perceived cause of a disability; i.e., whether it was acquired or innate. Those who become disabled after an accident or a disease are more likely to be accepted compared to those who were born disabled because the latter are perceived as a result of a curse, witchcraft or a genetic mutation. Those who were born disabled in some areas are discriminated and seen as outcast.

Generally youth are very tolerant to having PWDs in various proximity levels to them, with the exception of PWDs being boyfriends/girlfriends and MCAs: as long as youth are benefiting in one way or another (money, networks, status, fun, etc.) from having PWDs around, then then it is not a big deal; yet, once PWDs become a burden, youth quickly distance themselves from such relationships.

Most PWDs feel either invisible or misunderstood or both in their communities. They reported feeling that people ignore them, the society does not explicitly plan for them to be included (e.g., no ramps or elevators to get to buildings); they re subject to stereotypes and stigma. Some also felt that people are taking advantage of them and their situation, e.g., cheating blind people of money when charging them for purchases.

BACKGROUND OF THE STUDY

Background

Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions of an individual or a group of individuals. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual/groups in involvement in life situations. (WHO). 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. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers. According to the UN, people with disabilities are those who have long-term physical, mental, intellectual or sensory impairments, which when combined with negative attitudes or environmental barriers, prevent them from taking a full and active role in society (un.org).

Major causes of disability globally are normally categorized as disease, idiopathic (unknown), congenital (born with), malnutrition, poverty, trauma (injury) and ignorance. Many people at some point in time experience some sort of limitation in their functioning because of a health condition or environmental barriers to participation and inclusion. There is likelihood that the increased incidence of disability is a result of the rise in chronic diseases, injuries, car crashes, falls, violence and other causes such as ageing, i.e. longer life expectancy across the globe. Most people with disabilities (PWDs) live in poor conditions without access to basic services, including rehabilitation services, and face difficulties in conducting their daily activities. Globally, PWDs are often marginalized. Most have no access to education, health, employment or rehabilitation (Africa Union of the Blind, 2007). The majority experience hardships as a result of widespread social, cultural and economic prejudices, stigmatization, and, often, abuse and violence.

Many factors can help improve the life of PWDs by making it possible for them to participate in such activities as work, schooling, taking care of the home, and being involved with family and friends in social, recreational and civic activities. Well Told Story, in partnership with UCL, will conduct a research study to understand the existing attitudes and perceptions of young Kenyans towards PWDs and execute a 12-month action research campaign to refine the understanding of Kenyan youth (15-24) attitudes towards PWD, the influencers and the contexts responsible for forming the attitudes, and will suggest a SBCC campaign to modify the attitudes, thus, removing one of the barriers for PWDs lifestyle improvement.

This reports gives a summary of findings from the Ground Truth study conducted in November, 2019.

Study Approach

Shujaaz used its Ground Truth research approach to collect data for this study. Ground Truth is a blended qualitative study that combines several data collection techniques analysis and interpretation. The unique feature of Ground Truth is that it never relies exclusively on the traditional techniques when collecting data. Rather, in the true spirit of the Boal-like street thereafter, it uses a range of participatory tools and stimuli to encourage openness and candor, including: use of scenarios and role plays.

Specific data collection techniques that Shujaaz employed for this study included:

- Focus group discussions (FGDs) with YP 15-24YO
- In-depth interviews (IDIs) with PWDs
- Key informant interviews with people working with PWDs (including parents and other caregivers)

While designing tools, we aimed to ensure appropriateness and relevance of participatory elements of the data collection to the specific group of youth taking part in each FGD. We fully understood that some groups were going to be less inclined to engage in activities than others, therefore, we monitored participant engagement and made necessary adjustments to the tools based on the pilot as well as on the first round of data collection.

Key objectives of the study

- Understand the current state of youth's knowledge, attitudes, norms and behaviours around persons with disability (PWDs).
- Understand the specific barriers to young disabled people accessing services, opportunities and information.
- Understand key sources of information and main influences behind the revealed attitudes, knowledge and behaviours.
- Segment youth by their attitudes and behaviours around PWDs for the purposes of the Shujaaz persuasion campaign.

Locations

With the exception of the former Eastern and North Eastern provinces, views from locations cutting across all other provinces were captured in the study. The specific areas were:

- Dandora (Nairobi, pilot)
- Siaya (Nyanza)
- Mombasa (Coast)
- Kilifi (Coast)
- Nyeri (Central)
- Chavakali (Western)
- Iten (Rift Valley)

FINDINGS:

YOUTH AND THEIR PERCEPTIONS, ATTITUDES, AND BEHAVIOURS RELATED TO DISABILITY AND PERSONS WITH DISABILITIES

FINDING:

1. *Youth knowledge about disabilities and PWDs*

Prelude: Observations regarding youth's knowledge on disability

Young people's awareness of disability is high:

- They were able to differentiate the two key forms of disability that is mental and physical disabilities.
- They could draw PWDs easily, which might be a result of direct contact or sensitization campaigns, frequent or not.
- Because of various sensitization campaigns, they are able to speak almost authoritatively about the causes of disability as well as the community's perceptions towards PWDs.
- There were cases where the youth interviewed were unable to differentiate truths from myths. The myths have become so pervasive within the community thereby acting as a primary source of knowledge about disabilities.

Youth's definitions of people with disabilities

Young people tend to separate physical and mental disabilities and think of them differently:



Physical Impairment

Those without limbs or whose bones are weak making them dependent on assistive technology.

Causes:

- Congenital
- Illnesses
- Accidents (e.g., car accidents, snake bites etc.)
- Sorcery



Mental Impairment

Those not in the right state of mind for example insane people or those with mental illnesses.

Causes:

- Congenital
- Hereditary
- Drug abuse
- Sorcery

Visual definitions of PWDs

When asked to draw people with disabilities, most young people drew people with physical impairments because:

- They are the most visible in the community and most have had contact with them in one way or another
- Physical disabilities are easier to draw than mental disabilities. The youth preferred to mention examples of people with mental disabilities but mainly through imitations. This was because most of them do not know the names of the mental disabilities but know how the conditions manifest physically.



Sample drawings of people with disabilities.

What youth think are the causes of disability

Agreed-on causes

- **Congenital** – Those born with a disability
- **Accident** - A person can become disabled through road carnage.
- **Heredity** - Disability passed down through genetics for example those who gradually lose their sense of sight.
- **Drug Abuse and carelessness**- one can end up been disabled due to own mistakes (for example the excessive use of drugs) or other, avoidable situations (for example a smoking, pregnant woman may cause the unborn child to be born with some form of disability).
- **Illnesses** - health issues or long illnesses. Cancer, for example, can leads to loss of body parts; cerebral malaria may cause mentally disability.
- **Mob justice**
- **Nutrition deficit** –lack of nutrients at an early age can cause some deformity leading to disability e.g. rickets & Kwashiorkor
- **Snake or other animal bites** - Cases of poorly treated or untreated snake bites can result in amputations.

Debated, unproven causes

- **Sorcery** – There is a group of young people who believe that disability can be caused by witchcraft and rituals and/or curses. For instance, siblings can bewitch each other in the fight for land or wealth; parents can sacrifice their children to gain material wealth; elders can curse people who they are dissatisfied with; *Albadiri* (mentioned by those in the Coastal areas) can be recited to curse someone; and children born out of incest become disabled.

NB: Most of those with strong religious beliefs don't believe in witchcraft and curses

FINDING:

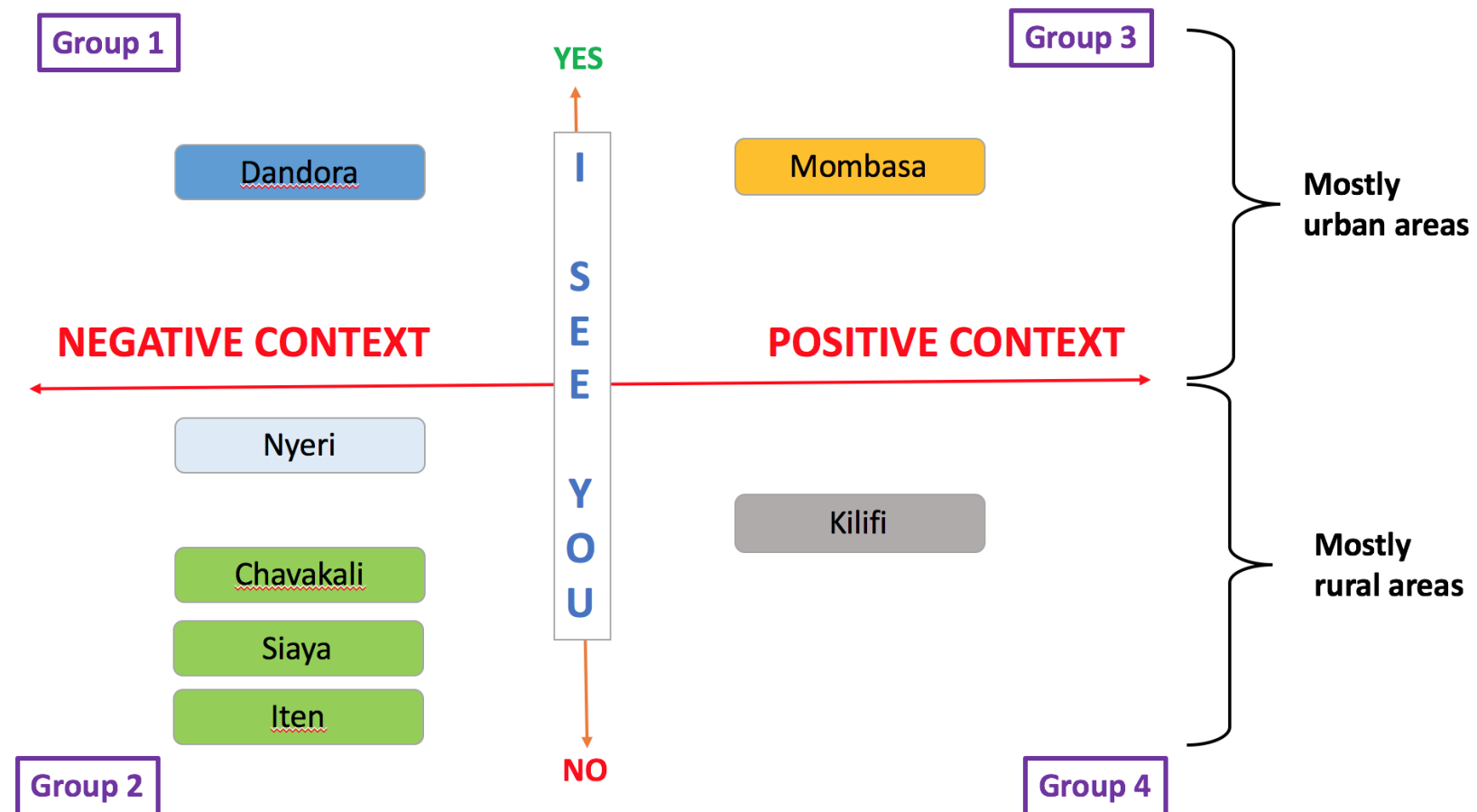
2. Youth segmentation by attitudes and behavior around PWDs

Youth segments by attitudes towards PWDs

Youth attitudes towards PWDs are defined by two key factors:

- visibility of PWDs i.e. how often youth see and interact with them in their own community; and
- the context in which youth encounters with PWDs happen – positive (PWDs are part of routine life vents) or negative (e.g., PWDs are a subject to abuse or are themselves perceived as rude and/or abusive).

Visibility and the type of context in combination shape community perception towards PWDs, which then defines youth attitudes.



Youth segments by attitudes towards PWDs

MOSTLY NEGATIVE ATTITUDES

GROUP 1: Exposure to PWDs is high; attitude towards them is somewhat negative (Dandora)

- PWDs are visible but in a negative context e.g. beggars on the streets, arrogant and sometimes rude.
- A number of youth felt that PWDs use their situation to their advantage for example, they would prefer to beg instead of working to earn a living.

GROUP 2: Exposure to PWDs is low, attitude towards them is negative (Iten, Chavakali, Siaya)

- Youth seldom see PWDs and mainly associate them with children's home - thus their circle of interaction is smaller.
- In these communities, most families hide people with PWDs; and because of the low visibility, myths and misconceptions prevail over accurate information and the general outlook towards PWDs becomes negative.

GROUP 3: Exposure to PWDs is high; attitude is positive (Mombasa)

- PWDs are visible to the youth and most are seen in a positive aspect because:
 - PWDs are all around them and are part of their lives. They live with them and even go to school with them.
 - They also see PWDs taking care of themselves by running small businesses (or hustles) i.e. most are independent and youth aim to promote them.
- There has also been a lot of sensitization by the government and other community-based organizations, which are trying to change the perceptions towards PWDs and improve the livelihoods of PWDs. As a result, the community's perception towards PWDs has shifted over time and they have become more accepting of them.

GROUP 4: Exposure to PWDs is low; attitude is positive (Kilifi)

- PWDs are not as visible, however, they live with in peace with the rest of the community; and the community assists in taking care of them when the need arises.
- The PWDs in these communities are also doing something positive with their lives for example, use their talents to earn a living.

Religion and religion-based community organizations play a big role in promoting positive attitudes towards PWDs by encouraging them to integrate in the community and encouraging the community (youth) to be tolerant, respectful, merciful, etc.

MOSTLY POSITIVE ATTITUDES

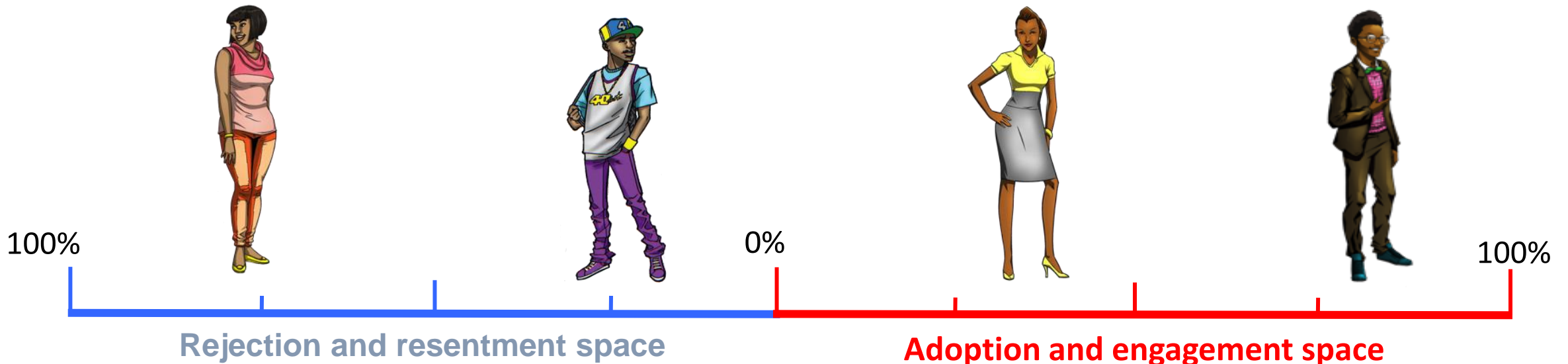
Youth segments as potential target audience for a media campaign

Group 2: Victim to horror tales
 Needs: Knowledge and PWD image correction via accurate information and stories of PWDs being part of a regular (positive) lives of their peers

Group 1: Victim to "narrow vision"
 Needs: Attitude correction via opportunities for routine positive interactions with PWDs in their every day lives

Group 4: Peaceful parallel co-existence with PWDs
 Needs: Behavior correction via meaningful joint activities with PWDs in their communities, including talent showcasing and hustle

Group 3: Positive daily co-existence, co-operation and integration with PWDs within a supportive community
 Needs: Become role models for youth in other groups



FINDING:

3. *Proximity to PWDs*

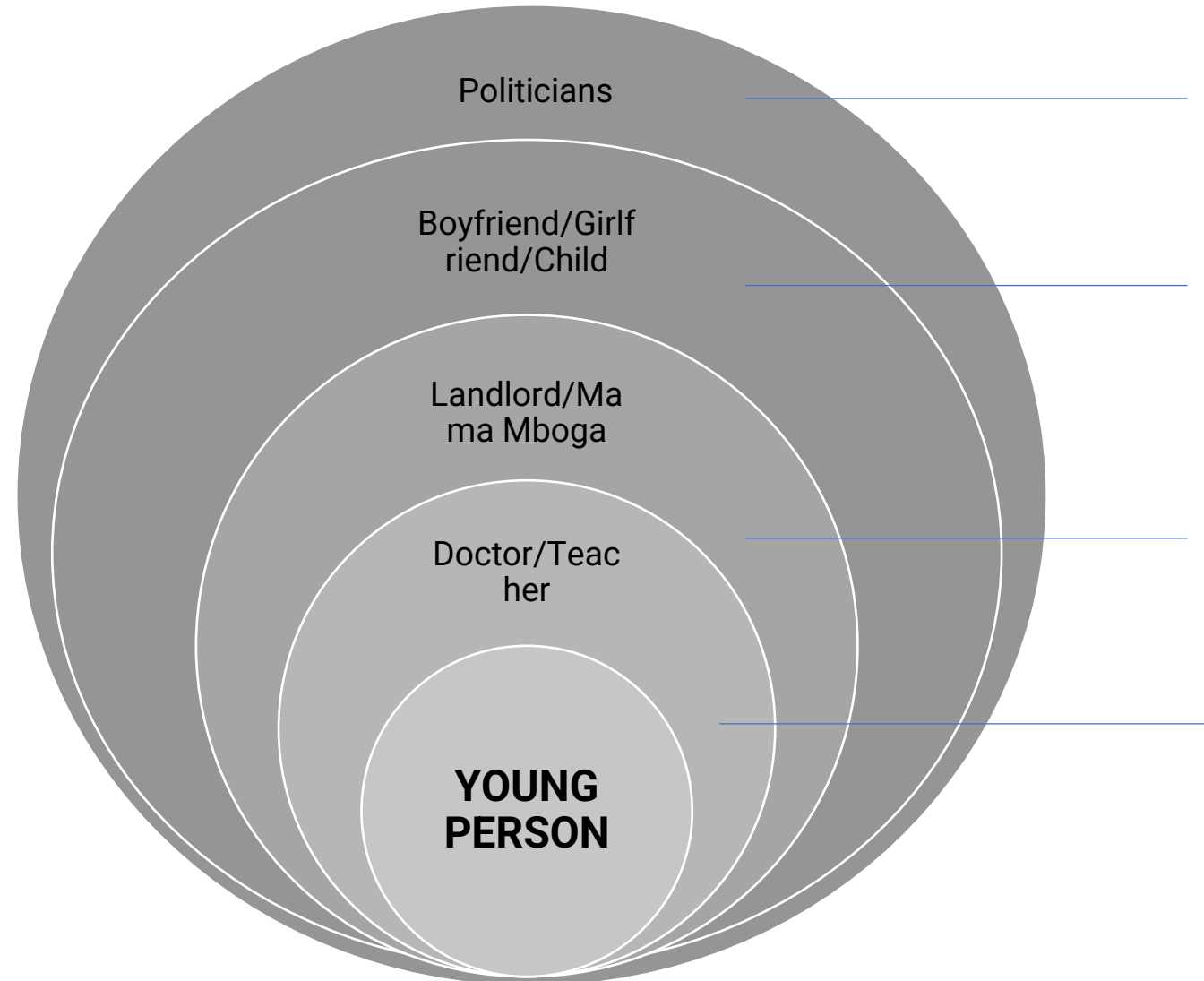
How close would youth want to be with someone who is disabled?

- When youth were asked how close they would want PWDs to be in their daily lives, most categorised them according to different factors. It was noted that they would not be comfortable when people that they care about became disabled but would not mind those who they least care about and they least interact with to become disabled.
- The young people based their level of proximity on different factors that included:

Love and affection	Occupation	Favors	Financial stability
<ul style="list-style-type: none"> Love and affection can be negative or positive. For people whom they love for example their children or their boyfriends/girlfriends, they would not want them to be disabled. The reasons mentioned included: <ul style="list-style-type: none"> The added responsibility that comes with taking care of a PWD The embarrassment of walking around with them; this could even lead to unfaithfulness in a relationship. Concern about what people in the community would say How would the disabled person take care of them when they need them, e.g. when they are sick 	<ul style="list-style-type: none"> For most youth, It doesn't matter when a professional e.g. a doctor or teacher, is disabled. By the time they become professionals, they have been accredited for the skills they possess therefore their disability poses no risk. <i>Some PWD professionals (e.g., doctors and teachers) have to put more effort in getting accredited and might be more skillful than able professionals. PWD professionals are also more attuned to the suffering/struggles of others.</i> Disabled politicians are also fine to have. However, there are some youth who would wish for politicians who get to power and embezzle fund to become disabled as a form of punishment. 	<ul style="list-style-type: none"> One can get favours from PWDs, who are shopkeepers or any type of leaders/persons in charge because other people will be neglecting them. Having a disabled person around one can be a blessing, specifically, they would preferential treatment for services and they will experience low cases of theft - because people feel ashamed to steal from disabled people (this depends on the community) 	<ul style="list-style-type: none"> A few young people would not mind having a disabled person in their life if it helps them build their financial status, including through networking and direct financial support.

Proximity to PWDs

Young people's view on how close they would like to be to PWDs on different factors such as what they are gaining from the PWDs and the type of disability.



Politicians are already perceived negatively by youth; a disability is believed to be yet another factor, which will help corrupt politicians justify embezzling funds and working less.

Taking care of a disabled person is involving and requires a lot of sacrifice. Although youth can date or would accept PWDs, this will not be their ideal choice in a situation. However, dating is more nuanced and other factors such as type of disability of the financial stability of a person will determine the possibility of dating.

Sentiment towards them is neither positive nor negative

It doesn't matter when a professional e.g. a doctor or teacher is disabled. By the time they become professionals, they have been accredited for the skill they possess therefore their disability poses no risk, however, *they might have better skills because they work harder than others and are sympathetic to other people's suffering and struggles.*

FINDING:

4. *Community perception towards PWDs*

The community's perception towards PWDs

Young people told us that most communities have accepted PWDs nowadays, largely as a result of education and sensitization sessions by the government and several non-governmental organizations who hold awareness sessions in the communities and encourage people to spread the word. Consequently, many caregivers no longer hide PWDs thus increasing awareness of the normalcy of their situation. This has helped reduce stigmatization towards PWDs.

However, there are still some people and/or communities with negative perceptions towards PWDs.

- Some communities still view them as a shame and cursed (*the Shujaaz team was given an example where a family separated because of the birth of a disabled child*) while others see them as a burden. Some people go as far as using traditional medicine to try and “cure” the disability.
- There are people who think that some disabled people are using their situation to get money e.g. by begging.
- Children who have been sacrificed for wealth are usually avoided. People are afraid of getting “infected”.

As a result, the communities with negative perceptions seldom involve them in community activities and will pay little or no attention to their opinions. Most in these communities also think that PWDs should not be given an opportunity to learn because they have a shorter lifespan. This leads to further stigmatization.

It is key to note, however, that some types of disability are “more acceptable” than others. For instance, those who become disabled because of accidents are not as discriminated against as the others.

Stories from the fields on community perception on PWD

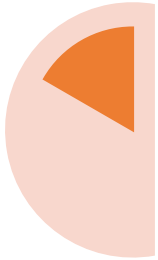
‘There is a child who used to be hidden, a big one, 11 years old. She used to have a problem with her neck, but people never saw her. But if you pass by the house you hear her voice, but she was never seen. And people would even say that there is a child being hidden. The only time when people saw her was when she passed on and we were all surprised that it was a big child.’

‘A disabled person was shortlisted for an interview, and he had to appear before a panel. One the day of the interview he realised that the building had no ramps or lifts. He had to rely on people to carry him from one floor to another, and then wait for other people to do the same. The interview went on well and he got the job. However, the person did not take the job because he sat down and thought of how he would be getting to work every morning and going home every evening.’

FINDING:

5. *Challenges PWDs face in their daily lives*

Challenges PWDs face



Lack of opportunities and discrimination

They are locked out from accessing some job opportunities that they would have otherwise preferred due to their physical limitations e.g. becoming a policeman/army.

The physical environment is not always fully PWD-friendly. One person gave up a job opportunity because the office was in a building that would be challenging to access on a daily basis.

Other employers lock them out of opportunities once they realize they are disabled.

Some communities do not accept disabled leaders therefore lock them out of leadership opportunities.

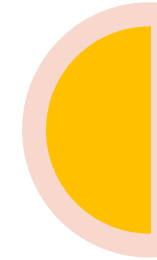


Lack of love

Lack of family love - some are abandoned by the parents and family.

Difficulty finding love or forming relationships with people of the opposite sex

Difficulties in socializing too because of their disability.



Little enabling information and limited formal support system

Lack of information about things that relate to them. For instance, most are not aware of the relevant opportunities or government exemptions set aside for them therefore making them prone to being taken advantage of.

Behaviors exhibited by PWDs that vexes other people

Behaviour of PWDs

- Most are seen to be aggressive and rude. There have been cases of PWDs in position of power mistreating or speaking rudely to other people. They also become abusive when people help them without asking but also when they want assistance and do not get any.
- They get annoyed easily and think that anybody who mistreats them does so because of their disability. Innocent questions or conversations can also get them annoyed especially if they feel as if they are being attacked.

Examples of experiences with disabled people

- *“During the census there is an enumerator who asked the owner of the house if his disability restricts him from doing certain activities. The owner was mad and started abusing the enumerator. But the enumerator was just doing his job. That question was part of the questions to be asked.”*
- *“There is a disabled person who works in the ID section of an office somewhere close to Dandora. The disabled person used to be a beggar. When she got this job, she changed completely. She speaks very rudely to people and makes someone uncomfortable of even speaking with her.”*
- *“There was one who I was talking to but since he was dumb, his friend was helping us interpret. At some point I started addressing the interpreter and this apparently agitated the disabled person who become angry and stopped speaking to me altogether. Unfortunately I didn’t understand what was going on. Only later was I told that they don’t like this.”*
- *“There was a day I was walking on the streets and there was a pool of mud. So I stood aside to let a lame guy pass and as he was passing me, he pushed me saying “we kwenda huko”. Yet I had stood aside to let him pass!”*

RECOMMENDATIONS

Recommendations for a media campaign

- It appears that the most effective way for young people to develop positive attitudes towards PWDs has been via normalized, frequent and positive engagements with them as part of their routine lives. We therefore recommend that stories of PWD characters are *imbedded* in other stories and participate on par with other Shujaaz characters in various daily activities. We believe, that creating a separate story focusing on PWDs would further highlight their separation from the community.
- Each of the four youth segments require a slightly different approach to the campaign, which can be emphasized via different media channels – for example, Groups 1 and 2 would benefit from traditional comic and radio stories supported by the engaging conversations through social media, while for Group 4 we would recommend face-to-face engagement with PWDs during Shujaaz monthly Konnect events. Finally, we believe that youth in Group 3 can serve as role models and positive deviants for modeling the campaign.
- The campaign need to address both fully-abled and differently-abled youth. It is important to showcase to PWDs the way they might be part in creating the misunderstanding that they are experiencing and/or what their contribution can be in redefining their role in the community.
- It is important to continue insight-generation activities alongside the main media campaign to gather more and more nuanced details on youth attitudes, behaviors perceptions and stereotypes about PWD and disability as well as about the attitudes, behaviors and challenges of the PWDs within their respective communal contexts.

Acknowledgements

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