Echoes of hope for women with psychosocial disabilities in Kassanda, Uganda

Mubende Women with Disabilities Association (MUDIWA)

With the support of Making It Work

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Mubende Women with Disabilities Association (MUDIWA) is an organisation of women and girls with disabilities in Uganda, committed to promoting the rights of women and girls with disabilities in all aspects of life.

MUDIWA works to respond to the injustices and barriers that hinder the participation of women and girls with disabilities in the district. MUDIWA's programme is anchored on five key intervention areas; Gender Based Violence Prevention and Response, Sexual Reproductive Health and Rights (SRHR), Education and Skills Development, Community Inclusion and Livelihoods, Advocacy and Organisational Effectiveness.

MUDIWA uses partnership as its approach to reaching its intended beneficiaries. The leadership of MUDIWA is made up of women with different disabilities including physical, sensory and intellectual disabilities.

Driven by a strong commitment to gender and disability inclusion, MUDIWA set out to uncover the realities faced by women with psychosocial disabilities in the district.

In March 2024, MUDIWA met with 60 women with psychosocial disabilities, 4 of whom had speech and cognitive challenges that required support from their caregivers. The women shared their experiences of living with psychosocial disabilities within their communities, their challenges, and their needs for inclusion in society.

This work was conducted with the support of Humanity & Inclusion's Making It Work Gender and Disability project, with technical guidance from Isabelle Lamaud, whose contributions were instrumental in shaping this report.

Our warmest thanks go to the 60 women and care givers who placed their trust in us.

We would also like to thank the MUDIWA structure members in the sub counties of Myanzi, Nalutuntu, Manyogaseka and Kiganda Town, Council Chairperson LC111s, Community Development Officers, In-Charge Health Centre 111s, District Health Officer Kassanda District, District Education Officer Kassanda who made all our meetings possible.

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Photos: credit MUDIWA
Cover page: Group picture with MUDIWA board member

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In loving memory of Namagembe Margaret Tendo, a courageous voice for women with psychosocial disabilities in Kassanda District and Board member of MUDIWA.
Her legacy lives on in every page of this report.

Introduction

Geographical scope

This study took place in the Central Region of Uganda, Kassanda District and we targeted four sub counties of: Myanzi, Manyogaseka, Nalutuntu and Kiganda town council within Kassanda South County in Kassanda District. Kassanda is a rural based district with 90% of the citizens practicing peasant farming. The people in Kassanda mainly grow maize, coffee, beans among others but also keep livestock such as cattle, goats and commercial fishing in some instances. In some sub counties like Kitumbi, Kijjuna and Bukuya, people are involved in gold mining activities.

Respondents and methodology

The participants in this study were key informants selected from different sectors of education, community development and health ; as well as the 60 women with psychosocial disabilities and care givers from the four sub counties.

Key informants provided valuable insights to enhance our understanding of the context and validate the content of our questionnaire. However, the primary source of information for this report came from discussions with women with psychosocial disabilities and their care givers, which allowed us to reflect on their lived experiences.

The key informants were individuals possessing substantial knowledge about behaviours, lifestyles, and practices influencing the access to services and lives of women with psychosocial disabilities. Specifically, the study conducted interviews with health professionals working in government facilities, community development officers at the sub-county level, and personnel in the education sector. Additionally, traditional healers from each sub-county were included in the interviews.

Key Informant Interviews (KIIs) :

- Sub-county Community Development Officers (4 people)
- Traditional Healers (4 people)
- Health Professional from Mubende Referral Hospital (1 person), Kasanda Health centre IV (1 person)
- District Education officer/Special Needs Education (1 person)

We interviewed a total of 60 women with psychosocial disabilities and their caregivers from four sub-counties: Myanzi, Kiganda Town Council, Manyogaseka, and Nalutuntu. Interviews were conducted directly, but for 4 women (3 from Nalutuntu and 1 from Kiganda), their caregivers spoke on their behalf due to speech and cognitive difficulties.

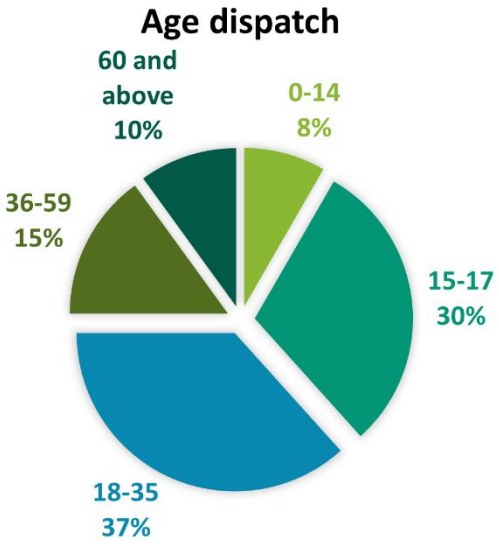
Both interview guides for the Key Informants and for the women were initially discussed with Lira District Disabled Women Association (LIDDWA) that produced a similar report in the "Voices of" collection: Voices of Women with Psychosocial Disabilities in Lira, Uganda – May 2024. Interview guides were further finalized by MUDIWA with the support of Robinah Alambuya from TRIUMPH Uganda and Sophie Pecourt from MIW. Informed consent was carefully sought and obtained from each participant, with adequate time given to ensure understanding and voluntary participation.

Interviews were conducted by John Mary Nsimbi, Program Manager, Winfred Namukwaya, Executive Director, and 3 MUDIWA Board members: Chairperson Ms. Nanteza Regina, Vice Chairperson Ms. Nantiba Specioza and Secretary Namukwaya Justine.

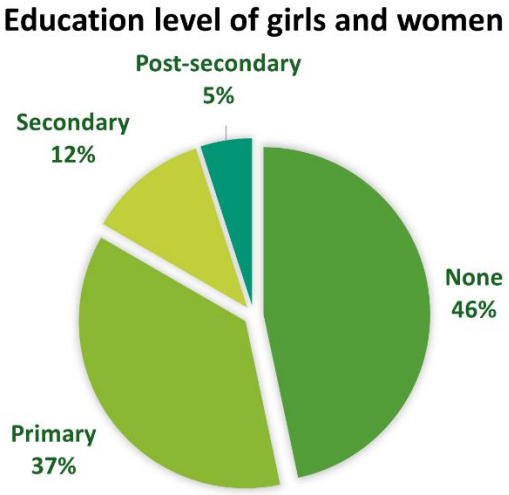
These women who spoke to us

To meet and talk with women with psychosocial disabilities, MUDIWA board members, and staff travelled to their respective communities, for those with speech and cognitive challenges they were interviewed through their care givers. Others were met at their homes, and those who were able to travel came to the places planned and communicated by MUDIWA.

The women interviewed showed a diversity of age, ranging from teenagers to seniors, as demonstrated in the graphs below.

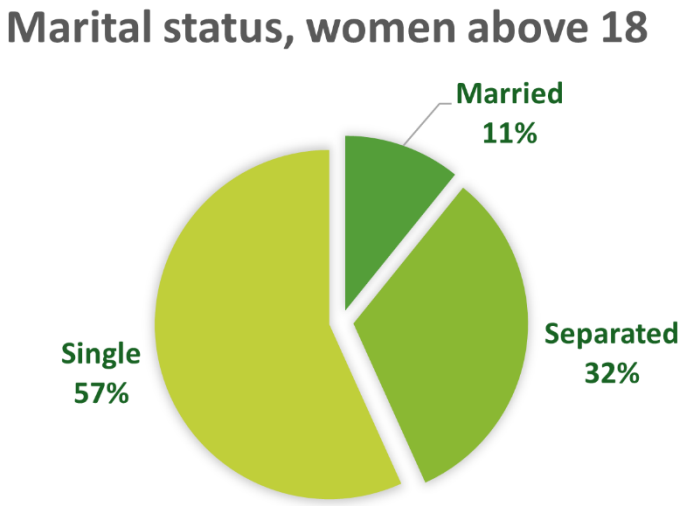


The women interviewed were asked about the highest level of education they had attained. As the graph below illustrates, nearly half of them, or 46%, reported having no formal education. 37% completed primary education, 12% reached secondary level and only 5% pursued post-secondary education. This highlights that the majority of the women interviewed had very limited access to higher levels of education.



Women were asked about their current marital status. Here, we present the results for adult women, defined as those aged 18 and over. The chart indicates that the majority of women above 18 are single, with a significant portion also separated. Only a small percentage are currently married.

It is important to note that, despite the legal marriage age in Uganda being 18, 5 of the girls aged 15–17 declared that they were married. None of the girls under 15 years old who were interviewed declared that they were married.



Key findings: Lived realities of women with psychosocial disabilities

Rejected and mistreated in all spheres of society

Facing restrictions on movement and restrictions on freedom

The women interviewed described living in an environment where their movements, interactions and freedom were restricted. They experience limited social interaction due to family rejection and a lack of support networks, which prevents them from participating in community activities and social events. Of the 60 women with psychosocial disabilities interviewed, 37 reported being 'not allowed' to go anywhere, while only five expressed having the freedom to move around as they wish. Additionally, nine women mentioned being able to attend church freely and seven said they attended functions and social events primarily to access food.

"My family fear the rath of the community because they think am dangerous to them, the moment, they see you they gang up and beat you up" one woman shared.

The study also shows that negative reactions from the community, ranging from insults to physical violence, limit women's ability to participate in community events or move freely within their environment. When asked if they feel free and safe when moving around the community, 46 out of 60 women reported having been insulted.

Struggling with relationships and family life

Out of the 60 women interviewed, 39 were single, 12 had become separated after developing a mental illness and only 9 were married.

The women said that if someone experiences mental health issues, there is a high chance that their marriage will end, and it is very difficult for those who are not married to find a partner.

Some mothers are denied the right to care for their children, even when they express an interest in doing so, which has consequences for the children themselves.

"Am struggling to have custody of my children even after losing my Marriage, my children are mistreated by my co-wife but I can't have access to my children"

Women also shared that they experience difficulties with friendships and struggle to form and maintain relationships at the community and family levels.

When asked how living with a psychosocial disability affected their participation in society, 37 out of 60 said that they did not socialise with other people, and a further 19 said that they were not close to their family members.

"Some of my children don't feel comfortable with my mental conditions, though my second born will always stand with me when I get relapses".

However, women with psychosocial disabilities have developed trust in some of their relatives, friends, and community leaders, to whom they can confide. During the interview, 55 women said they knew who to turn to for help with specific problems. Forty-seven of them said it would be 'friends in the village', while others mentioned their mothers or nuns at the church.

''when I get a problem, I go to the catholic convent; the nuns are my friends they give me food and treat me when am sick".

Their experience of violence is overwhelming

The women with psychosocial disabilities who participated in this study described facing violence and mistreatment in various areas of their lives.

When asked about the difficulties they face in daily life, 27 of the 60 women interviewed specifically mentioned rape and defilement. Eighteen also mentioned domestic violence. Some women with psychosocial disabilities are victims of sexual violence and have their rights denied.

"If a woman with psychosocial disability is raped the community does not take it seriously" - a health worker.

Other challenges that respondents faced in their daily lives included 'discrimination from the community' (cited by 30 respondents) and 'not being valued by people at home' (cited by 17 respondents). Thirteen women

mentioned family mistreatment in response to the first question, which asked how they felt that day.

When asked how their disability has impacted their relationships, 22 women said that men do not propose entering into a relationship with them, but rather "grab them at night".

Forced contraception, forced abortion

Violence includes losing control over one's body and being denied the right to make choices about reproduction, with women reporting forced abortion.

Out of 60 women, 53 said that they were unable to make choices about contraception and childbearing. As a health worker shared, “Family members are the ones who decide for them”.

“Instead of putting me on mental health drugs my family preferred to family planning pills for fear of me getting pregnant”.

Health workers report that relatives find it easier to enrol women with psychosocial disabilities in family planning programmes than in mental health treatment programmes.

During interviews, some women revealed that they had been coerced into having an abortion.

"I have been forced to abort twice, but the last one was so painful."

Dealing with mental illness is easier than dealing with the stigma

The study revealed that women with psychosocial disabilities struggle with low self-esteem due to a negative self-image and sense of self-worth. This is caused by societal attitudes, cultural beliefs and stereotypes surrounding mental illness and disability.

This stigma can lead to anxiety, depression, social withdrawal, self-blame and a lack of empowerment.

The women reported that dealing with the stigma was more challenging than managing their mental health. Of the 60 women interviewed, 55 reported stress due to insults, poor nutrition, and inadequate shelter. The remaining

respondents, however, expressed happiness simply because they were alive, had food, and their children were healthy.

Woman being interviewed by MUDIWA Executive Director

Tremendous barriers to care: Denied access to general and mental health care.

The women we interviewed faced tremendous barriers to accessing care. More than 90 per cent — 55 out of 60 — said that they were unable to access services that would support their health.

Seeking professional support

While 22 women said that they rarely visited health centres, 36 said that they had sought help at health facilities but received none.

Those who were treated by mental health professionals described positive experiences. One woman shared that she had gone with a friend to Mubende Hospital and that the nurses had been very kind.

Health professionals outlined the support they provide to women with psychosocial disabilities, including medication, psychosocial support and counselling. They also educate women about their condition and how to explain it to caregivers, help them to identify warning signs and drug side effects, and refer them for further treatment if necessary.

Lack of access to mental health medications

The study found that most women with psychosocial disabilities in Kassanda district were not receiving medication, primarily due to an inconsistent drug supply at nearby health centres. Health workers confirmed this issue, stating:

'The drugs are never available. The ones that are available are used to manage other conditions." For example, diazepam is used to control convulsions, but it can also be used as a tranquilliser and to treat alcohol withdrawal syndrome. We normally refer most patients.'

Additional factors contributing to the low uptake of mental health medicines include long distances and a lack of transport to health centres. Of the 60 women interviewed, 42 cited long distances as the reason for not taking medication. Some women sought medical treatment from health professionals at the regional referral hospital, which is 30 kilometres away. The medication provided is typically sufficient for one month, but it is

sometimes out of stock. In such cases, women are advised to purchase medication from private pharmacies, which is expensive.

Public transport operators occasionally deny women with psychosocial disabilities access to their services. In rural areas, motorcycles, locally known as 'Boda Bodas', are the primary mode of transport. Boda Boda riders are often reluctant to transport these women, citing concerns about potential harm or stigmatisation.

"I got into an accident while on a Boda Boda. The rider didn't want me to hold him for safety, so I fell off."

lack of regular access to sufficient food and clean water has a negative impact on treatment adherence: medication side effects are exacerbated when there is a lack of food and water, some women have reported that they have stopped treatment as a result.

Limited knowledge and skills by health workers

Interactions with health workers revealed that some of those working in nearby health centres lacked the knowledge required to deal with mental health issues.

"We lack skills to diagnose and treat such conditions" one health worker mentioned.

When asked about their experience of working with women and girls with mental health issues, health professionals also noted stigma and judgement from other health workers, as well as a fear of expressing themselves.

"What we have always done is to refer the patient to the regional referral hospital and at times they don't go there because of long distances, so family decides to keep the patient home or get alternative treatment from traditional healers", one health worker said.

Use of traditional healers as alternative treatment

Due to cultural beliefs that mental illness is caused by witchcraft, traditional healers are very influential in addressing mental health issues.

"The mental health conditions are associated to local ancestral and super divine powers so the health systems come in when the families are affected for example if the person is violent and severe", one health worker explained.

It was observed that family members often sought help from traditional healers before consulting conventional doctors. When asked who they first turned to for treatment for themselves or their children, 31 women and care takers reported visiting traditional healers before trying any other options.

"Unless the person affected with mental health challenges is of high calibre in society, most of the time they are not cared for" as a health worker further said.

Terrible living conditions

As well as facing high levels of violence and having limited access to healthcare, the women we interviewed reported living in deplorable conditions.

Community exploitation

Key informants noted that women with psychosocial disabilities who provide services to community members are paid significantly less than others for doing the same work. For example, fetching a jerrycan of water usually earns 500 Ugandan shillings, but these women may be offered as little as 100 shillings, or sometimes nothing at all except food. This leads to exploitation.

"They are not paid equal to the market price; some are only given food" as a community development officer said.

According to the findings, only 12 of the 60 women interviewed had a regular income from fetching water for people, washing clothes and tailoring, and some were involved in farming. The majority were involved in farming, mainly as part of a family business, and did not receive any of the profits.

Inadequate housing and sanitation

Many women highlighted inadequate shelter and clothing, which may be related to a lack of consideration for their needs by community members and family. The study found that 11 out of 60 women did not have a specific

place to live and that 46 women commonly struggled to sleep well. Most women with psychosocial disabilities do not live in adequate housing with their families and often have to share spaces with animals or sleep on verandas or in unfinished and abandoned structures.

"I sleep in the kitchen of a well-wisher"

Women with disabilities find menstrual hygiene management difficult, which compromises their dignity. They often lack access to sanitary towels, or do not know how to use them properly.

"When I am in my periods it is hard to get pads"

Insufficient access to and control over land and resources

Women with psychosocial disabilities have no access to land, which is a major source of income in rural areas. Of the 60 women interviewed, 51 said that they lacked money because they had nothing to do. However, women with psychosocial disabilities are willing to participate in income-generating activities if given the opportunity. 46 of the 60 respondents said they could not access any resources; only 12 were doing some form of work, such as gardening or helping at home.

Similarly, 43 of the 60 women interviewed had no access to land, and 12 had been evicted from theirs by family members and the wider community.

'We don't have a right to own land'

"When my father died my other siblings started fighting me until they chased me from the land which was given to me"

"They will give you a bush to clear after one season they ask you to surrender their land after you have wasted all that energy"

As mentioned earlier, almost half of the women interviewed did not attend school, while a further third completed primary education. The main reasons for dropping out were a lack of school fees, the death of a relative or carer, and mental health issues.

Education professionals confirmed that there were no accommodations or assistive devices in place to help girls with psychosocial disabilities overcome school challenges.

Woman being interviewed in Nalutuntu sub-county

Poor nutrition

Women with psychosocial disabilities receive limited care at the family level. They do not receive the same level of attention as other family members who may be ill. Women with psychosocial disabilities are sometimes denied food by their own families, who assume that they can find food anywhere. As a result, they often resort to eating food from rubbish bins and restaurant leftovers. Two respondents confirmed this, saying that they move between villages in search of good food from events such as weddings and funerals.

Some women with psychosocial disabilities have stopped taking their mental health medication due to its side effects. During our interviews, several women explained that they were unable to continue their treatment because the medication required adequate nutrition—which they did not have access to. The lack of sufficient food not only affected their general well-being but also directly contributed to low adherence to prescribed medication.

Trying their best to live a better life

Despite experiencing various forms of mistreatment, women with psychosocial disabilities demonstrate remarkable resilience.

They remain willing to be active and desire further training to enhance their skills. Out of the 60 women interviewed, 53 said that they would like to acquire further education or training. Many have developed coping mechanisms, such as establishing support networks with family, friends and community members for emotional support and practical assistance. According to the study, with support, women could venture into livelihood projects such as a bakery, poultry farming, mushroom farming, running a restaurant or shop, buying produce, running a salon, livestock farming, making soap, tailoring and fruit farming.

Participation in income generating activities

"Instead of staying home doing nothing I do crafts"

Some women with psychosocial disabilities are engaged in various activities, ranging from farming and animal husbandry to manual labour such as fetching water and cleaning clothes. However, they are paid less than other women without psychosocial disabilities for doing the same work.

According to the study, only 11 of the 60 women interviewed were involved in activities that provided them with a regular income. The rest said they participated in unpaid farming and domestic care work.

Able to defend themselves and their children

Despite facing discrimination, stigma and social isolation, some have asserted their rights and needs. They have built relationships with trusted friends, family members or peers, and developed coping mechanisms such as seeking counselling and attending church services.

By creating support networks, they are able to make ends meet. They find creative solutions to their daily challenges. 21 out of 60 women revealed that they had at least built a network of friends within their families and communities, while 11 mostly sought help from churches and well-wishers.

They demonstrate the determination and strength needed to care for their children and protect themselves.

"Am feeling happy that I have stabilized and happy with my children''

Claiming their rights

Through self-advocacy, women with psychosocial disabilities have asserted their rights and reclaimed what is rightfully theirs. The following quotes illustrate this.

'' I am taking care of the family land, the rest was sold including my share but now am taking care of the family land".

"I reported my case to MUDIWA seeking some help to ensure that the family surrender my piece of land which was taken away from me after getting a mental illness, despite the constant reminders they still think am not in my right mind to claim what belongs to me".

Some of the women interviewed said that they play a role in ensuring that community members understand their rights.

"I confront them and always raise awareness about our capabilities''.

"When they violate my right or for others, I report them".

Cross cutting issues

- **Social exclusion**

  Women with psychosocial disabilities often experience social exclusion, marginalisation and stigma within their communities.
  Discrimination against these individuals is common in education, employment, and healthcare.
  Negative attitudes and stereotypes towards women with psychosocial disabilities can lead to further marginalisation.

- **Human rights violations**

  Women with psychosocial disabilities often experience violations of their human rights, including the right to equality, dignity and freedom from discrimination. They lack access to justice such as legal capacity and access to legal aid. Institutionalisation of women with psychosocial disabilities can lead to further human rights violations.

- **Health**

  According to WHO, "Women with psychosocial disabilities face an elevated risk of developing comorbid conditions such as diabetes, obesity, and cardiovascular diseases"[1] although their access to mental health and other health services is limited.

- **Education**

  Women with psychosocial disabilities face barriers in accessing education including stigma and discrimination due to negative attitudes, belief and myth surrounding psychosocial disability.

- **Lack of family and community support**

  Women with psychosocial disability experience lack of family support including emotional, financial and practical support, they also face negative stereotypes and stigma.

[1] in "World Health Organization (2021). Addressing comorbidity between mental disorders and major noncommunicable diseases."

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This report documents the lived experiences of 60 women with psychosocial disabilities in Kassanda District, Uganda. Conducted by MUDIWA with the support of the Making It Work project, it highlights the challenges they face, including violence, stigma, and lack of access to care and education. Despite adversity, these women show resilience and a strong desire to live better lives. The findings call for urgent action to promote inclusion, dignity, and rights for women with psychosocial disabilities. This work is a step toward amplifying their voices and inspiring change.

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