“They don’t consider me as a person”

Mental health and human rights in Ugandan communities

mdac
mental disability advocacy center

MENTAL HEALTH UGANDA
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Support Our Cause

“They don’t consider me as a person”

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Foreword

I am humbled and privileged to be invited to provide a foreword to this report. The content is an eye-opener and highly informative. I have met and interacted with many people with mental health issues in Uganda and it is important for us to recognise that they are citizens of our nation. There is an urgent need for us to combine efforts and ensure that they can fully enjoy their human rights.

This report does two important things which are worthy of note. First, it presents the often unheard voices of people with mental health issues themselves. Secondly, when we listen to these voices, we see that they are frequently subjected to the most appalling abuses in their daily lives, including torture, ill-treatment, violence and exploitation. It is of deep concern that they tell us that these abuses take place in their homes and communities, as well as in hospitals, traditional healing centres, schools and work places. They have little faith in the police or justice systems. It is heartbreaking that in this century fellow Ugandans continue to experience such abuses with little or no protection.

The government has taken some commendable steps to advance and protect the rights of people with disabilities in Uganda. These include adopting a disability law in 2006 which is currently under review. This commitment has also been proclaimed internationally, through the Ugandan ratification of United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol in 2008. The Prevention and Prohibition of Torture Law was also passed in 2012, and the Constitution guarantees equal protection to all.

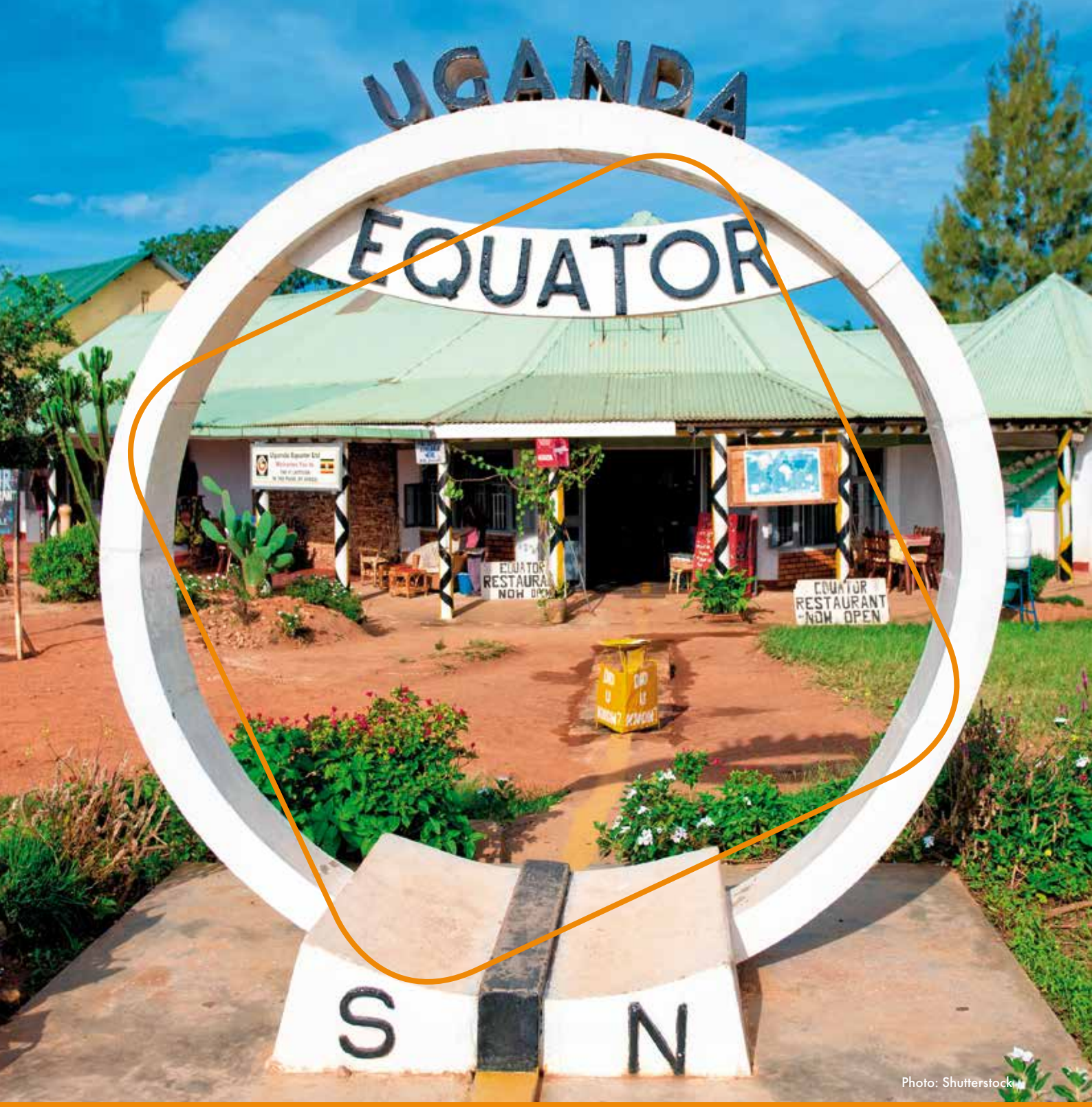
Yet, as people with mental health issues explain in this report, legislation alone is not enough to combat the widespread violence and discrimination they experience on a daily basis. People with mental health issues have dreams and aspirations in the same was as every other Ugandan citizen, and should be valued for the contributions that they can make to our society. We must start by listening to them.

The testimonies in this report should push Uganda to take action to combat stigma and stereotypes. These issues are not unique to Uganda, but are the basis upon which people with mental health issues are excluded and denied their fundamental human rights. Concrete and measurable plans must be put in place to challenge the present situation, and should engage stakeholders at all levels.

As Ugandans, we have a moral and legal obligation to take swift, targeted action and put a stop to gross and systematic human rights violations. Statistics show that a quarter of all Ugandan citizens will experience mental health issues at some point in their life. We must provide support to them, and to their families and communities. At the moment, the burden primarily rests heavily on families who are isolated, struggling and often impoverished. We need to show them that they are not alone.

This report provides the evidence-base required to reverse the present situation. I thank the Mental Disability Advocacy Center (MDAC) and Mental Health Uganda (MHU) for working with people with mental health issues to produce this groundbreaking report. I call on the Ugandan government and society to view this as an example of how much people with mental health issues have to offer our country. They must be brought in to help us as valuable actors in our common endeavour of developing our country. And it is my hope that the findings of this report are carefully examined in the present review of the 2006 Persons with Disabilities Act, along with other national development programmes.

Hon. Jovah Kamateeka
Chairperson
Committee for Human Rights
Parliament of Uganda



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"Everywhere you pass by, they keep saying – 'she's mad' and you keep wondering whether you are a human being at all."

Woman with mental health issues

1. Executive summary

> *"They would tie me and the ropes even entered the flesh, beat me before giving me medicine, because there was some medicine I used to bath with but it would itch and I felt my body was burning."*
>
> Man with mental health issues, referring to his experience in a traditional healing setting

> *"[I]f people's mind could change and they would begin to see mental patients as valuable people then it will be good."*
>
> Woman with mental health issues

This report documents the human rights abuses that people with mental health issues experience in Ugandan communities, told in their own voices. It is the first time that such an investigation has ever been undertaken in the country, and uncovers widespread discrimination, violence, abuse and neglect against a section of the population that often goes unheard. It is hoped that the report will spur concrete action on the part of the Ugandan government to ensure that communities are made safer, and that people with mental health issues are no longer victimised and denied their most basic human rights.

One of the crucial aspects about this research is that it was conducted with people with mental health issues, from the point of design through to analysis and offering conclusions and recommendations for action. In September 2013, the Mental Disability Advocacy Center (MDAC) and Mental Health Uganda (MHU) provided training in Kampala to a group of people with mental health issues to conduct research with their peers. The training was led by a consultant with personal experience of receiving psychiatric treatment. Subsequently, two training participants were contracted to conduct a total of 80 interviews across Uganda, 40 with people with mental health issues and 40 with their family members and carers. The testimonies that were gathered were striking, showing that torture, ill-treatment, exploitation, violence and abuse are a daily experience for many.

People with mental health issues have dreams and aspirations just like everyone else, but in Uganda they face major barriers in fulfilling these goals and being fully included in their communities. Stigma, discrimination and poverty were rife. In vivid terms, interviewees described the danger and abuse they experienced in a variety of settings, including at home and in their local communities. Some described that even those who were supposed to support or protect them were instead perpetrators of abuse, including the police and sometimes even family members. Often such incidents were not even considered as abusive, but rather a type treatment that people with mental health issues could expect as a 'norm'.

Negative attitudes were not confined to social relationships. Many interviewees described how persistent abuse and stigmatisation occurred in education, work and employment. The bidirectional link between poverty and mental health problems becomes even more pronounced when people are denied the opportunity of earning an income, and a number of interviewees described living in abject poverty as a result of being forced to leave employment or education. The pressures and strains on them clearly also affected their family members and friends. In some cases, the perception that interviewees were 'unproductive' resulted in them being isolated in the family home, or even worse, being tied, beaten, or locked up. At times the levels of abuse reached high levels of severity, including physical assaults, sexual abuse, and stoning.

Exclusion, isolation and a lack of support overwhelmingly characterised the lived experiences of the majority of interviewees. Most said they were unable to afford even bare essentials such as food, clothing or housing, placing them at the mercy of families or friends, or causing them to turn to begging or stealing. While some family members offered real support to their relatives with mental health issues, this was not always the case.

Cycles of abuse appeared to continue in relation to treatment, both in conventional psychiatric facilities and in traditional healing centres and churches, where people with mental health issues were frequently taken by force. Serious violations of dignity were reported in psychiatric hospitals, these experiences having a lasting impact on some. For example, people spoke of the humiliation of being placed in "cold rooms" in psychiatric hospitals where they were stripped naked and placed in concrete seclusion rooms without toilets, forced to sleep amongst their own waste.

The severity and consistency of abuse in all settings suggests that stereotypes are deeply rooted in popular social consciousness, and that people with mental health issues are seen as legitimate targets for punishment and coercion. In this context, it is perhaps unsurprising that most people said that consent to traditional or conventional treatment was non-existent, even though many interviewees spoke about their desire to receive help. In traditional healing centres, people reported being tied with ropes for several weeks leaving

permanent scars on their body, being forcibly tattooed, and being required to pray and take part in humiliating rituals. Their experiences were harsh in such centres, and in some cases resulted in death.

Simple freedoms that most people take for granted were denied or restricted, to the extent that some people reported that they couldn't even leave their homes without permission, or meet friends. Protective family members and carers could see nothing wrong this, instead seeing it as a duty. Often, severe restriction of movement was justified on the faulty perspective that people with mental health issues could never be trusted.

Living in the context of violence and restrictions, many people with mental health issues reported feeling distress, resignation, sadness and damage to their self-confidence. Some tried to hide their mental health issues due to likelihood of being targeted, or denied the opportunity of employment. In the case of those earning their income from farming and selling their produce, interviewees explained that they were forced to travel to markets far away from their homes in an attempt to avoid being exploited. People spoke about withdrawing from communities that treated them with fear, suspicion and superstition.

It is concerning that many people with mental health issues felt little trust in the organs of the state or the courts to help them improve their lives, or achieve redress for the dreadful violations that many had been forced to endure. Given the pervasive stigma against them, however, it is not surprising that people felt there was no point in complaining as the police or courts wouldn't take them seriously, or that they may even experience further repercussions.

This combination of issues represents a serious challenge to the Ugandan government in respect of its stated commitments to human rights. Uganda is a party to several international human rights instruments including the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and regional human rights instruments that prohibit all forms of torture, ill-treatment, exploitation, violence and abuse. Such rights, however, are largely illusory for the majority of people with mental health issues in the country. Fulfilling, protecting and promoting these core standards requires real action on the part of policy-makers and key state actors including the police, judiciary, health system and at local community levels. It requires that Ugandan courts recognise and enforce those rights, and end impunity for serious human rights violations, wherever they occur. And, perhaps most crucial for the long-term improvement of the lives of Ugandans with mental health issues, the government has a legal and moral obligation to tackle the discriminatory attitudes which allow human rights violations to take place.

The report sets out a number of conclusions developed with people with mental health issues who have reviewed this report or were otherwise involved throughout the process. Their voices must now be heard: they have a right to be involved in improving their own lives, strengthening their communities, and being included on an equal basis in Ugandan society. Developing an evidence-base on madness and distress, ensuring safety and protection, regulating traditional healing and psychiatric hospitals, providing mental health (psycho-social) supports and community services, and capacity-building and peer support were all identified as key priorities by interviewees and those involved in the research. It is now hoped that representatives of the Ugandan government will take action.

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"I want to see changes in my family like looking at someone with mental challenges with positive attitudes."

Man with mental health issues

2. Introduction

This report documents the voices of people with mental health issues in modern Uganda, presenting their daily, lived realities and highlighting the impact of deeply ingrained prejudices that many experience in their communities. It is one of two joint reports investigating the lives of people with mental health issues in Uganda, the other focusing on psychiatric institutions.[1]

Based on extensive research in 2013 and 2014, people with mental health issues explain in their own words the challenges they experience in becoming full and valued members of Ugandan society. The report is the first such project undertaken in the country and has been directly shaped by people with mental health issues themselves.

The present chapter documents how MDAC and MHU worked together with people with mental health issues to undertake research with their peers around the country. This chapter situates the findings of the research in the broader Ugandan context, before presenting the aspirations of people with mental health issues for their lives – many of which reflect the needs for stability, employment, privacy and health which most of us share.

2(A). Purpose and methods

The central purpose of the research was to document the voices of people with mental health issues and particularly their experiences of torture and ill-treatment in their communities. Rather than undertaking a descriptive analysis, MDAC and MHU made a decision at an early stage that the best way to conduct the research was with people with mental health issues themselves. Their voices frequently go unheard in Ugandan society, and this report seeks to redress that balance.

International human rights law is the lens through which the lives of people with mental health issues are analysed in this report. Uganda ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) in September 2008. For the first time, this treaty seeks to extend human rights protections to all persons with disabilities, including those with mental health issues.[2] It contains a number of rights for all people with mental disabilities, including an absolute prohibition on torture (Article 15), a prohibition on exploitation, violence and abuse (Article 16), protection for physical and mental integrity (Article 17) and the right to the highest attainable standard of health (Article 25). Through ratification of this instrument, the Ugandan government has voluntarily undertaken to protect, promote and fulfil the rights of all people with disabilities, and this report analyses the extent to which the government lives up to these promises.

At the national level, the Ugandan Constitution prohibits all forms of torture or cruel, inhuman or degrading treatment or punishment (Article 24) and sets out how people with disabilities have the right to respect and human dignity. Article 35 of the Constitution provides that the state and society should ensure that all citizens enjoy their full mental and physical potential (Article 35). In addition to these Constitutional guarantees, Uganda also passed the Prevention and Prohibition of Torture Act in 2012.

In determining whether these legal commitments have had any impact on the lives of people with mental health issues, MDAC and MHU applied elements of survivor/user-controlled research,[3] an approach close to emancipatory disability research.[4] This research approach places the experience and points of view of those directly affected at the centre of the human rights investigation. People with mental health issues took key roles throughout all phases of the investigation and

1 MDAC and MHU, *Psychiatric hospitals in Uganda: A human rights investigation* (Budapest: 2014).

2 In this report, the term 'person with mental health issues' is used primarily to refer to persons with psycho-social disabilities. Article 1 of the CRPD refers, inter alia, to people with *"physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."*

3 Peter Beresford et al, "Psychiatric System Survivors and Emancipatory Research: Issues, overlaps and differences" in *Doing Disability Research*, ed. Barnes C and Mercer G (Leeds: The Disability Press, 1997). See also Sweeney et al., *This is Survivor Research*, (Ross-on-Wye: PCCS Books, 2009), and Jasna Russo, *Survivor-controlled Research: A New Foundation for Thinking about Psychiatry and Mental Health,* Forum Qualitative Sozialforschung/Forum: *Qualitative Social Research*, 13(1), 2012.

4 Colin Barnes et al, *Reflection on Doing Emancipatory Disability Research in Disabling Barriers-Enabling Environment*, ed. Swain J, French S, Thomas C (London Sage 2004).

were directly involved in developing the research methodology, gathering data through interviewing their peers, data analysis and drawing up conclusions.

In September 2013, MDAC and MHU trained 12 people who had experienced mental health issues and treatment on how to conduct human rights research. In the course of the research, an interview guide was jointly developed to ensure that all aspects of the lives of people in their communities were fully considered.

Two trained participants were then contracted to conduct 80 interviews (40 with people with mental health issues and 40 with their relatives/carers) across four administrative regions in Uganda. This field research took place between November 2013 and February 2014. The researchers gathered testimonies and experiences relating to torture, ill-treatment, exploitation, violence and abuse. A more detailed description of the methodology and research design is provided in the Appendix.

Map indicating the locations where interviews took place.

2(B). Context

Uganda is in the heart of the Great Lakes region and borders the Democratic Republic of Congo, Kenya, Rwanda, South Sudan and Tanzania. The country occupies a total area of 241,038km²,[5] and has a population of 37.5 million.[6] The Uganda National and Household Survey 2009/2010 indicated that people with disabilities constitute approximately 16% of the population, slightly higher than the 15 percent estimated by the World Disability Report.[7]

Estimates of the proportion of the population with mental health issues vary considerably, ranging from 3.6%,[8] to 20%[9] and up to 35%.[10] The unemployment rate in Uganda is estimated at 4.2 percent[11], and over 80% of the work force is employed in the agricultural sector.[12] The literacy rate is estimated at 73% (82% male and 64% female) with an average life expectancy of 54 years (55 years for female and 53 years for male).[13]

Similarly to the situation in other African countries - and other countries around the world - people with mental health issues are often perceived as abnormal and are viewed with fear related to risks of aggression and violence. There is a widespread perspective that the onset of mental health issues is linked to spiritual matters, representing punishment from ancestors, or is sometimes linked with being bewitched or possessed by evil spirits.[14] Religion plays an influential role in these belief systems and the treatment that people with mental health issues experience, and negative perceptions of people with mental health issues are reinforced through the mainstream media.[15]

Ugandan society is predominantly made up of Protestant Christian and Roman Catholic faith communities.[16] It is commonplace for people with mental health issues to be taken to traditional healers for spiritual or faith healing. Kisiizi Hospital, which is run by the Church of Uganda, has a mental health section that provides both inpatient and outpatient mental health services alongside prayers.

5 CIA World Factbook, 'Uganda', available online at: https://www.cia.gov/library/publications/the-world-factbook/geos/ug.html (last accessed: 6 December 2014).

6 World Bank, *Data: Uganda*, (2013), available online at: http://www.worldbank.org/en/country/uganda (last accessed 6 December 2014).

7 Government of Uganda, Ministry of Gender, Labour and Social Development, "Guidelines on Disability", (2012), p. 7.

8 Uganda Bureau of Statistics, *Uganda National Household Survey Report* 2005/2006, (Kampala: 2006).

9 Basic Needs Uganda, 'Uganda', available online at: http://www.basicneeds.org/where-we-work/uganda/ (last accessed: 6 December 2014).

10 Joseph Kiwaulo, 'Mental Health- Over 11.5 million Ugandans suffer disorders', News Vision Uganda (4 April 2010), available online at: http://www.newvision.co.ug/D/9/34/715142 (last accessed: 6 December 2014).

11 Uganda Bureau of Statistics, *National Household Survey Findings* 2009/2010, available online at: http://www.ubos.org/UNHS0910/chapter4_%20time%20use.html (last accessed 6 December 2014).

12 CIA World Factbook, 'Uganda', available online at: https://www.cia.gov/library/publications/the-world-factbook/geos/ug.html (last accessed: 6 December 2014).

13 Ibid.

14 Sussie Eshun and Regan A. R. Gurung, eds., *Culture and Mental Health: Sociocultural Influences, Theory, and Practice,* (Wiley-Blackwell, January 2009).

15 F Kigozi et al, 'Media and Mental Health in Uganda', *Africa Journal of Psychiatry,* May 2010: 13, 125-127.

16 Roman Catholic 41.9% and Protestants 42% (Anglican 35.9%, Pentecostal 4.6%, Seventh-Day Adventist 1.5%), Muslim 12.1%, others 3.1%, none 0.9% (2002 census). CIA World Factbook, 'Uganda', available online at: https://www.cia.gov/library/publications/the-world-factbook/geos/ug.html (last accessed: 6 December 2014).

2(C). Aspirations and desires

Whilst this report primarily focuses on human rights violations that people with mental health issues experience in Uganda, it is important to highlight that interviewees also expressed their aspirations and desires – many of which are not so different from those of other Ugandans. In this section, we present these.

In the vast majority cases, people with mental health issues expressed the desire to improve their quality of life – particularly improving their financial situation as well as learning new skills or continuing education. Overwhelmingly, interviewees expressed the wish to have greater autonomy and freedom, and wanted an end to restrictions that are all too prevalent in their lives. Many interviewees simply wished to be treated as equal members of their communities.

"I would like to get my own room, a bed and at least something to eat and even work to do."
Woman with mental health issues

"I would like my neighbours to recognise me as a normal person and to allow me to make decisions when in a meeting... when I want to go with my friends they should not stop me."
Man with mental health issues

"I want them [family carers] to leave me to go do my own things like if I want to go and visit my friends because sometimes I also get fed up of the place."
Woman with mental health issues

People with mental health issues reported receiving very little support to achieve their personal wishes and goals. When researcher asked a woman with mental issues if anyone was willing to support her to achieve her wishes, her response was:

> *"Nobody and I don't think there's anybody. Nobody trusts me. They think if they give me money I will just spoil it. [...] Because of this history of mental illness and the things I used to do when I was ill, they think I will do those same things [...] so nobody trusts me."*

Several interviewees used the end of their interview as an opportunity to ask the researcher for some support, which also indicates that people with mental health issues and their families are frequently left to cope on their own.

Interviewees were asked what changes would need to happen in their communities and more broadly in Ugandan society for them to be included. They spoke about the need for changes in attitudes, financial aid, medication supply, protection from negative attitudes and tackling violence. Others also spoke about the need to improve knowledge of human rights, changes in the law, extending community-based services and alternatives to hospital treatment, and sharing information about madness and distress with other members of the community.

"First of all, we need to change the attitude of our parents, community and members of community concerning mental illness; that is the most pressing thing."
Woman with mental health issues

"I want my [people] to understand that mental illness is not a crime. When someone becomes mentally ill they should be taken to the hospital not to the police."
Man with mental health issues

"I want to see changes in my family like looking at someone with mental challenges with positive attitudes."
Man with mental health issues

"Us, the patients, should feel happy about ourselves and happy that we are okay and other people should also take us like other normal people."
Woman with mental health issues

People with mental health issues and their families/carers called for equal treatment with other members in the community, called for discrimination and abuse to be tackled, and expressed the desire to be given responsibilities like other community members. The brother of a man with mental health issues said:

> *"Some of us look at them as useless people, insult them, beat them, not knowing that no one asked for it [mental illness], it just comes up on you abruptly. So I suggest that we, other people, look at them as part of us, take care of them, be together with them so that they can feel loved in the community."*

Abuse, violence and exploitation were never far from interviewees' minds. In some cases, this caused them and their families/carers to call for separation, in order to avoid those who would seek to harm them. Others also spoke about the need to tackle the high rate of homeless which people with mental health issues experience. One woman explained:

> *"Especially those on the streets, we need to get for them a permanent home. Because these people are left on the street, they are raped, they are beaten up, so we have to get for them a permanent home, where they can be treated and kept busy."*

Another woman with mental health issues shared a similar view:

> *"Some are going through hard life like those who spend their time in garbage places. Thank God I never went through that but I really feel sorry for them. [...] I would like to see a big house built for them where they are collected and looked after."*

This tendency to call for separation was also reflected by family members and carers of people with mental health issues, many of whom received no support for the important roles they played in providing support. Some expressed

feeling completely overwhelmed, particularly when they also experienced targeting due to their caring responsibilities. The mother of one man with mental health issues said:

"If they would get for them [people with mental health issues] something to do and also get a place where they can be put together in their group, give them support and save us because we suffer a lot."

The mother of a woman with mental health issues added.

"[T]hey [the government] should find them something to do or get a place for ill people where they know that they belong there."

The majority of interviewees raised the lack of availability of psychiatric drugs as one of their biggest priorities. This appeared to be of equal importance to both people with mental health issues and their families, and reflects a lack of other treatment options such as psychotherapeutic approaches and counselling. As will be seen in later sections of this report, the vast majority of people with mental health issues, their families or carers, and psychiatric professionals could hardly imagine alternatives to psychiatric drugs as the main form of treatment.

"The most important thing at the moment is drugs. We have shortage of drugs and yet with our condition we cannot do without drugs."
Woman with mental health issues

"Drugs, very good drugs should be provided, and then also support for some income generating activities whereby one can have money and can even buy these drugs."
Man with mental health issues

"The most important issues are to pray for people with mental illness and that they should be protected, not beaten but given medication."
Man with mental health issues

The pricing and availability of medication was seen as a priority for carers and family members. The mother of one man with mental health issues explained that:

"... we [parents] could be relieved because once a child has started and adheres to the drugs, you, the parents can also be relieved. But without that many end up leaving their home."

Some even felt that taking drugs could prevent negative repercussions from other community members. The mother of one man with mental health issues explained:

"My opinion is that the mental patients should take the drugs, they should be prayed for God to help them because no one can be happy when his or her family is not ok. Mental illness is very dangerous because people can gather and even beat your child to death."

Interviewees also prioritised securing financial resources in order to combat poverty and widen their and education opportunities. Many interviewees said that their mental health issues should be acknowledged and approached like any other disability and that specific government support programmes would be necessary to tackle the discrimination that they experience.

"The government should also think about us in terms of education, giving us loans so that we can study and have employment.[...] We are not allowed scholarships, [...] the government only considers people who are physically disabled. [...] They describe us as people of unsound mind and they consider us as people who can't do anything."
Woman with mental health issues

"I am requesting if they [the government] could help us and give us some small jobs so that we can look after our children because if you go to ask for a job they just chase us away because they know we are mad so you find that the conditions we are going through are very difficult."
Woman with mental health issues

The wife of a man with mental health issues called on the government to "amend laws to ensure that at least some funds are available for people with mental health issues to start up employment opportunities like business, I think that could help them."

The mother of a woman with mental health issues added:

"Patients should get their own income because it gives them peace and they feel comfortable when earning for themselves."

Of real significance was the feeling of many people with mental health issues that their rights are not adequately protected on a larger scale. This included concerns about the lack of equal payment for employment, the low level of respect for their rights, and the lack of political and legal representation of people with mental health issues.

"I would like the property rights of people with mental health difficulties to be respected because I am worried that they [family] might sell the land any time and that they won't consider me because of my mental illness and that they won't give me my share."
Man with mental health issues

"People with mental illness should be allowed to make decisions because they are going through hard life since they are not allowed to make decisions."
Man with mental health issues

"They should treat us like other people and they should pay us equal money like others are paid when we do the same work."
Woman with mental health issues

"For me, I would like us, people with mental health difficulties to at least have a member of parliament who would present our concerns in parliament."
Man with mental health issues

The above findings demonstrate that people with mental health issues have dreams and aspirations just like everyone else. However, the next sections will show that they face significant barriers to taking their rightful place in their communities.

Photo: Shutterstock

"He is always hesitant to go to hospital so we find energetic people to help us take him. When we reach hospital he is given an injection and he sleeps."

Sister of a man with mental health issues

3. Living conditions and family

This section focuses on ill-treatment and abuses that people with mental health issues reported about where they live, sometimes at the hands of their own families or close relations.

3(A). Living conditions

The majority of people with mental health issues interviewed lived either with their parents and siblings or with their spouse and children. Out of the 40 interviewees, only two lived on their own at the time of the interview.

Table 1: Living situation of interviewees with mental health issues	
with parents (and siblings)	20
with spouse and children	15
with extended family	3
on their own	2
Total:	**40**

Most interviewees with mental health issues did not directly complain about their living situation, although many expressed the desire for improvement. Some people wished to move away from where they currently live and go somewhere else for a long time, while others wished for greater income in order to live in better conditions. A man with mental health issues reported how he would like to improve his living conditions to avoid relapses:

> *"I would like a better life because I do not want to disturb my mother since she is old now. Sometimes when we get misunderstandings I relapse again. I would like to get a woman so that we can renovate my house."*

The impact of extreme poverty was apparent in several testimonies. One 30 year-old woman who shared the same bedroom as her father described her living condition as "terrible". She said:

> *"Of course I am denied food because my dad does not give me food while knowing that I am not working. I am just surviving on God's mercy and my friends give me food but my dad cannot buy anything for me. Since morning I have not eaten anything yet and I am breast feeding. Even yesterday the neighbour is the one who gave me some food."*

She reported that she has lived like this for a long time and the only help she received was from one club house for people with mental health issues where she went to get a free lunch.

Lack of food was a major concern raised by many interviewees. A mother explained how feeding her daughter with mental health issues was her main problem since her daughter had an increased appetite when on certain medications – a problem that was commonly cited. Another woman with mental health issues reported:

> *"If I take medicine it requires me to have good food and I don't get it because of the famine."*

A quarter of interviewees with mental health issues reported that they had no income of their own (see Appendix, table 5). Many explained that they relied on the good will of friends or well-wishers, and others were forced to beg for money.
A woman with mental health issues put it in these words:

> *"I survive on relatives and other good Samaritans. [...] Because of the lack of money I have to beg."*

The living conditions of many people interviewed as part of the research were very poor. A father of one woman with mental health issues described their living situation as "helpless", and their standard of living as "terrible". Another father called on the government to assist people who are unable to pay their education fees and ensure that they could benefit from government assistance for people with disabilities. The brother of a woman with mental health issues said:

> *"Everybody should feel free. We can also change the situation by getting some income generating activities, social capacity building, so that these people can do their things to earn a living."*

The living conditions of people with mental health issues were characterised by poverty, lack of food, stress and no access to social protection programmes which place them at a significant social disadvantage. The natural pressures that such living conditions bring place significant burdens on people with mental health issues, their families and communities, and also lead to other forms of abuse and exploitation.

3 (B). Family

Almost half of interviewees with mental health issues reported abuse at the hands of their families, with over a third of relatives interviewed admitting that such things occur. MDAC and MHU are mindful that abuse in the family is a difficult topic for many people to talk about, and so it is possible that an even higher number of people with mental health issues go through similar experiences.

Excerpt 3. 1: An interviewee with mental health issues

Interviewee: My father left me land and farms which were sold; even the home was sold and they only left for me a very small plot.
Researcher: Did you have a share on what they sold?
Interviewee: No, I didn't.
Researcher: Why didn't you?
Interviewee: I don't know why they didn't give me, because my father left for me some things and money but my elder brother used it and only gave me fifty thousand shillings [approximately 14 EUR].
Researcher: Did you complain anywhere about what happened?
Interviewee: Yes, but they only call me a mad person.

Violent practices including verbal abuse (insults), denial of food, isolation, physical restraint and beating were reported to be commonplace. One interviewee reported being raped but the complaint was never followed up by the family as the perpetrator was a family member.

Verbal abuse and food denial

People with mental health issues described that harassment, threats and abusive language were a part of everyday life in the family home. One man with mental health issues explained that his father would often call him 'mad' when drunk and that he would frequently find no food at home. Another interviewee, a married woman explained her experiences with her husband in these words:

"My husband eats his money alone [spends money only on himself] and does not support us. He even does not respect me as a woman, saying that I am mad and not like the rest of human beings. He also verbally abuses me especially when I relapse [...] and says - take your madness away, I am tired of you."

A number of reasons were cited for denying food and water to people with mental health issues, including:

- The perception that they did not contribute to the family income;
- Low family income;
- People demanding more food when on certain types of medication.

3(B)(i). Isolation

People with mental health issues also spoke about how family members would isolate them in the family home, sometimes by locking them in separate rooms. A woman with mental health issues reported one of her experiences of being isolated:

"He [father] slapped me and locked me inside a room for two days. The neighbour came and opened the door. He was nowhere to be seen and came back after two weeks."

The practice of isolation seemed to be a relatively frequent occurrence. Another woman with mental health issues also explained:

"I was put in my own room and the caretaker would bring for me something to eat and go back outside."

Such practices were defended by family members, particularly as a response to period of crisis. The sister of one woman explained that "when she is mentally ill, she becomes bad so in most cases we lock her in the room". When researchers asked for how long, she responded: "She doesn't take long there. As soon as we see that she's fine, we open [the door] for her but, like, for about three hours until she's back to her normal state." The spouse of one man with mental health issues explained: "I lock him in until I get some neighbours to help and take hold of him and sort him out."

This form of restriction, however, was not limited simply to periods of crisis. Sometimes people would be locked up for other reasons, including:

- Because some families were embarrassed to see their family member with mental health issues on the streets;
- To restrain them from destroying things;
- To 'protect them' from being subjected to violence or abuse at the hands of community members;
- The fear that they might get lost if they escaped; and
- Sometimes for the mere conveniences of family members or carers.

The isolation experienced by people with mental health issues in the family home resulted in many living highly restricted lives, often due to negative attitudes or the limited understanding of family members or other people in the community.

3(B)(ii). Physical violence

Along with physical isolation, people with mental health issues and their relatives also spoke about the high prevalence and perceived normality of physical violence. In a number of cases, physical abuse was reported to occur over extended periods of time. In other cases it was reported to be a form of punishment. A man with mental health issues described one of his experiences:

"Firstly I was denied food. Secondly I was tortured. I even have scars from my step mother. [She was] overworking me without letting me go to school, chasing me out of home so I think it affected me so much."

When asked for how long this happened, the man responded "almost ten years, *[it started]* after I lost my father." The spouse of a man with mental health issues reported that her brother-in-law would beat her husband at home and she just watched and took no action.

The mother of a daughter with mental health issues also explained her daughter's experience:

> *"Even her grandmother herself has tried to beat her and told her to be obedient and remove the curse which she put on her. [...] The old woman threw a stone upon her and also brought a bottle to throw at her, and then people caught them before they started fighting."*

Family inaction to prevent such incidents was not limited to cases of people being assaulted by their relatives. Another spouse explained that her husband with mental health issues was beaten by members of the community and the family simply took him to the hospital after the incident. The spouse explained that: "We never minded also because we did not know how the world should treat people [with mental health issues]."

3(B)(iii). Restraint

Interviewees also reported that physical restraint was common, with family members and carers admitting to this as a way of controlling their relatives. Some people reported being restrained for days and even several months. A woman with mental health issues reported that her extended family members would tie her up at nights. Another woman explained how her father tied her for six months.

One mother spoke about her son being tied up locked him in a room:

> *"Once he walked a very long distance whereby he was caught and brought back home. So he was caught when the condition became worse and he was then tied up and left in the room for two days."*

Another mother explained the reasons why she would tie up her daughter:

> *"When she becomes rough she tends to run away, and that's why we take hold of her and we tie her and especially at night... for about 3 or 4 hours but she was tied even longer when she was at [*the name of a healing centre*]."*

Family members spoke freely about the use of restraint as part-and-parcel of everyday life. The spouse of a man with mental health issues explained:

> *"We get him and tie him with ropes, then we put him in the house or tie him to the tree in the home compound for two days, then he is taken to the hospital [...] We get strong men, tie him and bring a car and take him to the hospital."*

Tying people with mental health issues with ropes or manhandling them in order to take them to the hospital seemed to be very common.[17] The perceived normality of these practices can be seen from the following quotes of family members who were interviewed:

> *"It happened once and we tied his legs until we took him to the hospital and he accepted to take medication. That is when we untied him."*
>
> Mother of a man with mental health issues

> *"He is always hesitant to go to hospital so we find energetic people to help us take him. When we reach hospital he is given an injection and he sleeps."*
>
> Sister of a man with mental health issues

> *"I can't handle him alone so I look for neighbours, about 2 or 3 people to come and hold him. Then they help me bring him to the hospital. [...] We first handle him in a good way – simply calling him and bringing him to the trading centre where they can get the means of transport and they take him to hospital. When the condition worsens and they see that they cannot handle him any more, they tie him up."*
>
> Spouse of a man with mental health issues

Some interviews with family members show that they perceive force not only as justified but also as a way of protecting and caring for their relatives. There seemed to be no other means available to deal with challenging situations. One husband explained the situation with his wife.

Excerpt 3. 2: Husband of an interviewee with mental health issues

Researcher:	Who ties her?
Interviewee:	I myself, and some other people help me.
Researcher:	Do you think that is the best way to treat her?
Interviewee:	There is no way you can protect her because if you put her in the house everything will be broken as long as she's mentally ill.

A mother also explained why her son was tied for two weeks to a tree:

> *"He could go across the road and cars tried to dodge him and therefore while dodging him, cars could almost get accidents. So the local council's chairperson got annoyed and told me to keep him home, and so I decided to tie him to the tree with ropes but would also take him from the tree when he got fine."*

It is clear from the interviews that families use such highly coercive and abusive practices out of exhaustion and a lack of any alternatives, and often because caring for their relatives was an isolating experience. A mother said this about her daughter:

17 MDAC and MHU, *Psychiatric hospitals in Uganda: A human rights investigation*, (Budapest: 2014).

"Of course there were times when she was aggressive so there could be exchange of words among family members and so on. We would not understand her and she would not understand us and I think that is when her brothers tied her up and took her hospital."

The sister of a man with mental health issues explained:

"When he relapses I am always alone to care for him. All the necessities are on me... it's because the others don't care and even more because he only likes me. [...] Okay – there are times when he relapses and it is difficult to handle but most times I just calm him down since he always listens to me."

People with mental health issues seemed to accept such practices as 'normal' and many of them did not view them as unjust. Some participants had internalised the widespread social opinion that the presence of mental health issues is a legitimate reason to be disrespected and degraded, and that such treatment is even for their own good.

One man explained:

"My parents have so much concern about my life and they always protect me when I have such problems, and I also have a brother. [...] When he sees me wandering around, he ties me up on the bed [...] so that I don't move up and down. It was for about two weeks, because I was manic. I like fighting and beating up other people, I have even refused treatment and those were the bad things – I did not improve in time."

Another interviewee with mental health issues reported:

"When I relapsed I wanted to beat them [wife and children] so my brothers caught me and tied me up with ropes and took me to the hospital."

When asked whether he complained anywhere about what happened to him, he responded:

"After I was taken to hospital, I became fine and I appreciated what they had done."

3(B)(iv). Interference with decision-making rights

The freedom of people with mental health issues to make decisions about their own lives, including where they go, who they see, and how they spend money was also explored. While some people felt that they had relative autonomy over their life, many reported wide-ranging restrictions about even making basic decisions for themselves, such as what they could eat or where they were allowed to go.

Two people with mental health issues stated that they were free to make all decisions about themselves, however their family memberssaid they they actually imposed a number of restrictions. One woman with mental health issues explained:

"My first born is with her dad and he does not allow me to see her on holidays. I only see her at school time and am not even allowed to get out of the gate with her. [...] Because he says that am mad, I might do bad things to her."

Restrictions to the autonomy of people with mental health issues were often linked to minimal income, and were particularly apparent where they lacked a source of income independent from their families or carers.[18]

"I don't feel autonomous because of the fact that I lack money. If I had sufficient money of my own to survive I would go and do anything I want but I am restricted by the fact that I get little money which is not enough for me to do what I want."

Woman with mental health issues

"I am a grown up person who is supposed to be independent but because I don't have anything which can bring me income I have no other ways and feel I have to be dependent."

Woman with mental health issues

Restrictions of women with mental health issues

Women, overall, were more likely to find themselves in a position of financial dependency, with the result that they were also more likely to report restrictions in terms of their autonomy. Here are some of the comments made by women who were interviewed:

"I feel bad because I see myself as a mature person but you will find even a young child wanting to decide for me."

"Sometimes I feel unhappy because some of her [aunt's] decisions are against my will."

"I feel it is okay because I am used to it."

18 MDAC produced a report on the right to legal capacity in Kenya earlier in 2014. It found that the decision-making rights of people with mental health issues were frequently restricted by customary practice rather than law, particularly by family members and members of the local community. MDAC, *The Right to Legal Capacity in Kenya,* (Budapest: 2014).

Some family members expressed ambivalence about the necessity of making decisions for their relatives with mental health issues, and that this was merelypart of everyday life when caring for their relatives. One spouse said in relation to her husband: "I feel it is okay because he can't decide on his own."

The mother of an adult woman with mental health issues also gave her opinion in the following terms:

> *"I am happy to do it [make decisions for my daughter] because our society does not have a welfare state so we cannot depend on government for decisions about health like is the case in other countries. In Africa the mother has to make decisions, especially the good decisions."*

The following is an excerpt from a conversation with a father who talked about making decisions for his daughter.

Excerpt 3. 3: Father of an interviewee with mental health issues

Interviewee: She is obedient to me and accepts whatever I tell her.
Researcher: Who makes the main decisions for her, for example when she wants to go somewhere, to do something?
Interviewee: Me or the mother.
Researcher: How do you feel making decisions for her?
Interviewee: I feel good, it's okay.
Researcher: What makes it okay?
Interviewee: That she cannot do anything else apart from what I decide for her.

Only one person among the people with mental health issues mentioned that he had tried to complain and look for legal support regarding his unhappiness at how he was treated at home. He said:

> *"I have been trying to forward my problems to local authorities about some of his [father's] behaviours which are unbecoming. [...] I tried to look for help from local councillors and clan leaders but still I am with my two parents."*

Photo: Shutterstock

"When they know that you're ill, the neighbours don't want to relate with you and they also discriminate you, like some may decide not to talk with you and they talk to other people."

Man with mental health issues

4. Ill-treatment in the community

For most people with mental health issues the manner in which they are treated in their local communities has a significant impact on their lives. It is also the setting in which people with mental health issues experienced the most significant forms of ill-treatment, frequently reflecting ingrained discriminatory attitudes.

Only six of the 40 interviewees with mental health issues reported positive relationships with their local communities. In these six cases, interviewees reported that their neighbours would display encouragement, understanding, and respect, would provide advice and empathy.

Unfortunately, these experiences were not the norm for the vast majority, with many reporting negative experiences ranging from verbal insults and threats to serious physical abuse and sexual assaults. The motivations for such forms of abuse and ill-treatment included negative beliefs and fears regarding mental health issues. One woman explained:

> *"If I want a loan, if I want to get married, or if there is any job they want people to do, they say: 'she's mentally ill, she has to stay at home.'"*

When asked why he had experienced abuse from members of his local community, one man with mental health issues hinted at superstitions surrounding mental illness:

> *"Well, some of them just believe that I was bewitched."*

A spouse explained how people react when they meet her husband:

> *"When he is going somewhere and meets people on the way they run away thinking that he is going to beat them."*

A sister also described a similar experience in relation to her sister with mental health issues:

> *"They abuse her, run away from her when she speaks funny things because they think she will beat them. When she's mad she becomes very tough."*

4(A). Negative attitudes, disrespect and exclusion

The accounts of people with mental health issues show that they frequently experienced negative attitudes, disrespect and exclusion from the life of their communities. A number of interviewees explained that some members of their communities would completely avoid any contact with them, and would disregard whatever they said. Many spoke about the profound feeling of isolation that this would cause them.

"When they know that you're ill, the neighbours don't want to relate with you and they also discriminate you, like some may decide not to talk with you and they talk to other people."
Man with mental health issues

"They treat me badly because they just refer to me as a mad woman. For example if there is a meeting they don't allow me to attend and in most cases they isolate me because of my mental difficulty."
Woman with mental health issues

"They treat me like a useless person. Even a child can be saying that I am mad [...]"
Woman with mental health issues

"Stigma is normal. When I go to a borehole [to fetch water], they can say 'this woman is disturbing us.'"
Woman with mental health issues

"People may not treat you badly or beat you, but there is a certain way they see you. Like, if you engage into a discussion they say you're a mad person. And even ceremonies in the village I cannot attend because they see me as a mad person, or when giving an idea in the village meeting people just laugh."
Man with mental health issues

Interviews with family members confirmed these attitudes. One daughter of a woman with mental health issues explained how their neighbours harboured strongly negative attitudes towards her mother, even to the point of outright expressions of disgust. The husband of another woman with mental health issues explained that his wife lived an isolated life and was made to sit aside and not mix with "normal people" on occasions such as weddings and introduction ceremonies.

In another interview, the wife of a man with mental health issues commented that her husband lost his friends because they would call him "a friend of no gain". Another spouse said people avoided visiting their home because they believed her husband would beat them.

People with mental health issues frequently reported being excluded from discussions and decision making processes which were of relevance to the whole community. A woman with mental health issues reported:

"They don't mind about me and what I am saying, they don't consider me as a person."

Another woman spoke about how she was excluded from community meetings:

"When they have got the gathering and they are putting up hands or saying something, they say: 'why are you also raising your arm, let's not ask her, let's ask the others.'"

Her daughter corroborated this account:

"In some gatherings, when she feels that she should raise her hand and give an idea about the main decision they are about to make, they feel she is mentally ill and say: 'you, mental woman please sit down, we don't want your opinions.'"

Other accounts from family members confirmed that people with mental health issues are disregarded by their communities as a matter of course. Many are denied the opportunity of acquiring leading positions in their communities regardless of their individual capabilities, solely because they were known for experiencing mental health issues.

Interviews showed that community members often treated people with mental health issues as if they could never recover or become fully-functioning members of the community. One man with mental health issues said:

"I am not recognised as an important person. During last elections I was denied a leadership position in the village local council."

When researchers asked why this happened, he explained that people would complain that he was "a mad person and can't do any work."

A spouse explained how her husband was chased away as catechist (religious teacher) from his church because he was not considered capable of doing anything good when he became mentally ill.

Negative attitudes such as these caused many people with mental health issues to withdraw from their communities, often reporting feelings of helplessness and grief. A woman with mental health issues said:

"In the environment where I live... when I see a fellow mental patient being mistreated I also feel the pain. Sometimes I end up losing my temper and sometimes I cry the whole day. I isolate myself and that is why I feel I don't like this place [her community]."

Another woman reported:

"Everywhere you pass by, they keep saying 'she's mad!' and you keep wondering whether you are a human being at all, and you wish to be dead."

Another man said: "It happens almost daily. So it has become like part of my life."

4(B). Insults, threats and physical assaults

Verbal insults from community members, and in particular the use of derogatory terms meaning 'mad' in local languages was a very common experience The frequency of such insults, even when they remained verbal, caused some interviewees deep emotional hurt, and meant they were even more likely to withdraw from their communities.

One man with mental health issues explained:

"They [community members] treat me very bad..., some can scratch on their heads to show that I am not mentally stable, they also discriminate us by preventing other people from talking to us. If someone wants to consult me, somebody else might stop them by saying that I can't say anything sensible."

Frequent insults meant that some people felt constantly unsafe. One woman with mental health issues described: "The boys scare me and say that if I walk at night they will do something to me." The friend of another woman with mental health issues explained how harassment could often be severe: "People want her to leave the place where she is staying... [so] they shout at her and abuse [insult] her that she is mad."

Interviewees described that the abuse that they experienced often became more severe. More than half (21 out of 40) interviewees with mental health issues had experienced physical assaults from their neighbours. These assaults included having stones thrown at them, being kicked, beaten, tied up or sexually assaulted. One man with mental health issues was shot in his arm, and paralysed as a consequence.

Physical violence was highly prevalent Describing a serious assault, one man with mental health issues treported:

> *"It was the worst experience in my life, I wasn't aware because many things were happening in my head. I was tortured, beaten and mistaken to be a wrong person."*

His wife said:

> *"He was beaten once because of being suspected to be a thief, yet he was not. But after realising that he was innocent they let him go."*

The man who was shot explained that:

> "When I was mentally ill they called them [*security officers*] to hold me, so he came with a gun and started shooting."

His mother also gave her account:

> *"He relapsed and started destroying everything at home, and then someone came to help trying to scare him to stop what he was doing. Suddenly an accident happened and his hand was shot."*

When asked what action was taken, the mother replied:

> "Nothing. We just left him [*the police officer*] because he is our relative."

Experiences of violence

"There was a time when I sat on someone's veranda and when he [the owner] found me there, he kicked me and I did nothing to him."
Man with mental health issues

"There are very many bars around here so people come and abuse me after drinking and others make my pit latrine dirty, and someone breaks the door of my latrine."
Man with mental health issues

"Some of them are people from my area beating my children and one of my boys was cut by someone whom I don't even know because I am mentally ill."
Woman with mental health issues

"When I relapsed, people beat me as if they were beating a snake and I tried to run, but they also ran after me while beating me, so I entered my friend's house. Then they caught me and tied me and threw me in the car and I was taken to hospital while tied with ropes."
Woman with mental health issues

"I came back home late in the night after struggling with those Boda (motor bike) men. They wanted to rape me but good enough I was in trousers and very strong so they gave up. They brought me back home and dumped me at our gate."
Woman with mental health issues

Family members corroborated the high levels of violence against their relatives in the community, especially during periods of mental health crisis or having 'relapses' as many described it. One sister reported that her brother had been beaten several times during his relapses, whilst the brother of another woman said that sometimes children would stone his sister.

The husband of one woman with mental health issues commented:

> *"She can go somewhere and they say 'tie her!' She may run mad from here but sometimes she has done nothing to them. [...] Of course those things normally happen to such people. When she is moving around they normally throw stones at her and sometimes they threaten her so they she stays away."*

Some interviews with family members leave the impression that verbal and physical abuse by community members during periods of mental health crisis are seen as normal or are even justified in some cases. The sister of one man with mental health issues said: "we don't take it [*verbal abuse*] as important because it always happens so we are used to it." A father commented: "I have seen them [*people with mental health issues*] around, whenever they are mentally ill, then they start stealing so they are beaten."

The wife of another man with mental health issues said:

> *"He is always so energetic when he is in crisis, people catch him and tie him on ropes... [Sometime he would be tied for] weeks until he at least gets okay and they take him to witchdoctor, but he would also be beaten there."*

A wife commented about her husband with mental health issues:

"He should be taken like other human beings, except if he turns to be ill." A man with mental health issues also explained: "I was beaten and tied with ropes that entered my skin but that was all caused by the illness."

4(C). Exploitation

Many people with mental health issues reported being exploited by other members of their communities, as well as being seen as easy targets for a variety of crimes. Eight interviewees reported such incidents. One woman with mental health issues said:

> *"I like the place where I live except those neighbors who disturb me by stealing my things."*

Another man said:

> *"Some friends steal my things and when I blame them for the theft they just confuse it with my sickness and they say I am mad. [...] Like my friend who stole my things: when I was accusing him of that theft he just blamed me that I had relapsed and that I don't take medicine and he was just threatening to tie me up in ropes and I just gave up accusing him."*

Some interviewees reported that their properties and land had been attacked and that no action was taken by the authorities. One subsistence farmer explained:

> *"The problem is that I have a project and pineapple plantation, but people come at night and destroy those pineapples."*

Excerpt 4. 1: A man with mental health issues explained what happened when he experienced a period of hospitalisation:

Interviewee: I had cows, goats, and a house so when I got ill I was taken to Butabika [psychiatric hospital] and spent two months there. When I came back I found the house burnt, the cows were cut and killed [...] I didn't get a chance to know the one who did all that. Even the goats where eaten.

Researcher: Did you try to do anything to regain your property that was destroyed?

Interviewee: Yes, I went to the local council chairperson and I told him but he said he wasn't able to help since he didn't know anything about what happened to my property.

The wife of another man with mental health issues explained how people would grab their land and cut down their trees with assistance from neighbours. A brother of a man with mental health issues told interviewers that the landlord cut down his brother's crops cultivated on the land he was renting. When his brother reported to the police, his he was the one to be imprisoned, rather than his landlord.

4(D). Escalation of conflicts and the police

On some occasions, it was reported that violence against people with mental health issues triggered the involvement of the police.In the course of this investigation, MDAC and MHU recorded only two cases of successful police intervention, where the perpetrators of physical assault were caught and punished. However, eight other people with mental health issues reported that police took insufficient or no action, even after serious attacks.

At times, the police themselves were said to be the perpetrators of abuse. A mother explained the experience of her son:

> *"Last year [...] he was working and then started walking at night and he was beaten and accused that he is a night robber. They beat him up to extent that he lost his tooth."*

When asked whether they made a complaint, the mother replied:

> *"No, I did not because we found him in the police station and we could not open a case. The police themselves drove us to the hospital and he was admitted."*

Rather than protecting the interests of people with mental health issues, some interviewees described that police intervention actually worsened their position rather than helping them to achieve justice. One man with mental health issues explained a particular situation:

> *"In the history of my illness, actually on many occasions, many bad things have happened and the worst experience happened in 2010 when I was arrested by police for no reason. I was detained in cells where inmates tortured me severely and I was not brought to court for hearing. The worst was that I was not taken to hospital but just left alone so I started wondering the streets and the torture that followed; that was the worst experience I have gone through."*

Another man who spent two days in a police cell described his experience:

> *"I would like to talk about the way police treat us, like when someone accused me wrongly I was arrested by the police and put into a cell. Because the complainant told them that I was mad and that what I was saying I am not sure about – I spent there a night not given food. The policemen were*

teasing me [and saying they were going] to shoot me. The following day, they wanted to force me to pay that person [the complainant], but I refused."

Interviewees also reported physical abuse in police stations, both at the hands of police officers as well as from other inmates. One woman described what happened when she had a conflict at work:

"My boss I think was interested in me but was not getting the feedback he wanted so he started placing cases against me and I ended up in prison. When I was in prison I remember I could disturb those people the whole night, because of mopping the female ward, and they were having sleepless nights. So they beat me up, they tore up their prison clothes and tied me up with those. They put me in a cell inside the prison and locked me up, so what I did was to untie myself and begin singing songs here and there, calling on my people. And even the prison guards; when I was coming out of prison they had to beat me up. I wonder why they decided to beat me up."

A man with mental health issues also described the violence he experienced at the hands of police officers and other inmates.

"They [family members] were giving me a lot of stress, there were some disagreements at home. They wanted to sell the land and I was opposing its sale, so they were against me and this made me relapse. They did not know what to do, and what they did was to take me to the police where I was beaten badly. I came out vomiting blood and with a lot of wounds. Both policemen and inmates were beating me.

Family members and carers also spoke about the high levels of violence that their relatives experienced when coming into contact with the police.

Excerpt 4. 2: The brother of one man with mental health issues explained that such incidents were common.

Interviewee: He was tortured [at the police station] but we worked upon it and they released him then we went back home.
Researcher: How was he tortured?
Interviewee: His fellow inmates beat him up.
Researcher: Did the policemen do anything against the torture he went through?
Interviewee: They said that it normally happens.

The father of one woman said the he felt that the abuse his daughter experienced while in custody caused her mental health issues:

"[S]he was put in a cell and from there to the prison where she was badly beaten. That precipitated mental illness which she had never suffered from before. I went to check on her but of course the case was in court and they took some time to release her. The condition was very bad when she was released. We brought her home but still the condition was bad. That is when we brought her to a mental hospital, but before that she had never suffered any form of mental illness and I have not had any member of the family suffering from mental illness."

Excerpt 4. 3: The mother of another woman with mental health issues described an occasion where there was no action despite an allegation of abuse at the hands of the police.

Interviewee: Firstly she was severely beaten by the police guards and then taken unconscious to the [psychiatric] hospital.
Researcher: Did you try to complain anywhere about what happened to her?
Interviewee: I was told to leave those things that since they beat her at the gate of the hospital. The medical doctor told me that they will handle those people but they never handled them at all.

From the perspective of some people who reported abuse at the hands of police, complaining was viewed as futile. After being released one man said:

"I told the local chairperson [about the abuse] and he told me to forget the issues."

4(E). Complaints of ill-treatment and coping strategies

Very few interviewees felt that they were able to gain justice for experiences of abuse or ill-treatment in their communities. Only one interviewee with mental health issues reported being able to take his case to court. He received support from a human rights foundation and was waiting for a tribunal hearing at the time of the interview.

Five people with mental health issues reported that they did not know how to complain about abuses they had experienced. Even if they were aware of the possibility of bringing a complaint, others reported that they thought such action would have little practical effect, ostensibly because of their mental health issues. According to one woman interviewed:

"I didn't know where I can go and complain because everyone takes me as a mad person."

The fear of making things was commonly cited by people with mental health issues as the main reason for not complaining about ill-treatment that they had endured. Another woman with mental health issues reported: "I have never complained anywhere because I knew nothing would be done," whilst a male interviewee said: "There can be some trouble if you try to complain." *When asked to explain the kind of trouble he responded,* "They [*community members*] can beat and even abuse."

Twelve interviewees described how their attempts to put in complaints at the police or local councils had largely been ignored due to the fact that they were known as 'mentally ill'.

One woman explained:

> *"I tried to report [theft] to local council and also I went to police, but the local council followed to the police and told them that I am mentally ill, that I didn't know what I am saying."*

Experiences of complaining about ill-treatment

"I got fed up of police because even if you complain they do nothing, [the] only say that I am a mad man."
Man with mental health issues

"When I get a problem at home and report to the local council in a meeting they just tell me I shouldn't disturb them. For example I told them in one meeting that my crops are being stolen but they told me not to disturb them and that I am mad."
Man with mental health issues

"The problem when you take your case to police is that they don't consider it if the ones you are accusing obstructs you, saying that you have become mad, that you are not taking medication. [...] You have nowhere to complain once you are mentally ill. Even if you take a complaint to the local council, they don't value your complaint, they say that, after all, you are mentally ill."
Man with mental health issues

Family members and carers who were interviewed also expressed little faith that complaints would be taken seriously or investigated. The husband of one woman with mental health issues explained:

> *"Yes, I tried to complain to the local councils about her [wife] being beaten and treated badly. They say that she is mad therefore a mad person cannot settle issues with a normal person."*

The lack of redress for such abuses caused a number of people with mental health issues to report resignation to their lot and a distrust towards their communities.

Excerpt 4. 4: An interviewee with mental health issues
Interviewee: I have been complaining [*about verbal abuses*] to the local council committees but they do nothing about it. [...]
Researcher: How do you feel about those people?
Interviewee: I don't feel well and feel degraded.

In order to cope with abuse and ill-treatment, people with mental health issues reported withdrawing from their communities and avoiding contact with other people, further deepening their feelings of separation and isolation.

One man with mental health issues explained that avoidance, however, didn't help in the longer-term:

> *"I try the escape mechanism as a model of approach by trying to avoid such kind of people and move away from the areas where such kind of things happens though it is not at all a helping factor or approach. This means that it does not take away the problem I am facing."*

Another woman said that having a close friend was crucial for her in cope with the stigma associated with having a mental health issue:

> *"I have always tried to forget things and start up a new life but it has always been difficult. I cannot forget the memories of my past because people will still know me as a person who has suffered mental illness. Sometimes the only way to relieve myself is to share my difficulties with a friend."*

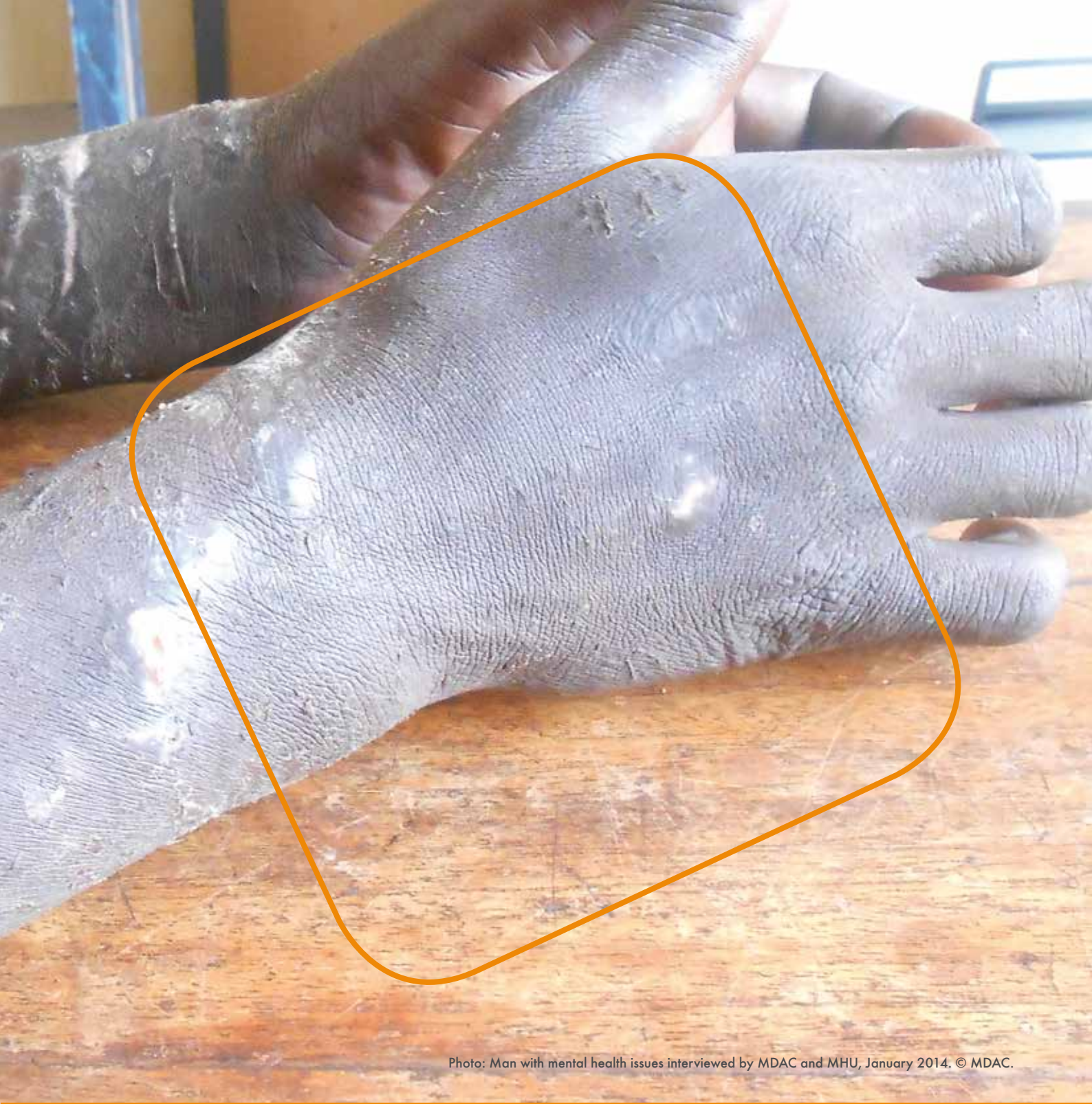

Photo: Man with mental health issues interviewed by MDAC and MHU, January 2014. © MDAC.

"They used to beat her [at the church], tie her with ropes, deny her food and she didn't even heal, and then she was taken to hospital."

The friend of a woman with mental health issues

5. Ill-treatment in service provision

The most common services that people with mental health issues accessed were traditional healers, as well as services provided by conventional psychiatric or mental health units at hospitals. The report which is jointly published with this, *Psychiatric Hospitals in Uganda: A human rights investigation,* also presents more detailed monitoring findings from Uganda's psychiatric facilities.

5(A). Traditional Healing

The term 'traditional healing' in this chapter refers to a variety of forms of non-conventional treatment, including those provided by churches and witchdoctors. The present investigation shows that non-conventional treatments are likely to be the first form of treatment experienced by the majority of Ugandans with mental health issues.[19] Interviews showed that 26 out of 40 people with mental health issues had experienced such forms of treatment. Table 2 shows places of treatment reported by these 26 interviewees.

Table 2: People with mental health issues: experience of traditional healing	
witch-doctors	10
church[20]	9
both witch-doctors and church	6
herbalist	1
Total:	**26**

MDAC and MHU found that only three interviewees had tried traditional healing on their own initiative and that the rest had been taken for traditional healing by their family members or carers. People who were kept in traditional healing facilities reported periods of stay between one night and one year. The following testimonies describe the bewildering, abusive and coercive practices that they endured, often without their consent. The first is from a woman with mental health issues:

> *"When the night came, I was taken to a room. We were very many people. After reaching the room, they encircled the room with darkness, they started drumming, singing and clapping. Then the witchdoctor told me to undress myself and poured some herbs on me and said that the ancestors are treating me."*

A male interviewee spoke about the treatment he received from a traditional healer:

> *"[A] man [...] then hit me with a metal on my mouth because my mouth could not talk. [...] So that person came and hit me with a metal. That's when I had bitten my tongue. I could talk but I never understood what I was talking but for them – they understood. When they hit me I came back to my senses [...]".*

Excerpt 5. 1: A man with mental health issues:
Interviewee: They would tie me and the ropes even entered the flesh, and beat me before giving me medicine, because there was some medicine I used to bath with but it would itch and I felt my body was burning.
Researcher: For how long would they tie you with ropes?
Interviewee: Three weeks.

19 This is similar to the findings of an investigation by MDAC and the Mental Health Users Network of Zambia (MHUNZA) on human rights and mental health in that country. To read more on traditional healers and mental health, see the report: MDAC and MHUNZA, *Human Rights and Mental Health in Zambia* (Budapest: 2014), available online at: www.mdac.org/zambia (last accessed: 6 December 2014).

20 The church in this table refers only to cases when people with mental health issues were admitted there for a certain length of time. The widespread attendance at churches for intense short duration prayer sessions at times of mental health crises was not investigated in detail.

Experiences with traditional healers

"[T]hey would also smoke, they tell you to smear things that were itching which was hard for me."

Woman with mental health issues

"I was meant to sleep in the witchdoctor's shrine alone yet they didn't give me anything to cover myself and nothing to eat. [...] The witchdoctor asked for a goat which he slaughtered for the spirit that later came, and they started placing finger nails everywhere on my body so that they were removing the illness."

Man with mental health issues

"They [people with mental health issues] were beaten, their hair was cut off, they would cut their bodies to put in medicine [...]"

Spouse of a man with mental health issues

Out of 26 interviewees who reported undergoing traditional healing practices, four reported that they hadn't had negative experiences. These four interviewees reported being treated in churches. Two of these, however, reported observing physical abuse against others.

The vast majority of interviewees, however, reported severe forms of physical abuse whilst undergoing traditional treatments, including tight restraints, isolation, physical violence and the denial of food and water. Their testimonies are presented here.

Excerpt 5. 2: A woman with mental health issues
Researcher: How was your experience in church?
Interviewee: They used to beat me since they were also confused.
Researcher: Why would they beat you?
Interviewee: I think because I would disorganise them and also shout a lot.

Excerpt 5. 3: A man with mental health issues
Interviewee: It was really not easy when we reached there, the witchdoctor slaughtered a hen on my head and poured the blood, they made me drum up to morning so that the spirits could come to me but they didn't come, and in the afternoon I felt very bad though they were trying to help me.
Researcher: How did you feel about that experience while there?
Interviewee: I felt very bad since I didn't get relieved and I lost hope in life and world. [...] I was tied on ropes and they wouldn't care about [me].
Researcher: For how long were you tied on ropes?
Interviewee: It was like one month.

Excerpt 5. 4: A man with mental health issues
Interviewee: I was beaten badly and also tied tightly with ropes to the point of entering my flesh, I have the scars.
Researcher: Who would tie you?
Interviewees: The workers of the witchdoctor.
Researcher: For how long would they tie you?
Interviewee: Three days. [...] At times I would feel hungry but no one would give me something to eat.

Interviews with family members and carers confirmed the severe forms of physical abuse that took place in traditional healing settings. The wife of one man spoke of the experiences of her husband at a witchdoctor:

"He really suffered when he was there like being tied on ropes, beaten. The witchdoctor had people to care for the patients but the only thing that they would do was to beat them."

The friend of a woman with mental health issues said:

"They used to beat her [at the church], tie her with ropes, deny her food and she didn't even heal, and then she was taken to hospital."

While describing the abusive practices in traditional healing settings, family members expressed different opinions. Some were rather distant and neutral as to the practices described, while others expressed ambivalence, and some regretted taking their relatives to traditional healers. Some family members and carers, however, believed that these forms of treatment were good for their relatives.

Excerpt 5. 5: Brother of a man with mental health issues
Researcher: What do you say about treatment from witchdoctors?
Interviewee: They treat well.
Researcher: Did you see him [brother] going through any bad experience at the witchdoctor's place?
Interviewee: He was tied with ropes and was naked.
Researcher: Why did they tie him with ropes?
Interviewee: Because he had a lot of energy and in order to keep him in one place.
Researcher: For how long would he be tied with ropes?
Interviewee: Two months.

Excerpt 5. 6: Mother of a woman with mental health issues
Interviewee: Yes, they would beat and tie them with ropes, but mine did not go through that because she never disturbed them.
Researcher: Who would beat them?
Interviewee: The witchdoctors had his workers who would grind medicine, so they would beat them.
Researcher: Why did they beat them?
Interviewee: So that they could sleep.

Excerpt 5. 7: Husband of a woman with mental health issues

Interviewee: The problem with the witchdoctors is that they don't have mercy because they beat her and tie her tight on the plantation. Then it's me myself who feels pity and regret why I brought her there.

Researcher: Why do they beat her?

Interviewee: They say that a mentally ill person has a lot of energy because they are very strong.

Excerpt 5. 8: Mother of a woman with mental health issues

Interviewee: They would tie her, and when they see that she was a bit okay they relieve her, then they tie her again.

Researcher: What is your opinion on the kind of treatment she received there?

Interviewee: It wouldn't have been bad but the ropes injured the skin; that was the big problem. I saw that that was bad.

The mother of one man with mental health issues reported that another person undergoing treatment at a traditional healing centre died after undergoing particularly abuses practices. Several interviewees also criticised traditional healing for failing to deliver any results and also for being expensive – "eating lots of money", as one interviewee put it. None of the interviewees had initiated any complaints relating to their experiences in traditional healing settings

5(B). Psychiatric hospitals

In the course of this project, MDAC and MHU have also produced a report documenting findings from the first ever human rights monitoring in psychiatric hospitals in the country.[21] This section, however, present the perspectives of interviewees regarding treatment in psychiatric hospital experiences when outside the hospital.

Interviewees with mental health issues reported undergoing between one and six admissions to the various psychiatric facilities across the country, with periods of stay ranging from two weeks to two months in length. The most frequently cited hospital was Butabika hospital, the national referral mental health hospital based in Kampala. Interviewees also referred to their experiences at regional, district and private mission hospitals around the country, including in Arua, Gombe, Gulu, Kabale, Kasangati, Kisiizi, Lacor, Mbarara, Mityana, Mpenja, Mulago and Soroti.

5(B)(i). Admission

The majority of interviewees with mental health issues reported being taken to psychiatric hospitals by their family members. In a small number of cases, interviewees reported being admitted with the assistance of police.

The admission procedure described in the majority of interviews described the person with mental health issues being taken to the hospital in ropes by their relatives, injected with medication that made them immediately fall asleep, and subsequently being placed into seclusion for first couple of days. A man with mental health issues explained what happened:

> *"Most of them [patients] are brought when they are tied with ropes, after which they take them to the room then inject them to sleep and when they sleep they admit them so after they wake up they can start treating them."*

Another man with mental health issues described the admission of other people into the hospital:

> *"I remember on my ward, there were two people that were brought in ropes and these people were injected there with a strong injection which makes people sleep like being half dead."*

The friend of a woman with mental health issues described the way that her friend was admitted by her brother:

> *"The brother slapped her and put her on a motorcycle and took her to the hospital. And in the hospital she was put in the seclusion room for about a week."*

5(B)(ii). Seclusion and violence

The use of seclusion was widely reported by people who had been admitted to psychiatric hospitals, lasting for periods between one night and one month. Most of the people reported that they received food, and were allowed to bathe and use the toilet while in seclusion, however this was not always the case. A woman who was admitted to one regional hospital said that the conditions in made her unable to eat:

> *"We could bathe every day but I refused to eat food because the place used to be untidy - where I was brought it was not clean."*

21 MDAC and MHU, *Psychiatric hospitals in Uganda: A human rights investigation* (Budapest: 2014).

A man with mental health issues who experienced admission to a different hospital said that his time in seclusion was more restricted:

"I was put in the seclusion room for four days, I wasn't bathing and I was not even seeing the sun."

Another man described the conditions in a seclusion room.

Excerpt 5. 9: An interviewee with mental health issues
Researcher: How did the room look?
Interviewee: It was very dirty and smelled badly.
Researcher: What made it dirty?
Interviewee: Me urinating there.
Researcher: Were you given chance to go and bathe, get food?
Interviewee: They can't give you food and even bathing - they can't allow you to go and bath.

A number of interviewees described seclusion rooms in psychiatric hospitals as "cold rooms". A man explained why this was:

"First they strip you naked and throw you in the cold room, sometimes the security men can throw you there when the doctors are not aware. If no one takes care you can even miss lunch and supper. And some people are even put there for a week, yet you're not supposed to be there for more than two days."

Here is another woman's experience of seclusion upon admission to a hospital:

"At the time they were admitting me the security officers were tough on me, they strangled my arm, they wanted to break my arm then they took me to the seclusion room. When I reached there, the security officer kicked me and pushed me inside and locked the door. [...] Seclusion room is a dark room like when you're in it, it's a deep hole, it has no windows, it has a tall door and only ventilators, and it's very cold. They put you in when you are totally naked. When I was there some patient came and opened the door and I forced myself out then I started moving naked in the corridors and the cleaners helped me, brought me the uniform and I put it on."

Some interviewees described violence as a common experience inside psychiatric hospitals. The perpetrators included other patients, hospital staff, and also visiting family members. One woman explained how staff would slap her if she refused to swallow medicine. Another woman reported what she noticed in the hospital: "I found that those who were disobedient were beaten but I was not beaten." As seen in the interview below, one of the things that constituted disobedience was refusal to take drugs while relatives also used violence in the hospitals.

Excerpt 5.9: Family member of a person with mental health issues
Interviewee: She told us she saw others were beaten heavily, tied even for weeks and you see the hands bleeding and legs.
Researcher: Who would tie those people and beat them?
Interviewee: Their relatives who would be with them in the hospital.

Other interviewees reported witnessing or being tied themselves whilst in psychiatric hospitals, being placed in seclusion as a punishment for perceived disobedience, and being forcibly medicated. However, not all family members considered such coercive practices to be negative. Below are testimonies from two fathers.

Excerpt 5. 10: Father of a woman with mental health issues
Interviewee: She was admitted to the [seclusion] room because she was stubborn. She had to be isolated in the room otherwise she was fighting and wanting to go back home.
Researcher: For how long was she isolated in that room?
Interviewee: Six months.
Researcher: How did the room look?
Interviewee: It was nice.
Researcher: While in the room, did she have access to bathing and meals?
Interviewee: Yes we could go there and bathe her, give her food, give her drinks since she wanted to drink all the time.

Excerpt 5. 11: Father of a woman with mental health issues
Interviewee: We, the parents and doctors scared her to take the medication and that if she doesn't – that we will beat her.
Researcher: Are there any other patients that went through bad experiences in hospital?
Interviewee: Some were beaten by their caretakers.
Researcher: Do you mean that when your relatives are taken to hospitals, they allow caregivers?
Interviewee: Yes, they do.
Researcher: When your relative was forced to take medication, how did you feel about it?
Interviewee: I didn't feel bad because I also wanted her to take the medicine.

5(B)(iii). Interaction with hospital staff and complaints

The majority of interviewees described minimal interaction between themselves and staff when admitted to psychiatric hospitals. One woman with mental health issues explained the conversation as a "question and answer session".

It is worth noting that none of the interviewees complained about incidents of ill-treatment and abuse in psychiatric hospitals. This was because they either did not know where to complain or because they were fearful of repercussions. Others did not know how to complain.

Overall interviewees' perspectives regarding their experiences in psychiatric hospitals were divided. Some people clearly articulated their negative feelings and opinions. One man with mental health issues said:

> *"It [the hospital stay] was not good, you feel like you are almost in a prison, you are not allowed to go anywhere; the entire time is spent on premises. And even the problem of food, I could get tired of poscho [beans and maize]."*

Despite the negative experiences, the majority of interviewees with mental health issues judged their stay in psychiatric hospital more positively than their experiences of non-conventional healing. The most valued aspects were access to psychiatric medication and the overall reduction in the symptoms of their mental health issues.

The pharmacological approach to treatment was broadly accepted by the vast majority of interviewees with mental health issues, as well as by their families and carers, despite many being unaware of the names of the drugs being used. This clearly reflected a lack of any available alternatives, and represented a better choice than other non-conventional treatments that many had experienced in traditional healing settings. One man with mental health issues said:

> *"Well it [medication] has helped me to stabilise my mood and actually to socialise with other people."*

Another woman with mental health issues said:

> *"At times I think a lot but when I take the medicine I stop thinking."*

The major problems reported in relation to the psychiatric drugs, apart from their considerable price, were severe side effects such as feeling sleepy, tired and without much energy. When asked whether they wish for any other treatments, the majority of interviewees were unable to think what alternatives might be possible.

Photo: Shutterstock

"At times I work for people and they refuse to pay me, and those things hurt me. [...] I worked and they refused to pay me the money [after] I had worked for 6 months."

Man with mental health issues

6. Education, work and employment

Education and employment are the most important aspects facilitating the inclusion of people with mental health issues into their communities. They also foster independence and autonomy. Yet, many interviewees described the ways in which they were denied these opportunities, commonly as a result of ingrained stigma and discrimination at places of work, as well as in educational settings.

6(A). Education

The majority of interviewees with mental health issues reported having discontinued their education due to a lack of finances. A smaller number of interviewees reported dropping out due to mental health issues arising in the course of their studies. Interviewees also talked about the lack of support.

"Well right away after [...] the first episode I tried to continue with my studies, only that I could not manage balancing medication, trying to mobilise finances to cater for tuition and then work, so those were difficult conditions. The experience was not good and it caused me a lot of stress."

Woman with mental health issues

"His mental illness started at school and there was nobody to help him. So he ended up like that – as a mad person. But if there were some ways like today I think he would have continued."

Brother of a man with mental health issues

MDAC and MHU also found out that in situations where mental health issues emerged in the course of education, interviewees experienced a lack of knowledge and support in schools.

"[T]he worst thing to handle is a relapse at school because people will pin you against certain names, they lower your self-esteem and if you don't stay calm you may end up not completing school."

Man with mental health issues

"When I was becoming a bit better I returned back to school and when I reached the class that's when the pupils used to take my seat and I could not find my place. [...] I feel that they were not comfortable sitting next to me because I was ill. [...] The teachers also used to fear me. [...] They had no other alternative but to tell pupils not to disturb me as they also feared me."

Woman with mental health issues

Discrimination, isolation and bullying were commonly reported by interviewees as a reason for the discontinuance of education:

"I would relapse and the teachers would say 'you leave her because she's mentally ill', and so the children would isolate me. Even if a teacher asked a question in class, they wouldn't allow me to give an answer saying that I am mad, so I didn't enjoy school because they would isolate me calling me mad girl."

Woman with mental health issues

"Of course they [pupils] used to beat her, tease her, and push her out of the line for food so she always used to be the last to eat food during lunch time."

Sister of a woman with mental health issues

Two interviewees reported having complained to their headmasters and the school administration. In one case the situation improved, but not in the other one. "I complained but they wouldn't help and only said that if am tired of school, I should go back home because their school is not for mad people", reported one woman with mental health issues.

6(B). Work and employment

People with mental health issues and their family members highlighted the importance of being able to work and generate an income in order to become self-sufficient. Nevertheless, some of the interviewees who were employed at the time of interview reported that they had chosen not to disclose their mental health issues at work due to the risk that they might lose their jobs. Others described how they received little or no support, and faced discrimination in the workplace.

6(B)(i). Disclosing mental health problems

A significant issue for people working in public service was the dilemma whether to disclose or hide their mental health issues. The majority said they had made a conscious decision not to disclose their mental health issues in order to avoid ill-treatment and discrimination, and the risk of losing their only source of income. One woman with mental health issues said:

> *"People discriminate you when they know that you have a mental problem, that's why I hide it so that I would earn something to eat."*

Another man who had hidden his mental health issues spoke about discrimination in the workplace:

> *"Once they realise that you have a mental problem, they don't employ you, so it was my choice to hide my mental health problem from my employer. If I disclosed it to them during interview, they would have not employed me. [...] They have now come to realise on their own, but I have not disclosed for the sake of my job."*

Interviewees said that negative social attitudes were a key barrier in gaining or maintaining a job. One man with mental health issues said:

> *"When I try to look for a job, people say [...] they can't use a mad person. If you get a chance and someone gives you something to do, he will keep saying – will this mad person manage work?"*

The sister of a woman with mental health issues also commented:

> *"Whenever she goes to ask for the job they ask people about their life and they don't employ her, because they say that she will spoil their things since she is mentally ill, and she misses chances because of that."*

6(B)(ii). Discrimination and lack of support

Only two interviewees felt that they could be open about their mental health issues at work. One was working for a mental health NGO and the other was a teacher. The latter reported that when his colleagues could see his condition worsening, they allowed him to go home and rest.

However, several people reported insults and prejudice. One man reported:

> *"Like when they want to send you, they call [you] by different names like 'kataala', mad person and I really feel bad.*

Excerpt 6. 1: A woman with mental health issues

Interviewee: He [*supervisor*] got in a quarrel with me over the sim-card which was actually mine, claiming that I have picked it from his bag. [...] He was saying that it seems I am mad, I don't know what I am saying and I should live in a rubbish pit of my own.

Researcher: Did you try to do something about it?

Interviewee: Yes I reported the matter to the manager, and he was forced to apologise because he even found his sim-card later in his bag, I then forgave him.

Such incidents were not always resolved positively, with four interviewees reporting losing their jobs on the basis of their mental health issues. One woman with mental health issues said:

> *"I was taking drugs and I got side effects of drugs, then the supervisor told me to rest and while I was resting the managing director came and found me sleeping. Then he landed on my problem and they dismissed me. [...] They said: 'We are going to give you your money you have worked for but we can't work with a mad person.'"*

A quarter of people with mental health issues interviewed reported that they were self-employed, either selling goods or occasionally working for others, but that they were likely to be treated less-favourably:

> *"The problem is that if someone knows that you have a mental disorder they look down at you, even if you ask for a fair payment for a certain task they want to give you less."*

The sister of a man with mental health issues explained how people would take advantage of people with mental health issues:

> *"I think some people may assume he can't understand and remember. For example they can take his things and they don't pay as they think he is mentally ill."*

Another man explained how he was exploited by his employer, reflecting similar situations experienced by a number of people interviewed:

> *"At times I work for people and they refuse to pay me, and those things hurt me. [...] I worked and they refused to pay me the money [after] I had worked for 6 months."*

Farmers selling their produce reported facing similar problems, with some saying that they needed to travel to markets in other areas where they were not known in order to be able to sell their produce at a fair price. A woman with mental health issues explained:

"If I sell to [my produce] to those who are near and who know about my mental illness, at times they take my goods and they don't pay me the amount of money I want. [...] I travel very far where they do not know me so that they buy from me."

A male farmer also described how local community members would take advantage:

"When the time for selling comes and if the one buying knows that you have mental difficulties, they just tell you any price they want. If you complain they refuse to buy until you accept their price."

Relatives and carers confirmed such practices. The daughter of a woman with mental health issues in self-employment explained her mother's experiences:

"Some of them [...] give her the money she has asked for and pay her in time, but others don't want to pay her [and] ignore her [because] she is mentally ill. When she reports, they do not listen to her, they ignore her, abandon and some of them take her things away intentionally. [...] When she reports to the local council they say she is mentally ill and that she is lying."

An important issue faced by farmers with mental health issues is that they reported being denied access to the support of the National Agricultural Advisory Services (NAADS), which provides assistance to farmers and subsistence producers, pointing to discrimination in the provision of government services.

Excerpt 6. 2: A male farmer with mental health issues

Interviewee: They [*NAADS*] refuse us to enter the groups they make because they say we shall disturb them because we have mental illness. And if you don't belong to any group so the one giving out the service of NAADS can't reach you. [...] I would like those groups that help people, like NAADS, to also help us, like giving us something like birds to rear and coffee, because we also have children to look after and to sustain our homes.

Researcher: Do you mean there is a reason why NAADS doesn't give you assistance?

Interviewee: Yes, they say that we are people with mental illness and we shall destroy their things if they give them to us.

Excerpt 6. 3: Male farmer with mental health issues

Interviewee: Sometimes when it comes to giving out things like from NAADS, people with mental illness are not given.

Researcher: Have you been able to complain to the authorities?

Interviewee: Yes, I went to Sub County Eastern Division, and told them also to consider people with mental illness but they have not responded positively.

Excerpt 6. 4: Spouse of a farmer with mental health issues

Interviewee: Like, those groups of National Agriculture Advisory Services haven't been supportive because he is a person with mental illness.

Researcher: Has he ever tried to get support by those groups?

Interviewee: Yes.

Researcher: What did they say?

Interviewee: That he is mentally ill. They are discriminated because of mental illness. They think that what is given to them will not be used well.

Particularly in rural areas, many people with mental health issues spoke about the importance of subsistence farming or running their own small businesses, especially where there was a lack of industry. To do so, they spoke about the need to receive initial financing or small development loans, although a number reported that banks or other credit unions were unlikely to help them. One woman told researchers:

"In Uganda people with mental health difficulties are not allowed to access a loan, that's why I lack money to start a business."

Another woman reported being refused a loan because of her mental health issues:

"Even if they borrow me they say that I don't know what to use it for, if they give me it will be as if they have just thrown it away."

Interviews with relatives confirmed this denial of startup credit for small businesses to people with mental health issues.

Excerpt 6. 5: Spouse of a man with mental health issues

Interviewee: The income is not good, yet he could begin something but he can't get any loan in a bank since he is mentally ill.

Researcher: Has he ever tried to get a loan?

Interviewee: Yes, he tried and he failed.

Researcher: What reasons did they give for not giving him a loan?

Interviewee: They say he is mentally unstable.

Interviews clearly showed that widespread prejudices against people with mental health issues have a serious impact on their ability to earn an income, often placing them in extreme forms of poverty and making them totally reliant on the goodwill of family or carers. The cycle of poverty, mental health issues, discrimination and social isolation meant that many interviewees reported severely restricted lifestyles. The accumulation of these experiences often weakened social ties between them and their communities, and many interviewees reported feelings of resignation and withdrawal.

Photo: Shutterstock

"The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."

Article 1, UN Convention
on the Rights of Persons with Disabilities

7. Human rights standards and tackling ill-treatment

The previous chapters of this report overwhelmingly depict widespread and ingrained forms of discrimination against people with mental health issues in Uganda at home and in their communities, as well as barriers to achieving an income and abuse at the hands of traditional and conventional medicine practitioners. Of particular concern is that the majority of people with mental health issues reported experiencing serious forms of ill-treatment, neglect, violence, abuse and hostility, along with a failure of authorities to take action.

In the same way as all other members of society, Ugandans with mental health issues have the right to protection from such forms of abuse and exploitation. From a legal perspective, Ugandan government authorities also have obligations to tackle these problems. This section presents the key human rights standards and points out the actions that Ugandan authorities should prioritise in ending the discrimination so vividly described in the above testimonies.

7(A) Human rights standards

Uganda is party to several international human rights instruments having the status of binding international law, including the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and its Optional Protocol.[22] The purpose of the CRPD is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity".[23]

People with mental health issues are, for the purposes of the Convention, "persons with disabilities" and are thus entitled to the range of rights sets out in the Convention. The CRPD calls for the removal of disabling barriers which may hinder the full and effective participation in society of people with disabilities on an equal basis with others.[24]

7(A)(i). Right to be free from torture, ill-treatment, exploitation, violence and abuse

Under international human rights law, all forms of torture, inhuman or degrading treatment are absolutely prohibited in all circumstances, and this standard is also outlined in African regional law.[25] The UN Convention against Torture and the CRPD both establish requirements on governments to take steps to protect people with disabilities from abuse.[26] The CRPD's longest provision is focused on preventing and providing remedies for all forms of exploitation, violence and abuse.[27] The CRPD requires governments to ensure that all healthcare professionals provide care "on the basis of free and informed consent".[28]

The UN Special Rapporteur on Torture has clearly stated that the "criteria that determine the grounds upon which treatment can be administered in the absence of free and informed consent should be clarified in the law, and no distinction between persons with or without disabilities should be made".[29] The UN Special Rapporteur recommends banning seclusion and restraints. Even if applied for a short period, these "may constitute torture and ill-treatment",[30] and are thus banned under international law.

22 Uganda ratified the CRPD on 25 September 2008.

23 CRPD, Article 1.

24 Ibid.

25 At the regional level, the African Charter of Human and Peoples' Rights (ACHPR) prohibits *"all forms of exploitation and degradation of man"* including torture, cruel, inhuman or degrading punishment and treatment (ACHPR, Article 5). It guarantees the highest attainable state of physical and mental health, and provides for special protection for the *"aged and the disabled"* and gives everyone the right to a *"general satisfactory environment favourable to their development"* (Articles 16, 18 and 24). These apply equally to people with psycho-social disabilities (Article 2 and 3). Additional protection is provided to women with psycho-social disabilities through the Protocol to the ACHPR on the Rights of Women in Africa, which obliges States to provide special protection to ensure their right to freedom from violence, including sexual abuse, discrimination based on disability and the right to be treated with dignity (Article 23 of the Protocol).

26 CRPD, Articles 15 and 16 respectively. See also CAT, Article 11; ICCPR, Articles 7, 10(1)(2), 10(3) and 16; CRC, Articles 19(1) and (2) and 23.

27 CRPD, Article 16.

28 *Ibid.* Article 25(d).

29 UN Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, 1 February 2013, A/HRC/22/53.

30 *Ibid., at para.* 23.

7(A)(ii). Right to Community living

This is one of the core rights in the CRPD provided in Article 19 and sets out the "equal right of all persons with disabilities to live in the community". The provision specifies that everyone has the right to choose where and with whom to live, and places a duty on governments to take effective and appropriate measures to facilitate the full enjoyment of this right by all persons with disabilities, along with ensuring that they can access services that are provided to the general population. Recognising that some people with disabilities will require more specific support to ensure their full inclusion in the community, the CRPD also calls on governments to establish a range of disability-specific community support services, so as to prevent isolation or segregation and abuse.

7(A)(iii). Right to Liberty

The CRPD stipulates that the presence of a disability cannot be a valid criterion in detention decisions,[31] a provision which is the focus of intense international debate.[32] The Committee on the Rights of Persons with Disabilities (CRPD Committee) has called on States to repeal laws and prohibit the detention of children and adults with disabilities with reference to their disability status. This includes ending the involuntary hospitalisation of people with mental health issues.[33]

7(A)(iv). Right to Health

The right to health has two dimensions. It entails freedoms which include the freedom to provide or withhold consent to health care services. The right also includes entitlements such as "early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities".[34]

The duty is to "provide these health services as close as possible to people's own communities, including rural areas," and to "provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons".[35]

7(A)(v). Right to legal capacity

The CRPD provides that all people with mental health issues have the right to make decisions in their lives, and that they should be provided with the support they need to make decisions if they need. Article 12 of the CRPD requires that the government ensures that their decisions are recognised and protected.[36] The removal from people with mental health issues of the right to make decisions about how to live their life exposes them to harm, including in healthcare settings where forced treatment is still prevalent in many countries, including in Uganda. MDAC's research on the right to legal capacity in Kenya and peoples' testimonies above show that relatives and medical practitioners frequently make decisions for people with mental health issues regardless of their will or preferences, which constitutes a violation of Article 12.[37]

7(B) State human rights obligations

This section provides general and specific recommendations to the Ugandan authorities on some of the measures required to address the abuses that people with mental health issues have described in this report. It draws from the CRPD and UN CRPD Committee's concluding observations while also highlighting human rights obligations derived from domestic laws when appropriate. State obligations can be both general[38] and specific with regard to the different forms of abuses reported.

7(B)(i). Fulfil the right to live in the community

The right to live in the community with equal choices and access to regular and disability specific services should be fulfilled.[39] People with mental health issues should have the opportunity to be actively involved in decision-making processes in their communities,[40] which requires their full inclusion and participation in the community (mere presence in community is not enough).[41] Measures including legislative, administrative

31 CRPD, Article 14

32 See, for example, the written comments of the governments of Germany and Denmark on the draft general comment on Article 12 of the CRPD by the UN Committee on the Rights of Persons with Disabilities, available online at: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx (last accessed: 6 December 2014).

33 UN Committee on the Rights of Persons with Disabilities, General Comment No. 1, 11 April 2014, CRPD/C/GC/1; UN Committee on the Rights of Persons with Disabilities, Concluding Observations of the Committee: Azerbaijan, 12 May 2014, CRPD/C/AZE/CO/1.

34 CRPD, Article 25(b).

35 CRPD, Article 25.

36 CRPD, Article 12(1), (2) and (3).

37 MDAC, *The Right to Legal Capacity in Kenya*, (Budapest: 2014).

38 CRPD, Article 4.

39 CRPD, Article 19, and Article 3(d).

40 CRPD, Preamble (0).

41 CRPD, Article 19.

and judicial steps should be taken to prevent people with mental health issues from being subjected to torture or cruel, inhuman or degrading treatment or punishment.[42]

The pervasive isolation and abuse reported by people with mental health issues clearly shows a need for action to be taken to tackle the underlying negative attitudes associated with mental health issues in the country. In shifting these attitudes, the government must also take social and educational measures which protect people with mental health issues inside and outside their homes, as well as measures to ensure justice is obtained for victims of exploitation, violence and abuse, including gender-based violence.[43]

Ensuring access to justice for the serious violations, including responsive complaints and investigations systems, should be prioritised.[44] The lack of safety for people with mental health issues requires urgent attention in other areas too. As such, the Ugandan government should prioritise the following actions.

1. Collect data and information on violence and abuse against people with disabilities, using this evidence-base to develop policy responses which tackle the causes;
2. Establish institutional mechanisms for the early detection of situations in which violence may occur, particularly through undertaking targeted investigations in areas identified by people with disabilities themselves;
3. Ensure that there is no culture of impunity for violations of the rights of people with mental health issues, including through the diligent investigation of allegations or violent acts and ensuring that legal processes are accessible and responsive to the needs of victims, including prosecution of those who are responsible;[45]
4. Give people with disabilities access to protection mechanisms such as temporary shelters and therapies to aid their recovery from violence, abuse and exploitation in an anonymous manner and ensure full accessibility of these mechanisms;[46]
5. Develop indicators to determine the extent of violence, abuse and exploitation of against people with disabilities in a way that is sensitive to gender, age and other differences;[47]
6. Develop specific training and protocols for the investigation of cases of violence against people with disabilities;[48]
7. Involve people with mental health issues themselves to develop a comprehensive violence strategy to prevent and punish exploitation, national violence reduction strategy; and
8. Publish information on complaints and decisions on behalf of people with disabilities who are victims of such offences on a regular basis.[49]

7(B)(ii). Raise Awareness

The Ugandan government has an obligation to raise awareness throughout society to foster respect for the rights and dignity of people with mental health issues, and to combat stereotypes and prejudices which lead to harmful practices against people with mental health issues.[50] The CRPD Committee has identified a number of actions that states can take, and many of these are directly relevant to the Ugandan context too:

1. The government should undertake awareness-raising campaigns on the rights of people with mental health issues using various formats, media and modes of communication including braille and sign language and other accessible formats,[51] aimed at:
   a. eliminating prejudices and stereotypes;[52]
   b. challenging socio-cultural discrimination in public life;[53]
   c. promoting people with disabilities as independent and autonomous rights holders and informing all persons with disabilities of their rights, especially those living in rural areas;[54]
   d. focusing on dignity, capabilities and the contribution that people with disabilities can make to their communities, and to society;[55] and
   e. fostering a culture of respect for rights using information, communication and education.[56]

42 CRPD, Article 15.

43 CRPD Article 16.

44 Ibid, Article 16(2)

45 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Argentina, 8 October 2012, CRPD/C/ARG/CO/1.

46 Committee on the Rights of Persons with Disabilities, Concluding Observations of the Committee: Costa Rica, 12 May 2014, CRPD/C/CRI/CO/1.

47 Ibid.

48 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: El Salvador, 8 October 2013, CRPD/C/SLV/CO/1.

49 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Paraguay, 15 May 2013, CRPD/C/PRY/CO/1.

50 CRPD, Articles 8(1)(a) and (b)..

51 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Costa Rica, 12 May 2014, CRPD/C/CRI/CO/1; Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: El Salvador, 8 October 2013, CRPD/C/SLV/CO/1.

52 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Austria, 30 September 2013, CRPD/C/AUT/CO/1; Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Azerbaijan, 12 May 2014, CRPD/C/AZE/CO/1.

53 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Sweden, 12 May 2014, CRPD/C/SWE/CO/1.

54 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: China, 15 October 2012, CRPD/C/CHN/CO/1; Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Costa Rica, 12 May 2014, CRPD/C/CRI/CO/1.

55 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Peru, 16 May 2012, CRPD/C/PER/CO/1.

56 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Paraguay, 15 May 2013, CRPD/C/PRY/CO/1.

2. Train relevant government officials (including health, legal, educational and social work professionals, as well as members of the judiciary, police, elections officers, media practitioners/journalists and other staff) on the rights of people with disabilities, and especially officials at the local level dealing with people with disabilities;[57] and
3. Promote disability education as a cross-cutting theme in university and other professional courses, and promote training on the CRPD for people with disabilities and their representative organisations using accessible formats and media.[58]

In Uganda, the mandate to raise public awareness on disability issues and the rights of people with disabilities rests with the National Council for Disability.[59] While the Council and others[60] may have carried out some disability awareness raising activities, there is a need for more targeted awareness-raising on the rights of people with mental health issues, particularly at the local community level.

7(B)(iii). Access to justice

The Ugandan government has an obligation to guarantee effective access to justice for people with mental health issues on an equal basis with others. The government's obligations here include training those working in the administration of justice, such as police officers, about how to appropriately deal with people with mental health issues.[61] Specific actions should be:

1. Rolling out standard and compulsory modules on how to work with persons with disabilities for police officers, prison staff, lawyers, members of the judiciary and court personnel;[62]
2. Ensuring that this training targets officials in both rural and urban areas;[63]
3. Guaranteeing that people with mental health issues have the same substantive and procedural legal guarantees as others in the context of criminal proceedings;[64] and
4. The provision of free legal assistance.[65]

7(B)(iv). Living conditions

The majority of people reported living in conditions of extreme poverty, which has a clear bidirectional link with their mental health issues. The CRPD highlights the critical need to address the negative impact of poverty on people with disabilities.[66] The Convention further emphasises the importance of mainstreaming disability issues into relevant strategies of sustainable development,[67] and calls for governments to guarantee the right to social protection and an adequate standard of living for people with mental health issues and their families.[68] This includes adequate access to food, housing and the continuous improvement of living conditions as core elements in reducing poverty.

Development priorities should be inclusive of the needs of people with mental health issues, and should carefully take into account both the gender perspective and variations between rural and urban areas.[69] When allocating budget, the Ugandan government should ensure that people with disabilities are closely involved.[70] Monitoring the implementation of the policies should include people with disabilities.[71]

Domestic Ugandan legislation also requires the state to take action to promote social justice and economic development,[72] including ensuring that all citizens have access to decent shelter and food security.[73] The Ugandan government has plans to set up national food reserves,[74] and is currently developing a Food and Nutrition Bill.[75] These developments should specifically address the particularly vulnerable positions of people with mental health issues outlined in this report. The government has also committed itself to promoting and including the issues related to people with mental health issues into all its broader economic and social development policies and programmes.[76]

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57 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Tunisia, 13 May 2011, CRPD/C/TUN/CO/1.

58 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: El Salvador, 8 October 2013, CRPD/C/SLV/CO/1.

59 National Council for Disability Act 2003, section 6.

60 Such as the Disability Department at the Ministry of Gender, Labour and Social Development, District Councils, Vulnerable Persons' Unit of the Uganda Human Rights Commission, Senior Community Development Officer in charge of disability at local government level, the National Union of Persons with Disabilities, etc. This has been noted by Mental Health Uganda.

61 CRPD, Article 13.

62 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Australia, 21 October 2013, CRPD/C/AUS/CO/1.

63 Committee on the Rights of Persons with Disabilities, Committee's, Concluding Observations: El Salvador, 8 October 2013, CRPD/C/SLV/CO/1.

64 Ibid.

65 Ibid.

66 CRPD, Preamble paragraph (t).

67 CRPD, Preamble paragraph (g).

68 CRPD, Article 28.

69 Committee on the Rights of Persons with Disabilities, Concluding Observations of the Committee: Costa Rica, 12 May 2014, CRPD/C/CRI/CO/1.

70 Committee on the Rights of Persons with Disabilities, Concluding Observations of the Committee: El Salvador, 8 October 2013, CRPD/C?SLV/CO/1.

71 Ibid.

72 Constitution of Uganda 1995, Objective XIV, National Objectives and Directives Principles of State Policy.

73 Ibid, Objective XIV(b).

74 Constitution of Uganda 1995, Objective XXII, National Objective and Directives Principles of State Policy.

75 Uganda Ministry of Health, "The Second National Health Policy", 2010, p .6.

76 Persons with Disability Act 2006, section 3(e).

Some people with mental health issues reported that they were denied access to social protection programmes.[77] The Ugandan Ministry of Gender, Labour and Social Development established a social assistance grant for empowerment in 2010/2011 to target poor households headed by persons with disabilities.[78] The grant targets the poorest districts and beneficiaries received UGX 21,000 (6.15 EUR) per month.[79] The number of people who with mental health issues who benefit from this grant is unknown. The poor living conditions of people with mental health issues place them in a particularly vulnerable position, and schemes such as the empowerment grants should directly address them.

7(B)(v). Families

The CRPD requires society and the state to protect the family as the natural and fundamental group unit of society, and to ensure that both people with mental health issues and their families receive the necessary protection and assistance they require to enjoy their human rights.[80]

Uganda fails on this obligation when families insult, isolate, beat, restrain and make decisions that go against the will and preferences of their relatives with mental health issues. Uganda is required to adopt immediate, effective and appropriate measures to raise awareness about people with mental health issues at to foster respect for their rights and dignity.[81]

People with mental health issues have the right to enjoy freedom of movement, liberty and security of person.[82] Unlawful or arbitrary deprivation of this right by family members should therefore be tackled.[83]

Domestic Ugandan legislation criminalises sexual violence such as rape, indecent assault and defilement,[84] and specifically protects women and girls with mental health issues from sexual exploitation.[85] However, as can be seen from the testimonies in this report, legislation alone is insufficient and the Ugandan government must put a strong focus on enforcement.

Ugandan law also prohibits any form of torture or cruel, inhuman or degrading treatment or punishment,[86] and guarantees the right to freedom from exploitation, violence and abuse.[87] These rights and freedom are not subject to any derogation.[88] The 2012 anti-torture law of Uganda expanded the scope of acts that may constitute torture to cover the acts of individuals acting in a private capacity.[89] As such, it is important that these legal provisions do not remain on paper, but are given effect.

7(B)(vi). Traditional healing

The Ugandan government must also take steps to abolish customs and practices that constitute discrimination against people with disabilities in including in traditional healing settings.[90] In Uganda, there is no legal or policy framework that regulates the actions of traditional healers.[91] To prevent the occurrence of exploitation, violence and abuse, Uganda should establish effective monitoring systems of traditional healing practitioners and centres.[92] People with disabilities and their representative organisations should be involved and participate in the monitoring process.[93]

Taking action to regulate and monitor traditional healing is consistent with Ugandan law, which mandates the protection of traditional practices in a way which upholds fundamental rights.[94]

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77 Jane Namuddu et al, 'Evidence on Graduation from Uganda's Social Assistance Grants for Empowerment (SAGE) Scheme and the Feasibility of Promoting Sustainable Livelihoods for Labour Constrained Households through a Linkages Approach' (Conference, Kigali, 7 April 2014).

78 Also, other households headed by people who are considered vulnerable such as orphans.

79 Uganda's Initial Status Report of 2010 to the CRPD Committee (unpublished and unsubmitted).

80 CRPD, preamble paragraph (x).

81 CRPD, Article 8(1)(a).

82 CRPD, Article 14(1)(a).

83 Ibid. See also Committee on Rights of Persons with Disabilities, Statement on Article 14 of the CRPD: 12 Session, available online at: http://www.ohchr.org/EN/NewsEvents/Pages/newssearch.aspx?NTID=STM&MID=Committ_Disabilities (last accessed: 6 December 2014).

84 Uganda Penal Code (CAP 120), sections 123, 128 and 129.

85 Ibid., section 130.

86 Uganda Constitution of 1995, Article 24.

87 Uganda Constitution of 1995, Article 25.

88 Ibid., Article 44(a).

89 Prohibition and Prevention of Torture Act 2012, section 2(1).

90 CRPD, Article 4(1)(b)

91 Currently, Uganda has a Traditional and Complementary Medicine Bill. Government of Uganda, Ministry of Health, 'Second National Health Policy', (2010), p .6.

92 CRPD, Article 16(3).

93 CRPD, Article 33(3).

94 Constitution of Uganda 1995, Objective XXIV, National Objectives and Directives Principles of State Policy.

7(B)(vii). Psychiatric hospitals

The violations reported by people with mental health issues in psychiatric hospitals also require careful focus on the part of the Ugandan authorities, particularly in challenging outdated and discriminatory practices such as seclusion, restraint and high levels of violence and abuse. In particular, the following actions are recommended to the government of Uganda:

1. Establish a national mechanism for the prevention of torture so that people in institutional settings, specifically including psychiatric hospitals, are monitored on a regular and ongoing basis;[95]
2. Develop guidelines for the prevention of violence against people with disabilities in institutional settings, including identification, investigation and mandatory prosecution of state employees who perpetrate abuses;
3. Collect and publish data on violence and abuse in institutional settings, and publish violence reduction strategies which tackle the causes identified;
4. Promptly and diligently investigate allegations of violent acts, ensuring that there is no culture of impunity for human rights violations;
5. Make adjustments to complaints and redress systems as required, to guarantee access to justice for victims of human rights violations in psychiatric hospitals;[96]
6. Review and abolish legislation that allows for the deprivation of liberty of a person on the basis of the presence of a disability, including in respect of people with mental health issues;[97]
7. Repeal legislation that authorises medical intervention without the free and informed consent of the person concerned, including the involuntary detention of people in mental health facilities and the imposition of compulsory treatment in hospitals;[98]
8. Strengthen the development of rights-based community psychiatric and other services;[99]
9. Abolish the use of restraints, including tying and chaining people in all circumstances;
10. Train medical professionals and personnel on the right to freedom from torture and ill-treatment, as well as identifying and preventing these forms of abuse.

In addition to these actions, the UN Special Rapporteur on Torture has also clearly stated that the "criteria that determine the grounds upon which treatment can be administered in the absence of free and informed consent should be clarified in law and no distinction between a person with or without disability should be made".[100] The Special Rapporteur has further recommended the banning of seclusion and restraints as these acts "may constitute torture and ill-treatment" in breach of international law, even where such practices are used for a short period.[101]

Medical and nursing bodies in other countries have developed guidelines that detail the ways that psychiatric and other medical staff can reduce the use of restraints and other coercive practices, including through adoption of' techniques such as enhanced observation, de-escalation methods and advance discussion with patients of their preferences.[102] While international practice varies, there is evidence of an increased consensus that mental health care can and should be carried out in the least restrictive manner possible.[103]

7(B)(viii). Education

People with mental health issues have a right to education without discrimination and on the basis of equal opportunity.[104] The Ugandan government is required to have an inclusive education system at all levels and ensure that:

1. People with mental health issues are not excluded from the general education system because of the presence of mental health issues;[105]
2. Provide individual support within the general education system including through the provision of reasonable accommodation, adjustments and supports;[106]
3. Train professionals and staff who work at all levels of the education system, specifically to develop their awareness of the rights of people with disabilities, including people with mental health issues;
4. Ensure that people with mental health issues are supported to access general tertiary education, vocational training, adult education and lifelong learning, on an equal basis with others;[107]

95 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Argentina, 8 October 2012, CRPD/C/ARG/CO/1.

96 Ibid.

97 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Australia, 21 October 2013, CRPD/C/AUS/CO/1.

98 Ibid.

99 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observation: Paraguay, 15 May 2013, CRPD/C/PRY/CO/1.

100 See, for example, Mental Disability Advocacy Center, Cage beds and coercion in Czech psychiatric institutions, (Budapest: 2014), Chapter 8.

101 UN Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Mendez, 1 February 2013, A/HRC/22/53, para 23.

102 See for example: Royal College of Nursing, Violence: The short-term management of disturbed/violent behavior in in-patient psychiatric settings and emergency departments (2005).

103 MDAC, Cage beds and coercion in Czech psychiatric institutions, (Budapest: 2014), Chapter 8.

104 CRPD, Article 24(1) and Article 4(1)(e).

105 CRPD, Article 24(2)(a).

106 CRPD, Article 24(2)(c) and (d).

107 CRPD, Article 24(4).

5. Intensify efforts to ensure that all children receive a full compulsory education, paying particular attention to those in rural communities;[108]
6. Set targets to increase participation and completion rates by students with disabilities at all levels of education and training;[109]
7. Adopt a plan and allocate the requisite budget for the compulsory training of teachers in inclusive education techniques;[110] and
8. Ensure that parents of children with disabilities are not oblige to pay for education.[111]

Every form of discrimination in the education system against persons with disabilities is prohibited.[112] In this regard, people with disabilities, including people with mental health issues, are entitled to benefit from affirmative action during admission to public universities in Uganda.[113] At an official level, equitable access to education and training is promoted for all disadvantaged groups,[114] and affirmative action is included in Ugandan government education programmes.[115]

Despite these measures, it is clear from the testimonies in this report that not every person with mental health issues is fully enjoying the right to education, and those that do often suffer bullying or other ill-treatment and abuse. It is recommended that a cross-departmental focus be placed on tackling these issues in practice, particularly in rural parts of the country.

7(B)(ix). Work and employment

People with mental health issues have an equal right to work including the opportunity to gain a living through freely chosen work in an open, inclusive and accessible environment.[116] Disability-based discrimination is prohibited in respect of recruitment, hiring and career progression.[117]

The Ugandan government has the obligation to guarantee just and favorable working conditions for all people with mental health issues, including equal remuneration for equal work, protection from harassment, and the right to redress for grievances.[118] The government should also promote opportunities for the self-employment for people with mental health issues so that they can start their own businesses. Other obligations include ensuring the provision of reasonable accommodations and adjustments in the workplace,[119] and promoting the employment of people with disabilities in the public sector.[120]

The Ugandan government should take action in the following areas:

1. Increase the diversity of employment and vocational training opportunities for persons with mental health issues;[121]
2. Provide tax incentives for companies and persons who employ people with mental health issues, and develop self-employment programmes;[122]
3. Grant people with disabilities access to soft loans;[123]
4. Establish mechanisms for redress when the labour rights of persons with mental health issues are violated;[124]
5. Raise awareness among employers and promote the employment of persons with disabilities in the private sector, as well as establish employment quotas in the public sector;[125]
6. Use awareness raising campaigns targeting the private and public sector calling on them to remove cultural barriers and prejudices against persons with disabilities.[126]

108 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Argentina, 8 October 2012, CRPD/C/ARG/CO/1.
109 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Australia, 21 October 2013, CRPD/C/AUS/CO/1.
110 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: El Salvador, 8 October 2013, CRPD/C/SLV/CO/1.
111 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Tunisia, 19 October 2011, CRPD/C/ESP/CO/1.
112 Persons with Disabilities Act 2006, section 6.
113 University and Other Tertiary Institutions Act 2001 (amended 2003 and 2006).
114 See the Business, Technical, Vocational Education and Training (BTVET) Act (No 12), 2008.
115 There are programmes on Universal Primary Education, Universal Secondary Education and Business and Vocational Technical Training.
116 CRPD, Article 27.
117 CRPD, Article 27(1)(a).
118 CRPD, Article 27(b).
119 CRPD, Article 27(f) & (i).
120 CRPD, Article 27(g).
121 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Tunisia, 13 May 2011, CRPD/C/TUN/CO/1.
122 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Peru, 16 May 2012, CRPD/C/PER/CO/1.
123 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Paraguay, 15 May 2013, CRPD/C/PRY/CO/1.
124 Ibid.
125 Committee on the Rights of Persons with Disabilities, Concluding Observations of the Committee: Costa Rica, 12 May 2014, CRPD/C/CRI/CO/1.
126 Committee on the Rights of Persons with Disabilities, Committee's Concluding Observations: Argentina, 8 October 2012, CRPD/C/ARG/CO/1.

At the official level, all citizens of Uganda are guaranteed the right to work.[127] Disability-based discrimination is prohibited,[128] and people with disabilities are allowed to access all occupations, including lawful business.[129]

The testimonies in this report, however, again portray an implementation gap between law and practice. Several interviewees shared experiences regarding denial of access to the Ugandan government-sponsored National Agricultural Advisory Services (NAADS) programme. This is a poverty alleviation initiative targeted at the farming sector, crucial in the country given the high rates of subsistence and agricultural farming. Under this programme, households with people with disabilities should be given preference, but it appears that this does not take place in practice.

It is also worth noting that people with mental health issues face barriers to accessing business startup loans. These barriers and practices should be challenged, in line with Article 12(5) of the CRPD.

127 Constitution of Uganda 1995, Article 25.

128 Persons with Disability Act, section 12.

129 Persons with Disability Act, section 13.

Photo: Uganda, April 2014. © MDAC.

"The struggle continues; there are many untold stories and many people not yet reached."

Robinah Alambuya

8. Conclusion

The UN Convention on the Rights of Persons with Disabilities (CRPD) and Ugandan domestic law obliges the Ugandan government to promote, protect and fulfil the human rights of people with mental health issues on an equal basis with other Ugandan citizens. The voices of Ugandan people with mental health issues show, however, that they experience multiple forms of abuse in all areas of their lives. Abuse is pervasive and includes discrimination, torture, ill-treatment, exploitation and violence. Negative perceptions and stereotypes appear to be part of the general fabric of society, and prejudice is seen to be the norm. The low social status accorded to people with mental health issues not only limits and restricts their lives, but fundamentally denies them their right to dignity and becoming full members of their communities.

Of particularly concern is that most interviewees spoke about high levels of violence and abuse, pointing towards a culture of impunity for abuses against people with mental health issues. Unless decisive action is taken by the authorities of Uganda to provide protection and redress, it is clear that many more people with continue to experience gross human rights violations. There are no easy solutions, but it is clear that the high levels of abusive practices uncovered in this report will require synchronised and determined action at many different levels, including at central central, regional authorities and engagement with local communities and families.

The recommendations that are set out in this report should be seen as a starting point for those who have the authority to take action. In the following sections, we stress the need to strengthen the knowledge-base relating to madness and distress, and improving the awareness and implementation of human rights protection mechanisms. There is need to take specific action to tackle abuses in traditional healing settings and psychiatric hospitals, and to do this as part of a broader push to provide psycho-social support and community-based services to people with mental health issues. It is also clear that capacity-building and awareness-raising activities will be key in challenging the discriminatory attitudes presented in this report, and this should be done in close collaboration with people with mental health issues themselves, and their representative organisations.

8(A). Knowledge base of madness and distress

The testimonies of people with mental health issues and their families and carers clearly show a broader social attitude which treats madness and distress as things to fear and combat. This attitude starts at the family level and extends into communities, treatment centres, the education system and work places. At worst, these negative perceptions fundamentally influence the self-image of people with mental health issues themselves and internalising the negative attitudes around them. It is clear that tackling these attitudes will take time and consistent effort.

There is need to develop a more nuanced knowledge-base on mental health and distress. A well conceptualised strategy should address the social factors and complexity of human crisis, and should go beyond the biomedical approach to mental health issues.

8(B). Safety and protection

It is clear that many people with mental health issues quoted in this study simply do not receive the same level of protection from abuse and redress for violations that other members of society would expect. Even allegations of torture, ill-treatment or abuse fail to be investigated. Police and local councils, which are supposed to serve a protective function, are sometimes perpetrators themselves.

There is an urgent need to end this culture of impunity, and to ensure that state agents afford equal protection to all members of society. The government cannot wait for the attitudes of police officers and local council chairpersons to change. The gravity of many of the violations uncovered must serve as a catalyst for immediate action.

8(C). Traditional healing

Interviews with people with mental health issues and their families and carers uncovered serious human rights violations and abuses in traditional healing settings. On a number of occasions, traditional healing centres appeared to be exploitative for financial or other gain. Such practices must be subjected to consistent monitoring and regulation, rather than being allow to operate outside the field of the law.

It appears that some traditional healers perpetuate and cash-in on the social prejudices associated with madness. Many interviewees felt that they couldn't even complain about abuse, for fear of retribution. Again, the culture of impunity for serious human rights violations must be ended, including through prosecution of those who commit abuses.

8(D). Mental health (psycho-social) supports and community services

The majority of people with mental health issues only experience "interventions" from psychiatric or other services during mental health crisis. The "alternative" to psychiatric drug treatment often means being exposed to severe abuse from community members or traditional healers. Psychiatric drugs seem to minimise the occurrence of violence in the communities. However, continuous sedation cannot represent a long-term solution and is also unethical. Services must be developed in a way which provides people with genuine support, rather than simply providing people with psychiatric medication. It must be aimed at helping people become included in their communities, not sedation.

In communities, most people with mental health issues are left without adequate support and they become entirely reliant on the goodwill of family members and friends, even in respect of their basic needs. The majority of people do not know where they can gain information, advice, emotional and social support, even if these exist.

8(E). Working with communities

In peoples' communities, stigma of mental health issues is so pervasive and destructive. Therefore changes need to occur in the communities. However, there seems to be no signs that government spending on mental health targets community services since there is no state funding of community mental health care.[130] Ugandan government currently defines it mental health budget as it spending on Butabika National referral mental health hospital and the undeterminable amount that goes to regional referral hospitals. Also, changing attitudes towards mental health issues needs to take place in villages where people with mental health issues live. Both the delivery of care and education of neighbours and friends should take place in communities and in hospital.

8(F). Capacity building and peer support for people with mental health issues and their organisations

The voices of people with mental health issues are all but absent from broader public debate. If greater understanding and inclusion of people with mental health issues is to be achieved, they must be provided with forums to speak out their own truths, and organisations such as Mental Health Uganda and Heart Sounds Uganda should be supported and strengthened when tackling the problems identified in this respect. Many interviewees with mental health issues found this research to be a rare opportunity to talk to their peers and have their experiences listened to and valued. In communities where they are largely silences and isolated, facilitating their gathering and self-organisation can provide a powerful opportunity for them to provide each other with support, and tackle the issues that they jointly face. Efforts should be made to link local groups and they should also be provided with the opportunity to link with the broader regional and international movements of persons with disabilities and people with mental health issues.

130 MDAC and MHU, *Psychiatric hospitals in Uganda: A human rights investigation,* (Budapest: 2014).

Appendix

Research design and methodology

The four administrative regions were chosen in order to capture the variety of living conditions of people with mental health issues across different parts of Uganda. In each of these regions 10 people with mental health issues and 10 family members/carers were interviewed, totalling interviews with 80 people. The overall methodology was developed closely with people with mental health issues themselves, reflecting a survivor/user-controlled method.

Interviews were semi-structured and covered the main areas of a person's life in the community. The interview guide aimed to capture individual experiences and views based on the interviewees' own order of preference. Besides experiences with both psychiatric and traditional healing practices, MDAC and MHU also explored the occurrences of ill-treatment in community and family settings, in the course of education and at work places. Further interview areas included the possibilities of legal and psycho-social (mental health) support, as well as the personal wishes and aspirations of interviewees. The main purpose of the interviews was to document the realities of people with mental health issues in their own words.

Each of the interviews with people with mental health issues were followed by an interview with another person from their closest surroundings – usually a family member. The purpose of interviews with family members was to understand better the context in which the person with mental health issues lived. MDAC and MHU were particularly interested to understand the extent to which family members acknowledged the forms of ill-treatment experienced by their relatives. All interviews were recorded and transcribed.

The following tables show the areas and the venues of interviews.

Table 3: Areas	
rural	44
urban	36
Total:	**80**

Table 4: Interview venues	
participant's home	47
hospital	22
school	7
other[131]	4
Total:	**80**

Fieldwork

At an early stage of the project, Mental Health Uganda identified 10 people with mental health issues in each of the four regions who were interested in sharing their experiences. We aimed at an equal number of women and men as well as an equal distribution of people from rural and urban areas.

A total of 12 people with mental health issues received training on human rights research and documentation in September 2013 in Uganda. Jasna Russo, MDAC consultant and an experienced social researcher with personal experience of receiving psychiatric treatment conducted the training with contributions from Eyong Mbuen, MDAC Africa Project Manager. An interview guide was developed and jointly revised and finalised in the course of this training. Finally, Kayondo Nobert and Nyeko Jolly John Paul who both have personal experience of receiving psychiatric treatment were appointed as field researchers. Each of them was responsible for conducting interviews in two administrative regions, which means that each conducted and transcribed a total of 40 interviews.

131 Church premises, somebody else's home, etc.

The interviews were conducted in Ateso, English, Lou, Luganda, Lukiga and Kinyankole. In 14 interviews a person from Mental Health Uganda membership organisation acted as an interpreter. Other than that, all interviewees with mental health issues were interviewed on their own with the exception of one person who used sign language with the assistance of a family member.

The average duration of interviews was about one hour and the participants were generally open and willing to share their experiences (especially after being aware that the researchers were also people with personal experiences of mental health issues). At the end of the interview many used the opportunity to talk informally to the researcher and gain information and advice in regard of their particular situation. Some family members in central and western region were reluctant to share information because they feared being eventually prosecuted for wrongs done to their relatives with mental health issues. The contact persons from Mental Health Uganda helped establish the trust of these family members clarifying the research purpose again.

The biggest challenge of the field work was scheduling the interviews as well as reaching interviewees' homes in areas with poor road conditions.

Qualitative data analysis

The analysis conducted with English interview transcripts using software for qualitative analysis NVIVO (version 8). Thematic analysis was performed by Jasna Russo (the same MDAC consultant who conducted the research training). In order to structure the considerable amount of data, she developed a coding frame that consisted of 14 main and 104 single qualitative sub-categories. The categories reflected the main topics of the interviews and the sub-categories reflected the topics identified in the collected material.

Additionally 26 quantitative categories were created for the demographic data and some other numeric information (number of hospital stays etc).

Besides the very tight project time line, the biggest challenge of the analysis was the fact that the consultant who conducted the analysis was not from Uganda and therefore lacked direct knowledge of the socio-economic and cultural context. MDAC and MHU addressed this through continuous communication with the two field researchers in the course of analysis as well as ensuring their input into the interpretation of the findings.

Demographic information

The table on the next page provides a breakdown of the demographic information of interviewees, both for people with mental health issues and their family members or carers. We are grateful all of those who gave up their time to speak with our field researchers, without which this project would not have been possible.

Table 5: Demographic data				
Interviewees	**People with mental health issues**		**Family members**	
	n	*%*	*n*	*%*
Gender				
Male	**19**	*47.5*	**25**	*62.5*
Female	**21**	*52.5*	**15**	*37.5*
Age[132]				
< 20	**4**	*10*	**2**	*5*
21-30	**8**	*20*	**5**	*12.5*
31-40	**17**	*42.5*	**11**	*27.5*
41-50	**6**	*15*	**3**	*7.5*
51-60	**3**	*7.5*	**7**	*17.5*
> 60	**2**	*5*	**12**	*30*
Marital status				
Married or long-term relationship	**20**	*50*	**28**	*70*
Single	**15**	*37.5*	**6**	*15*
Divorced	**3**	*7.5*	**1**	*2.5*
Widowed	**2**	*5*	**2**	*5*
Not recorded	**0**	*0*	**3**	*7.5*
Education				
No formal education	**1**	*2.5*	**1**	*2.5*
Primary education (1-7)	**9**[133]	*22.5*	**15**[134]	*37.5*
Ordinary level (senior 1-4)	**11**	*27.5*	**11**	*27.5*
Advanced level (senior 5-6) or equivalent	**12**	*30*	**7**	*17.5*
Certificate (1 year university)	**1**	*2.5*	**0**	*0*
Diploma (2 years university)	**4**	*10*	**1**	*2.5*
Bachelor's degree (3 years university)	**2**	*5*	**5**	*12.5*
Children				
None	**15**	*37.5*	**6**	*15*
1-2	**9**	*22.5*	**3**	*7.5*
3-4	**7**	*17.5*	**8**	*20*
5-6	**6**	*15*	**9**	*22.5*
7-8	**1**	*2.5*	**1**	*2.5*
9-10	**2**	*5*	**3**	*7.5*
> 10	**0**	*0*	**8**	*20*
Not recorded	**0**	*0*	**2**	*5*
Source of income				
No personal income	**10**	*25*	**4**	*10*
Self-employed	**10**	*25*	**14**	*35*
Employed in public service or NGO	**9**	*22.5*	**4**	*10*
Farmer	**9**	*22.5*	**15**	*37.5*
Pension	**2**	*5*	**3**	*7.5*
Total	**40**	*100*	**40**	*100*

132 The youngest interviewee with mental health issues was 17 and the oldest 69; among family members the youngest was 18 and the oldest 86.

133 Three interviewees with mental health issues have completed primary 7 and five have discontinued their education earlier.

134 Six family members have completed primary 7 and nine have discontinued their education earlier.

The final table sets out the relationship of family members of people with mental health issues who were interviewed along with their relatives.

Table 6: Relationship to interviewees with mental health issues.	
parent	16
partner (husband/wife)	11
sibling	8
aunt/uncle	2
friend	2
daughter/son	1
Total:	40

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