

# The Right to Legal Capacity in Kenya



***"I felt like an animal  
going to a slaughter  
and I had no choice"***

***Yusuf's story***

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## Foreword

Recognising and respecting the decisions of people with disabilities is very important in advancing human rights in our communities. While most people with disabilities face barriers to exercising their right to decision making, people with psycho-social (mental health) disabilities and people with intellectual disabilities experience greater restrictions, limitations and denial of their right to make decisions for themselves and to have those decisions respected. Indeed, where their views on decisions ought to be sought it is assumed that they are incapable of offering solutions to issues affecting them. This happens both within the framework of the law and outside the law.

I am truly humbled to write this foreword. I have had many personal encounters with people with disabilities. My late father was confined to a wheel chair as a result of cancer and it was very painful watching the difficulties that “suddenly” appeared; things that had been taken for granted by all of us in the family now had to be carefully planned for. Amazing was the assumption of some people that by being in a wheelchair my father also had a mental disability.

During my tenure as Chairperson of the Kenya National Commission on Human Rights, we carried out a study on funds allocated to educate people with disabilities. It was saddening to realise that the Kenyan government spends very little on educating people with disabilities and does not assess the types of supports which each child needs to be supported in inclusive mainstream schools. A careful reading of this report will shed light on the importance of providing education as means of enabling people with disabilities to take control and charge of their lives.

In our communities the responsibility for caring for people with disabilities is often entirely on family members. As a result, these dealings are based on private and socially acceptable norms that have no direct reference to legal or human rights standards. It is unsurprising, therefore, that family members – often the carers/providers of basic necessities – believe they should make decisions for those they care for. Sometimes, decisions are made with good intentions and in other cases the family members do not know what to do. Since we have been socialised to believe and think that we know better than people with disabilities we make decisions in total disregard to their opinions, views and feelings on the issue.

During my tenure at the Kenya National Commission on Human Rights (KNCHR) we not only had programmes directly dealing with people with disabilities but also endeavored to differentiate and to recommend actions targeting people with a range of different impairments. It was evident that one of the “dark” areas of disability rights is the subject of discussion in this report. There were various efforts including an incisive position paper by Commissioner Lawrence Mute on Legal Capacity, which generated significant debate internally and was the basis for exploring possibilities of coming up with a more sensitive legal and policy framework. This report has significantly expands this focus by bringing in the perspectives of those directly affected, including carers.

In publishing this report it is commendable that MDAC has worked with NGOs and researchers in Kenya to bring to all of us as Kenyans (governmental officials, family members or service providers and others) who deal

with people with psycho-social disabilities and people with intellectual disabilities the realities of what they face, and how they feel about how we treat and view them. It is a powerful message that requires us to rethink our actions, attitudes, approaches and processes. One of the most fundamental rights that accrue to all human beings is that of autonomy, dignity and respect, and the message in this report is clear that these rights apply in their fullest forms to the citizens whose voices are captured in this report.

Having ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD), Kenya is under an obligation to ensure that its Article 12 is complied with. The first and most important mind shift is to recognise the rights of persons with disabilities as being equal to all others and secondly to ensure that supports for someone to forge their way through life must be subject to safeguards to ensure that it respects the will, preferences and choices of the individual and to avoid and eradicate exploitation, violence and abuse that are prevalent. It must be recognised that like any other persons, people with disabilities can make wrong choices and this should not be ascribed to their disability because to err is human.

It is important that this report should be seen in the light of not only the CRPD but also within our constitutional context; consequently, it is my hope that it will inform our legislation and policy processes. It is clear from this report that if we work with people with disabilities and their families we can find solutions even for complex issues. It is evident that as a society we need to invest in public sponsored services for persons with disabilities. Juma's experience in Appendix 1 of this report makes this point: he would like to be more independent, but his mother believes she cannot allow this, resulting in both mother and son having restricted social lives. All the narratives lead to the unavoidable conclusion that there is great need for awareness amongst citizens. As communities and individuals we have collectively hindered the space and opportunities for people with disabilities, through our judgmental and intolerant attitudes. Underlying the concerns of caregivers is the issue of protection against a society who may not understand, who will stigmatise and who may even harm people with disabilities. In my view this is a great indictment on us that we cannot on the whole be trusted to treat with respect and dignity our members in positions of vulnerability.

Finally the report through analysis has given recommendations. Some are quick and easy, for example nothing bars courts and medical personnel from requiring the presence and listening to people with psycho-social and intellectual disabilities to determine their views, opinions on proposed actions and giving due regard and weight to these views. However the state must put in place protective and supportive mechanisms that are accessible and responsive to persons with disability. The Commissions set up under Article 59 of the Constitution in particular the Kenya National Human Rights Commission must vigilantly play its role as a national monitoring mechanism under Article 33 of the CRPD. Civil Society such as Kenyan NGOs and MDAC and other international NGOs must continue with their advocacy and awareness creation and together they must work with the state, state agencies, elected leaders at both county and national level to ensure the full implementation of the CRPD. On its part the international community should continue to support all the stakeholders in this regard not only through funding but also mutual exchange of best practice.

*Florence Simbiri Jaako*  
*Former Chairperson, Kenya National Commission on Human Rights*



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## Executive Summary

**“I think if you have people who care for you and people who love you, people who will tell you ‘Look here, you are sick and we are taking you to the hospital’ and also give you a chance to express yourself in terms of what you want, then you will cooperate. But if you are forced, that is the time things get worse [...]. You feel traumatised, you feel the decision made was not in the right direction [...]. I think the family should be aware that when they have a sick person they have a duty to ensure that he is respected as a human being. They should also help the person to make the right decision, rather than seeing the person as a bother to them [...]. It would be good if there is a group of people with an office nearby which advocates for persons with mental disability, that when you have a problem you can go to their offices and they can assist you with decision-making other than making decisions on your own and at the time when you are sick.”**

*Yusuf, a man with a psycho-social disability*

**“I don’t think I would get children. I will tell you something, you see here [lifts up the blouse and reveals a scar on her stomach] here I was made an operation [...]. This is contraceptive, all of us had been done like this, we cannot get children [...]. Nobody asked me [if I want it]. They should have asked me, because I love children [...]. I feel bad, but what can I do now?”**

*Atieno, a woman with an intellectual disability*

**“The government should be able to provide support to people with disabilities so that they are productive like the way Chumo is being supported by our community[...] The community should love these people and also show them that they are human beings just like any other person and we should not refer to them by the use of bad words. People should know how to communicate and deal with people like Chumo.”**

*Friend of Chumo, a woman with a psycho-social disability*

This report seeks to answer the question: “To what extent does Kenya guarantee the right to legal capacity for people with intellectual disabilities and people with psycho-social (mental health) disabilities?”<sup>1</sup> It shows that Kenya must take immediate action to ensure comprehensive recognition of the right to legal capacity of all people with disabilities in the country, and that the State must take a lead to tackle social prejudices which disadvantage the vast majority.

The right to legal capacity is recognised as one of the most important shifts ushered in by the UN Convention on the Rights of Persons with Disabilities (CRPD). Guaranteed in Article 12 of the Convention, legal capacity is the mechanism through which the self-determination of people with disabilities is given legal recognition. It serves a dual purpose, guaranteeing the legal recognition of people with disabilities and their decisions, and ensuring access to supports in order to exercise their legal capacity.

As such, the right to legal capacity seeks to redress the historic lack of legal recognition provided to many people with disabilities, particularly including people with intellectual disabilities and people with psycho-social (mental health) disabilities. It requires States to take the lead in moving away from restriction and denial of the decision-making rights of people with disabilities (‘substituted decision-making’) towards ensuring their autonomy in all areas of life and the right to access support in exercising this (‘supported decision-making’).

One of the most significant findings of this report is the way in which ingrained social prejudices against people with mental disabilities leads to significant restrictions being placed on their independence and autonomy on a daily basis. Stereotypes of people with mental disabilities are reflected in a legislative framework which systematically denies them legal recognition in a wide variety of areas including education, employment, management of property and land and access to healthcare.

The testimonies from people with intellectual disabilities and people with psycho-social (mental health) disabilities presented in this report provide a compelling case for the need for legal and social reform. Many of them, in their own words, describe the restrictions placed upon them on a daily basis, limiting their freedom to move, to associate with others, even to make decisions about marriage and founding a family. The effects of social isolation and discrimination are brought into even starker contrast in the testimonies of women with mental disabilities, many of whom reported experiencing gender-based violence, rape and even forced sterilisation.

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1 Throughout this report we use the term ‘people with mental disabilities’ to refer both to people with intellectual disabilities and people with psycho-social (mental health) disabilities where the content is relevant to both groups.

The most important findings of this report are:

- 1 **Kenyan laws cluster people with psycho-social (mental health) disabilities and people with intellectual disabilities together arbitrarily.** Legislation provides for the appointment of guardians, estate managers or public trustees when an adult with a “mental disorder” is considered incapable of managing their affairs, accompanied with custody orders when the court thinks the adult is incapable of taking care of themselves. The problem with this is that the law categorises all these groups as incapable, without engaging with the support needs of each individual as required by the CRPD.
- 2 **The vast majority of people with mental disabilities experience restriction of their decision-making rights through informal social processes within the family and local communities.** This interacts on adults in many ways, restricting their day-to-day lives including whether or not they are in employment, or even in seeking redress against violence or abuse. The majority of people with mental disabilities and their families have little access to supports and the tendency is that this leads to isolation and, in many cases, over-protection.
- 3 **The denial of decision-making rights of people with mental disabilities is even more pronounced in the case of women and younger people,** and many are unable to complete education and gain employment as a result. Testimonies from people with mental disabilities clearly show that greater independence and social inclusion are achieved when they are able to engage in employment.
- 4 **The judicial process for determination of an adult’s legal capacity fails to place any emphasis on their choices, will or preferences.** Instead, laws are premised on an assumption of the adult’s incapacity, contrary to provisions of Article 12, CRPD.
- 5 **Safeguards of the rights of people with intellectual disabilities and people with psycho-social (mental health) disabilities are completely inadequate.** Those that do exist are based on their perceived ‘best interests’ rather than their choices, will or preferences.
- 6 **There is a lack of comprehensive statistical data of the number of people who have had their legal capacity restricted.** It is impossible for the State to plan and give proper effect to the human rights of people with disabilities unless such information is collected and forms the basis of policy-making.

Kenya underwent political changes during the research period. Among these changes, the adoption of a new Constitution in 2010 and has transformed the governance structure of the country, particularly following the 2013 general elections. Law reform processes followed the adoption of the Constitution and many of these reform processes are ongoing. A draft Mental Health Bill (2012) which will replace the 1991 Mental Health Act (Cap 248) has been accompanied by efforts of the Kenyan National Human Rights and Equality Commission and other stakeholders who have been pushing for legal capacity law reform.

The report is structured into two parts. **Part One** presents the background to the research, before outlining important aspects of Kenya's legal and social systems, the political context, definitions regarding people with disabilities, data and statistics and the way in which the right to legal capacity is guaranteed under international law. **Part Two** provides a detailed analysis of Kenya's compliance with Article 12 CRPD using four main indicators developed from MDAC's extensive research in the area of legal capacity. **Appendix 1** sets out a distilled version of the interviews with people with disabilities and their carers/families, while the research methodology is set out in **Appendix 2**.

The research involved a law and policy analysis, focus group discussions and interviews with 74 people including people with psycho-social (mental health) disabilities, people with intellectual disabilities, their families and carers, and a variety of other stakeholders across Kenya including officials at the Ministries of Health, Education and Social Policy, and at the Kenyan National Human Rights Commission. The report offers an important insight on challenges to the realisation of the right to legal capacity for people with mental disabilities in the country, and provides recommendations aimed to bring Kenya into compliance with its obligations under the CRPD.

## Recommendations to the Kenyan government

Kenya's legal capacity system fails to meet the standards set by the UN Convention on the Rights of Persons with Disabilities (CRPD), and particularly the requirements of Article 12. In 2011 the Kenyan government submitted its report to the UN Committee on the Rights of Persons with Disabilities. The report contained an express intention to take legal steps to move from substituted to supported decision-making arrangements. In order to assist in implementing this commitment, which would bring Kenya closer to compliance with Article 12, MDAC recommends the following to the Kenyan government:

- 1 **Introduce legislation and enabling regulations to guarantee the right to legal capacity in all areas of life for people with mental disabilities**, including in accessing justice, healthcare and treatment decisions, the exercise of political and civil rights, family life and marriage, property and land law, and in the criminal justice system for both victims and perpetrators. Legislation which acts as a barrier should be abolished without delay.
- 2 **Abolish formal substituted decision making regimes to ensure that law respects the will and preferences of individuals.** Section 107 of the Children Act and Section 26 of the Mental Health Act (Cap 248) should be abolished as they allow for the deprivation or restriction of legal capacity by courts and directors of psychiatric hospitals.
- 3 **Remove the terms “unsound mind”, “mental incapacity” and “mental infirmity” from the statute books. These offensive terms perpetuate unhelpful stereotypes throughout society.** They currently appear in, inter alia, the 2010 Constitution Article 83(1)(b), the Local Government Act 2010 Part V, paragraph 53(c), and the Election Act 2011 section 9.
- 4 **Take urgent steps to combat social stigma and prejudice faced by people with mental disabilities and which have the effect of restricting exercise of legal capacity.** Public awareness campaigns, developed in conjunction with people with mental disabilities themselves, should be rolled out nationally.
- 5 **Combat informal substituted decision-making within families and communities** by asking people with disabilities, their carers and local leaders to identify promising practices of support mechanisms which respect and strengthen individual autonomy. Such promising practices should recognise the central importance of family, friends and local communities in supporting people with mental disabilities to exercise their right to legal capacity. The government should collate promising practices and share them across the country and internationally.
- 6 **Initiate pilot projects on supported decision-making in various regions**, and commission external evaluation, the learning from which should be shared with NGOs and policy-makers across and outside the country.

- 7 **Ensure that the National Bureau of Statistics and National Council for Persons with Disabilities fulfil Kenya's obligations under Article 31 of the CRPD to collate appropriate and disaggregated data of people with disabilities** – especially data relating to people with psycho-social (mental health) disabilities and people with intellectual disabilities. Data should set out the number of people with disabilities who have and do not have national identification cards. Statistics must be made available to people with disabilities and their representative organisations, and should serve as the foundation for evidence-based policy on the provision of supports to people with disabilities.
- 8 **Promote the training of government officials, magistrates, judges, psychiatrists and other medical practitioners, public trustees and police officers alongside community/traditional leaders** on the right to legal capacity and the provision of supports to exercise legal capacity. In doing so, Kenya will be fulfilling its obligations under Article 4(1)(i) of the CRPD.
- 9 **Raise awareness among people with disabilities, their relatives and carers, and the general community about their human rights, including the right to legal capacity.** These actions should include making use of different media options, radio, television, newspapers and should target all levels of the education system. This will help Kenya fulfil its obligations under Article 8 of the CRPD.
- 10 **Introduce legislative, administrative, social, educational and other appropriate measures to protect people with disabilities both within and outside their home from exploitation, violence and abuse** as provided in Article 16(1) of the CRPD. In order to prevent abuse, people with disabilities and their carers should be provided with information and education on how to avoid, recognise and report instances of abuse as required under Article 16(2) of the CRPD and ensure that all facilities and programmes serving people with disabilities are independently monitored as provided under Articles 16(3) and 33(2). Also, instances of exploitation, violence and abuse must be identified, investigated and where appropriate prosecuted as provided in Article 16(5) of the CRPD, and victims of abuse should be provided with protection services that are mindful of gender and age-specific needs as set out in Article 16(4).

The rich testimonies from people with mental disabilities which form a substantial part of this report attest to the complex challenges that they face on a daily basis when making decisions about how to live their lives. It is vital that the government takes the lead in ensuring that legal and policy barriers are removed. Clearly many of the barriers faced by people with mental disabilities flow directly from negative perceptions and discriminatory social perspectives, and these will not be changed overnight. In advancing the right to legal capacity, it is essential that the government involve people with disabilities themselves, including children with disabilities, through their representative organisations at all stages – an obligation set out in Article 4(3) of the CRPD.

# Part One:

## People with disabilities in Kenya - context

### 1. General Background

This section sets out the context within which the report has been written. It begins with why MDAC has written this report and looks at the legal and social systems in Kenya, political context, definitions relating to people with disabilities, data and statistics and the concept of legal capacity as defined in international law.

#### 1.1 Why have we written this report?

The Kenyan government expressed its commitment to shift away from substituted decision-making to supported decision-making in August 2011 in its report to the United Nations Committee on the Rights of Persons with Disabilities.<sup>2</sup> This report aims to contribute to the legal capacity law reform process established by the Kenya National Commission on Human Rights (KNCHR) in June 2012 that sets up a technical team to discuss how Article 12 of the CRPD can be realised in Kenya.<sup>3</sup> In the process of developing this report, KNCHR developed a draft briefing paper on legal capacity in June 2013, which acknowledges MDAC's guidance and assistance as we shared information and discussed issues of legal capacity with the consultant who was contracted by KNCHR.

MDAC has examined the effect of guardianship laws in many countries in Europe, where laws have remained relatively unchanged for decades.<sup>4</sup> Since the adoption in 2006 of the UN Convention on the Rights of Persons with Disabilities (CRPD), substantial law reform is taking place in several jurisdictions, as governments realise the importance and urgency of bringing their legislation into conformity with the Convention.<sup>5</sup> Collaborating with Kenyan Association for the Intellectually Handicapped, Users and Survivors of Psychiatry Kenya and Basic Needs Kenya, MDAC launched an investigation into guardianship, legal capacity and human rights in the country. The objective was to identify the strengths and weaknesses of laws and policies, as well as look at what life is like for people with disabilities in Kenya.

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2 Initial Report to the CRPD Committee, 31 August 2011, 26.

3 Personal Communication with Lawrence Mute, former Commissioner at the Kenya National Commission on Human Rights. MDAC office Budapest, Hungary: 14 June 2012.

4 Mental Disability Advocacy Centre, *Guardianship and Human Rights in Serbia*, (2006), *Bulgaria* (2007), *Czech Republic* (2007), *Georgia* (2007) *Hungary* (2007), *Kyrgyzstan* (2007) and *Russia* (2007). In October 2013 we published a report entitled *Legal Capacity in Europe* (2013).

5 In 2012, Czech Republic abolished total deprivation of legal capacity and introduced supported decision-making, advance directives, guardianship without restriction of legal capacity and representation by members of the household. The new law takes effect in 2014. Prior to 2012, Latvia had only plenary guardianship (full incapacitation), but this was abolished and the country introduced partial guardianship (restriction of legal capacity) and alternatives to guardianship in 2012. MDAC continues to advocate for the introduction of supported decision-making in Latvia.



We began by analysing the legislative and policy framework and practices in Kenya and its impact on the rights of adults with psycho-social (mental health) disabilities and those with intellectual disabilities on exercising their right to legal capacity. We selected Kenya for our investigation because in March 2010 we met several leaders of disability NGOs and with the Kenya National Human Rights and Equality Commission (then the Kenyan National Commission on Human Rights) in Nairobi, who asked us to explore the theme, and to feed in to their law and policy reform advocacy. Kenya adopted a new Constitution in August 2010, and this has been applauded by many human rights advocates for advancing human rights – on paper, at least.<sup>6</sup>

We conducted our investigation in two phases. The first stage was to carry out a legislative and policy review, looking at laws, policies and regulations that impact on legal capacity, as well as conducting structured interviews and focus groups with key stakeholders in the country. Since law and practice frequently diverge (in Kenya as much as elsewhere), in April 2012 we gathered testimonies from adults with psycho-social (mental health) disabilities, those with intellectual disabilities and their family members and carers. These testimonies are presented as personal narratives in **Appendix 1** of this report and provide powerful accounts of the lives of people with disabilities across the country. The methodology of the research is set out in **Appendix 2**.

We sought to answer four questions, which all flow from Kenya's obligations under the CRPD:

- 1 Does the law recognise people with disabilities as persons before the law?
- 2 Are people with disabilities enabled to exercise legal capacity on an equal basis with others?
- 3 Can people with mental disabilities exercise legal capacity in all aspects of life?
- 4 What kinds of supports are available for people with disabilities who may need them in exercising their legal capacity?

## 2. Legal and social systems in Kenya

Situated in East Africa, and with a population of about 40 million,<sup>7</sup> Kenya gained independence from the United Kingdom in 1963 and has since evolved into a multi-party electoral democracy. The 2010 Constitution, designed to be implemented progressively over five years, provides for people with disabilities to be treated with dignity and respect, to access educational institutions and facilities and sets out a quota that at least 5% of parliamentary seats should be reserved for people with disabilities.<sup>8</sup>

<sup>6</sup> Amnesty International USA, Kenya Human Rights, available at: <http://www.amnestyusa.org/our-work/countries/africa/kenya> (last accessed 9 March 2014). See also Freedom House, Kenya, available at: <http://www.freedomhouse.org/report/countries-crossroads/2012/kenya> (last accessed 9 March 2014).

<sup>7</sup> Kenya initial report to CRPD Committee, 31 August 2011, 6, which states that 80% of the population lives in rural areas.

<sup>8</sup> 2010 Constitution, Article 54.

Kenya's legal system is based on the common law system,<sup>9</sup> in which the sources of Kenyan Law<sup>10</sup> include general rules of international law. Treaties ratified by Kenya also form part of the domestic legal system,<sup>11</sup> and can be directly applied by Kenyan courts, tribunals and administrative authorities if there is a gap in domestic legislation.<sup>12</sup> Kenyan courts can also make findings of violations of international law.<sup>13</sup>

The principle of non-discrimination runs through the 2010 Constitution, which requires all State organs and officials, legislators and judges to abide by the principle.<sup>14</sup> This is important, given that people with disabilities have been victims of discriminatory laws and practices for decades. State organs and officials are mandated to make, execute and interpret laws in a non-discriminatory manner.<sup>15</sup>

Kenya has a multi-racial, multi-ethnic, multi-cultural and multi-religious society. People of African descent constitute roughly 90% of the population, and there are 42 main ethnic groups which are further grouped into many smaller sub-tribes.<sup>16</sup> Major religions include Christianity (78%), Islam (10%), African Traditional Religions (10%), Hinduism and Sikhism (1%). It is estimated that 46% of the population lives in absolute poverty, with 56% of Kenyans living on less than one US dollar per day.<sup>17</sup>

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9 Hauser Global Law School, *Researching Kenyan Law*, available at <http://www.nyulawglobal.org/globalex/Kenya.htm> (last accessed 9 March 2014).

10 Section 3 of the revised 2012 Judicature Act (CAP 8, Laws of Kenya, 1967) enumerates the primary sources of Kenyan law to include: The Constitution which is the supreme law of the land; Acts of Parliament; specific Acts of Parliament of the United Kingdom; certain Acts of Parliament of India; English Statutes of General Application in force in England on 12 August 1897; substance of the Common Law and Doctrines of Equity; African Customary Law and Islamic Law.

11 2010 Constitution, Article 2(5) & (6). Also, the Treaty Making and Ratification Act 2012 sets out the respective roles of executive, parliament and the public in the treaty ratification process. Ratified treaties now have direct effect and form part of the Kenyan legal system.

12 Kenya's initial report to CRPD Committee, 31 August 2011, 11.

13 High Court of Nairobi, CK et al v. Commissioner of Police et al, Petition no 8 of 2012, judgment 27 May 2013, available at: <http://theequalityeffect.org/160girlshighcourt2013.html> (last accessed 9 March 2014). The court found a violation of the Universal Declaration of Human Rights, the UN Convention on the Rights of the Child, the African Charter on Human and Peoples' Rights, and the African Charter on the Rights and Welfare of the Child.

14 Initial report to CRPD Committee under Article 35 of the CRPD, 31 August 2011, 9.

15 2010 Constitution, Article 10.

16 Initial report to the CRPD Committee, 31 August 2011, 6.

17 Ibid.

### 3. Political context

Kenya ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) on 19 May 2008. The ratification requires the government to adopt laws as well as modify or abolish existing laws, regulations, customs and practices that discriminate against persons with disabilities.<sup>18</sup> Further, the Constitution obliges the State to enact and implement legislation to fulfil its international obligations in respect of human rights.<sup>19</sup>

The government is well aware of its CRPD obligations, having acknowledged in a 2011 report to the United Nations Committee on the Rights of Persons with Disabilities that the right to legal capacity, embedded in Article 12 of the Convention, has yet to be realised for people with disabilities in the country, since many decisions are still being made “on behalf of people with disabilities without consulting them.”<sup>20</sup> It has further expressed a commitment to move from a substituted decision-making regime to one grounded in supported decision-making. It is this legislative reform process to which this report aims to contribute.

The 2012 Mental Health Bill seeks to repeal the 1991 Mental Health Act.<sup>21</sup> The Bill’s first reading in Parliament was in October 2012 and is now left with the 2nd and 3rd readings. Among the Bill’s objectives are to protect and safeguard the rights of people with “mental illness”,<sup>22</sup> a term defined in an ambiguous manner, rendering the scope of its application of dubious utility.<sup>23</sup> Amending the Mental Health Act is a step in the right direction since the current Act is obsolete, coming into force in 1989 and has not been amended since 1991. As such it fails to incorporate emerging human rights standards such as those enshrined in the CRPD.<sup>24</sup> The Bill sets out entitlements to choose and appoint a representative in any matter in a way which purports to respect the personal autonomy of the individual concerned, including through complaint procedures and appeals.<sup>25</sup>

The Bill, however, still allows for substituted decision-making, allowing for people with “mental illness” to be deprived or restricted of their legal capacity and to have a personal representative appointed.<sup>26</sup> A parent,

18 UN Convention on the Rights of Persons with Disabilities (CRPD), Article 4(1) (b).

19 2010 Constitution, Article 21 (4).

20 Initial Report to the CRPD Committee, 31 August 2011, 26.

21 Mental Health Bill (CAP 248 of the laws of Kenya), 2012, published on the Kenya Gazette as Supplement No. 115 on 21 September 2012.

22 2012 Mental Health Bill, Section 2(5).

23 It is not clear whether the Bill’s definition of “mental illness” covers people with intellectual disabilities. ‘Mental illness’ is defined in Section 3 as including any disorder, impairments, disabilities and handicaps of the mind including mental impairment as a result of alcohol, drugs and substance abuse, but does not include: cases where someone holds or refuses to hold a particular religious; philosophical or political beliefs; sexual promiscuity; sexual preference; engaging in immoral or indecent conduct; taking drugs or alcohol; or those demonstrating anti-social behaviour.

24 Kenya National Commission on Human Rights, *Silenced Minds: The Systematic Neglect of the Mental Health System in Kenya*, (Nairobi: KNCHR, 2011), 20.

25 2012 Mental Health Bill, Section 28(1).

26 2012 Mental Health Bill, Section 6(1).

spouse, adult offspring of the person, or a friend, relative or any interested person who takes charge of the person with “mental illness” can apply to the Magistrates Court for an order to be appointed to manage and administer their estate.<sup>27</sup>

Minimal safeguards are built into new legislation and they include the following:

- Courts are required to give the person with disability notice of the application against him/her unless it considers that service would be impracticable, inexpedient or ineffectual. Courts may also direct that a copy of the notice be sent to a relative of the person or to any other person the court thinks should receive the application.<sup>28</sup>
- Courts may require the person in question to be personally examined by the court, a doctor or any other person the court appoints, to assess their “mental capacity and condition”.<sup>29</sup>
- The court may make enquiries to ascertain the wealth and estate of the person and inform the public of the appointment of an estate manager through the Kenya Gazette for any possible objections.<sup>30</sup>
- The person in question or their personal representative has the right to produce independent medical reports or any other oral or written reports or evidence at any hearing that is relevant to their mental health status, and to attend and participate in any hearing.<sup>31</sup>
- An estate manager is obliged to follow the instructions of the court, and their powers over the estate are limited to what the court has expressly provided, subject to the provisions of relevant legislation. The estate manager shall not mortgage, transfer, or lease any immovable property for a period exceeding three years without permission from the court.<sup>32</sup>

These safeguards are insufficient, in MDAC’s view, to bring Kenyan law into compliance with Article 12 of the CRPD. The law is still dominated by a deficits approach, which treats the person as incompetent and hands over decision-making authority to someone else. The Bill fails to set out a procedure for a person with a disability to access the support that she/he may require to exercise their legal capacity, such as the support needed to appoint and work with a personal representative. Nowhere does the Bill specify that personal representatives are required to respect the will and preferences of the people they represent.

Other bills and policy documents are silent on how people with disabilities can access supports to exercise their legal capacity.<sup>33</sup> The Legal Aid Bill 2010 allows for applications for legal aid in respect of civil proceedings

27 2012 Mental Health Bill, Section 43(1).

28 2012 Mental Health Bill, Sections 43(4) and (5).

29 2012 Mental Health Bill, Section 43(6).

30 2012 Mental Health Bill 2012, Sections 44(1), (2), 45 (2), (3), (4) and (5).

31 2012 Mental Health Bill, Sections 28(3) and (4).

32 2012 Mental Health Bill, Section 45 (4) and (5).

33 Bills include the 2011 Children’s Act (2001) Amendment Bill, the 2007 Family Protection Bill, the 2007 Matrimonial Property Bill, and the 2012 Persons Deprived of Liberty Bill. Policy documents include the 2006 Draft National Disability Policy, the 2010 Draft Human Rights Policy, the 2003 Draft Mental Health Policy revised in 2007, and the 2011 Draft Social Protection Policy. All are silent on the issue of supported decision-making.

for minors and people with mental disability to be made by a person of full age and capacity (next friend or *guardian ad litem*).<sup>34</sup> In granting legal aid in criminal proceedings, the Legal Aid Commission considers whether the person is able to understand the proceedings or present his or her case.<sup>35</sup>

## 4. Definitions

The CRPD recognises that “disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.”<sup>36</sup> Article 1 states that people with disabilities “include those who have long-term 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”. This emphasises the diversity of disability and recognises that the law must seek to demolish social barriers that impede the lives of people with disabilities. In 2011, the World Health Organisation and the World Bank published *The World Report on Disability*, the first report of its kind and providing an analysis of disability-related policy responses and recommendations for actions at national and international levels.<sup>37</sup> The report notes that the notion of disability is complex, dynamic, multi-dimensional and contested,<sup>38</sup> illustrating some of the definitional difficulties and the need for a flexible and developmental approach to the law.

It is striking that there is no definition of ‘persons with disabilities’ in the Persons with Disabilities Act 2003, nor in the Constitution. ‘Disability’ is defined in Section 2 of the Persons with Disability Act as “a physical, sensory, mental or other impairment, including any visual, hearing, learning or physical incapability, which impacts adversely on social, economic or environmental participation”.

In 2007, the government came up with an unpublished draft Bill to amend this definition by including “whether arising from natural or artificial causes, which is irreversible and long term...”<sup>39</sup> after the word ‘physical incapability’ in the definition. In 2010 the government published a Bill to insert the words “or albinism” before physical incapability in the definition.<sup>40</sup> The 2010 Persons with Disability Bill has yet to have its first reading in parliament.

The Constitution defines ‘disability’ as “...any physical, sensory, mental, psychological or other impairment, condition or illness that has, or is perceived by significant sectors of the community to have, a substantial or long term effect on an individual’s ability to carry out ordinary day-to-day activities.”<sup>41</sup>

34 2010 Legal Aid Bill, Section 12 (1) and (2).

35 2010 Legal Aid Bill, Section 7(2)(e).

36 CRPD Preamble, Paragraph (e).

37 World Bank and WHO, *World Report on Disability*, 2011, see the aims of the report.

38 World Bank and WHO, *World Report on Disability*, 2011, 3.

39 2007 Persons with Disabilities (Amendment) Bill, Section 2.

40 2010 Persons with Disabilities (Amendment Bill), Section 2. This seeks to include people with albinism amongst the category of people identified as being disadvantaged under the 2003 Disability Act.

41 2010 Constitution of Kenya, Article 260.

The term “other impairment” in both of these provisions provide a non-exhaustive list of impairments. The Constitution allows disability to be determined with reference to the perception of significant sectors of the community, without defining what this means, leaving open the possibility of disability to be both overly broad (for example defining homosexuality as a disability) and narrow (for example failing to consider mental health issues as giving rise to a disability).

*The World Report on Disability* states that people with psycho-social impairments and people with intellectual impairments are more likely to be disadvantaged in a variety of settings than those with other forms of impairments.<sup>42</sup> This disadvantage is evident in the exercise of the right to legal capacity. The Kenyan government has also acknowledged that the right to legal capacity remains a challenge for people with disabilities in Kenya, particularly people with psycho-social (mental health) disabilities and people with intellectual disabilities.<sup>43</sup>

No universally-accepted terminology exists. Different cultures and languages use different labels. ‘People with intellectual disabilities’ is the term used by Inclusion International,<sup>44</sup> Inclusion Africa<sup>45</sup> and the Kenya Association for the Intellectually Handicapped.<sup>46</sup>

The term ‘intellectual disability’ has no agreed definition. MDAC uses the following:

An intellectual disability generally means having greater difficulty than most people with intellectual and adaptive functioning due to a long-term condition that is present at birth or before the age of eighteen. People with this label may have greater difficulty in carrying out everyday activities such as communicating and interacting with others, managing money, doing household activities and attending to personal care. While the term ‘intellectual disability’ is technically distinct from other ‘developmental disabilities’ these terms are often used interchangeably.<sup>47</sup>

The term ‘people with psycho-social disabilities’ is used by the World Network of Users and Survivors of Psychiatry, the International Disability Alliance, the Pan-African Network of People with Psycho-Social Disabilities (formerly known as the Pan-African Network of Users and Survivors of Psychiatry), Users and Survivors of Psychiatry

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42 WHO and World Bank, *World Disability Report*, 2011, 8.

43 Initial report to the CRPD Committee, 31 August 2011, 26 Para 121.

44 This is a global federation of family-based organisations advocating for the human rights of people with intellectual disabilities.

45 A Pan-African federation of associations of parents with a common mission and vision for children with intellectual disabilities, advocating for the rights of people with intellectual disabilities and their families. See <http://inclusion-international.org/category/regions/africa/> (last accessed 9 March 2014).

46 A parent-based Kenyan national organisation that works with parents and guardians of young people who have an intellectual disability and member organisation of Inclusion International and Inclusion Africa, also uses the term ‘people with intellectual disabilities’. See <http://kaihid.org/disabilityinfo/developmental-disability> (last accessed 9 March 2014). KAIH relied on the definition of ‘intellectual disability/cognitive disability’ provided by Centre for Disease Control and Prevention.

47 Mental Disability Advocacy Center, *Building the Architecture for Change: Guidelines on Article 33 of the UN Convention on the Rights of Persons with Disabilities* (Budapest: MDAC, 2011), 54.

Kenya and the UN Committee on the Rights of Persons with Disabilities.<sup>48</sup> MDAC describes the term as “those who experience mental health issues, and/or who identify as ‘mental health consumers’, ‘psychiatric survivors’, or ‘mad’. These are not mutually exclusive groups.”<sup>49</sup>

People with intellectual disabilities and people with psycho-social (mental health) disabilities in Kenya mostly depend on their families for social, financial, material and psychological support.<sup>50</sup> Due to this dependence on families, many people with mental disabilities experience restrictions on their decision-making rights, which is exacerbated by high rates of poverty and social inequality. Poverty, inequality and discrimination are interwoven, often in complex and mutually-reinforcing ways.<sup>51</sup> The bi-directional relationship between disability and poverty is well-established.<sup>52</sup> Poverty can increase the exposure of people with disabilities to discrimination especially in respect of making decisions which have financial implications.

## 5. Data and statistics

Article 31 of the CRPD sets out the State obligation to collect appropriate and disaggregated information, “including statistical and research data to guide them to formulate and implement policies” which give effect to the Convention. It also establishes the State obligation to disseminate statistics and ensure that information is accessible to people with disabilities and others.<sup>53</sup>

Various national bodies use different statistics about the numbers of people with disabilities in Kenya. One body puts the figure at 1.7 million and another at 1.3 million.<sup>54</sup> These numbers have been faulted as underestimates,<sup>55</sup> but in human rights terms numbers are less important than how people’s rights are secured. The National Council for Persons with Disabilities (NCPWD) has statutory duties to register people with disabilities including those

48 Committee on the Rights of Persons with Disabilities, Concluding Observation of the Committee: Tunisia, 13 May 2011, CRPD/C/TUN/CO/1, paragraph 8.

49 Mental Disability Advocacy Center, *Guidelines on Article 33 of the CRPD*, (2011), 55.

50 Initial report to the CRPD Committee, 31 August 2011, 7.

51 Equal Rights Trust, *“In the Spirit of Harambee: addressing discrimination and equality in Kenya”* (U.K: ERT, 2012), 38.

52 WHO and World Bank, *World Report on Disability*, 2011, 10.

53 In collecting and using the information states must comply to legal safeguards covering data protection, confidentiality and privacy of people with disabilities and internationally accepted norms to protect human rights, fundamental freedoms and ethical principles.

54 The Kenyan National Bureau of Statistics (KNBS) and the National Council for Persons with Disabilities (NCPWD) finalised the National Survey for Persons with Disabilities in 2007. The survey puts the number of people with disabilities at 1.7 million with about 80% living in rural areas. The survey estimates that people with mental impairments constitute 4.64% without any mention of people with an intellectual disability. The 2009 Population and Housing Census preliminary report puts the number of people with disabilities in Kenya at 1,330,312 of which 136,093 are people with mental disabilities (75,139 males and 60,954 females) without providing data on people with intellectual disabilities. The term ‘mental disability’ may have been used to include people with intellectual disabilities or this group is simply ignored.

55 Edah Maina, quoted in the Equal Rights Trust report on inequality and discrimination in Kenya, saying that there is lack of reliable and verifiable data on people with mental disabilities and she placed the estimate of people with intellectual disabilities at 1.3 to 3.6 million in the country. Equal Rights Trust, *In the Spirit of Harambee: Patterns of Discrimination and Inequality* (U.K:ERT, 2012) 140.

whose condition requires constant medical attention for the purpose of availing subsidised medical services.<sup>56</sup> NCPWD is mandated to co-operate with relevant government bodies during the national census to ensure that accurate figures of people with disabilities are obtained for the purpose of planning.<sup>57</sup> Kenya's National Bureau of Statistics (KNBS) is required to ensure that accurate statistics of people with disabilities are available.<sup>58</sup>

Neither of these bodies holds figures about the numbers of people under guardianship, those deprived of their legal capacity by the 2001 Children's Act or the 1991 Mental Health Act. To try and establish this figure, MDAC sent a letter in January 2013 to the High Court (via post and hand-delivered) asking for the statistics on people deprived of their legal capacity, although we received no reply to this request.

## 6. Legal capacity in international law

Legal capacity is the law's recognition of a person's decisions. The effect of denying or restricting a person's legal capacity either formally (through the law) or informally (outside the law) negatively impacts on many aspects of a person's life, including their ownership and management of property, financial affairs, employment, opening a bank account and seeking loans, marriage and parenthood, succession and inheritance, and voting or holding political office. Restriction of legal capacity restricts a person's access to justice due to a lack of recognition before the courts, meaning that forms of ill-treatment such as exploitation, violence and abuse can happen with impunity.

Kenya ratified the CRPD in 2008.<sup>59</sup> In 2010, the new Kenyan Constitution automatically incorporated ratified conventions, such as the CRPD, into Kenyan national law.<sup>60</sup> Notably, Kenya did not make any reservations on Article 12, indicating the government's willingness to implement the provision in its entirety and undertaking an obligation on the government to secure this right in practice for people with disabilities in the country.

Article 12 of the CRPD guarantees the right to legal capacity. Essentially it sets out some of the principles about how States need to shift away from substituted decision-making regimes. By "substituted decision-making" we include formal processes such as appointing guardians, estate manager, public trustee or courts' direct management of people's affairs and through informal norms that fail to respect the choices, will and preferences of adults with disabilities. Instead of substituted decision-making, States should adopt supported decision-making, by which we mean respecting peoples autonomy and decisions, avoiding making decisions for people based on notions of a perceived 'best interest', and to provide people with access to support they may need to communicate their decisions or to have their will, preferences and choices understood and respected.

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56 2003 Persons with Disability Act, Section 7 (c)(i) and (iv).

57 Ibid, Section 7 (1) (c).

58 2006 Statistical Act, Section 4, makes the Kenyan National Bureau of Statistics the principal government agency to collect, analyse and disseminate statistical data in Kenya.

59 Signed 30 March 2007; ratified 19 May 2008.

60 Constitution, Article 2(6).



## Article 12, CRPD

### Equal recognition before the law

- 1 States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
- 2 States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- 3 States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
- 4 States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
- 5 Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

The right to legal capacity in Article 12 refers both to the recognition of the individual as rights holder, as well as an actor in law throughout "all aspects of life".<sup>61</sup> Many domestic laws remove someone's legal capacity, which clearly does not comply with Article 12(2). The CRPD recognises that some people need support in exercising their legal capacity, so Article 12(3) mandates that States "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity". States must respect the agency of people with disabilities on an equal basis with others and must provide access to support for the exercise of that agency which a person may require (having a disability does not mean that the person requires assistance in all or every case).

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<sup>61</sup> Office of the United Nations High Commissioner of Human Rights (OHCHR), *Legal Capacity* (Background Documents for the Sixth Session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 1-12 August 2005), available at: <http://www.un.org/esa/socdev/enable/rights/ahc6documents.htm> (last accessed: 9 March 2014).

The support paradigm of Article 12 recognises that people with disabilities have an entitlement to informal or formal supported decision-making. Supported decision-making is not a model in itself, but rather a cluster of different models which can vary greatly, placing the individual concerned at the centre of the decision-making process. Models include setting up a specific support agreement with chosen support people,<sup>62</sup> or receiving support from a community-based organisation.<sup>63</sup> In any supported decision-making framework, primacy must be given to a person's "will and preference" (as outlined in Article 12(4) of the CRPD). This means that States must abolish substituted decision-making based on someone's perceived best interests. This refers to the situation where a substitute decision-maker (who may be a government official, a local community leader, teacher, carer/family member, a friend or a member of the community) makes a determination based on what they believe is in the best interest of the individual, which may not be the same as the person's will and preferences. A support paradigm demands that the people around the individual work hard to communicate with the individual and to provide the support necessary for them to express their will and preferences and to act on these.

A supported decision-making system should provide protection both for rights related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where, how and with whom to live etc.) as well as rights related to freedom from abuse and ill-treatment (right to health, right to bodily integrity, etc.)

Basic provisions and safeguards must be incorporated into the law and must establish structures to:

- 1 recognise and guarantee the right to legal capacity;
- 2 respect the autonomy, will and preferences of the individual;
- 3 ensure that support arrangements, once made, can be modified and challenged where necessary, in line with the will of the person concerned;
- 4 recognise that supported decision-making is built on relationships of trust;
- 5 assign clear roles to supporters to provide information to help people with disabilities make choices, and to assist the them to communicate these choices to third parties (such as banks, doctors, employers, etc.);
- 6 put in place adult protection systems to prevent and remedy exploitation, violence and abuse, as outlined in Article 16 of the CRPD;
- 7 carefully structure and monitor these provisions and safeguards to ensure that they do not over-regulate the lives of the individuals utilising them and become invasive and burdensome; and
- 8 ensure that third parties give legal recognition to the role of support people and to decisions made with support.

Human rights are interconnected and interdependent.<sup>64</sup> The right to make one's own decisions and have those decisions respected is only realisable if there are meaningful options to choose from. People with disabilities

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62 Canada, British Columbia, Representation Agreement Act, RSBC 1996, c. 405.

63 Swedish user-run service with Personal Ombudsperson (PO) for psychiatric patients, PO-Skane, available at <http://www.po-skane.org> (last accessed: 9 March 2014).

64 CRPD, Preamble (c).

in Kenya have limited choices due to a lack of community-based services.<sup>65</sup> The Kenyan government must coordinate across government ministries to ensure that meaningful options are made available in the services and support available to people with disabilities.<sup>66</sup>

The UN treaty body with the mandate to interpret the CRPD is the Committee on the Rights of Persons with Disabilities. It came up with a draft general comment on Article 12 in September 2013 and has called on States to:<sup>67</sup>

- Review laws allowing for guardianship and trusteeship and take action to develop laws and policies to replace regimes of substitute decision making by supported decision making which respect the person's autonomy, will and preferences;<sup>68</sup>
- ensure that persons with disabilities are provided with identification cards and documents on an equal basis with other members of society, ensuring that this contributes to the collection of accurate data which can be used to provide services;<sup>69</sup>
- abolish the practice of judicial restriction of legal capacity;<sup>70</sup>
- guarantee the exercise of civil rights including the right to marry to all persons with disabilities, to give and withdraw consent for medical treatment, access justice, to vote, and to choose their place of residence;<sup>71</sup>
- provide training in consultation and cooperation with persons with disabilities and their representative organisations at national, regional and local levels for all actors, including civil servants, judges and social workers on the recognition of legal capacity of people with disabilities and on mechanisms of supported decision-making;<sup>72</sup>
- prepare, legislate and implement a blueprint for a system of supported decision-making that includes recognition of all persons' legal capacity and their right to exercise it; and
- guarantee reasonable accommodation and access to support for people who require it to exercise legal capacity, including regulation to ensure that supports provided respects each person's autonomy, will and preferences. Feedback mechanisms should also be developed, to ensure that that various forms of support meet the needs of people with disabilities.<sup>73</sup>

65 CRPD, Article 19, which sets out the right to live in the community.

66 CRPD, Article 33 (1), which sets out the obligation to coordinate domestic policy.

67 CRPD Committee, Concluding Observations of the Committee: Tunisia, Spain, Peru, Argentina, Hungary, China and Paraguay, see: <http://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx> (last accessed: 9 March 2014).

68 CRPD Committee, Concluding Observation of the Committee: Tunisia, 13 May 2011, CRPD/TUN/CO/1 and Spain, 19 October 2011, CRPD/C/ESP/CO/1.

69 CRPD Committee, Concluding Observation of the Committee: Peru, 9 May 2012, CRPD/C/PER/CO/1 available at: <http://www.ohchr.org/Documents/HRBodies/CRPD/7thsession/CRPD.C.PER.CO.1-ENG.doc> (last accessed: 9 March 2014).

70 Ibid.

71 CRPD Committee, Concluding Observation of the Committee: Hungary, 22 October 2012, CRPD/C/HUN/CO/1, available at [http://www.ohchr.org/Documents/HRBodies/CRPD/8thSession/CRPD-C-HUN-CO-1\\_en.doc](http://www.ohchr.org/Documents/HRBodies/CRPD/8thSession/CRPD-C-HUN-CO-1_en.doc) (last accessed: 9 March 2014).

72 Ibid.

73 CRPD Committee, Concluding Observation of the Committee: China, 15 October 2012, CRPD/C/CHN/CO/1, available at [http://www.ohchr.org/Documents/HRBodies/CRPD/8thSession/CRPD-C-CHN-CO-1\\_en.doc](http://www.ohchr.org/Documents/HRBodies/CRPD/8thSession/CRPD-C-CHN-CO-1_en.doc) (last accessed: 9 March 2014).

# Part Two: Compliance of Kenyan law with Article 12 of the CRPD

## 1. Introduction

The last section provided relevant background about Kenya, looking at its social and legal system, political context, definitions relating to people with disabilities, data and statistics and outlined how the concept of legal capacity has been framed by international law. This section fleshes out the four indicators mentioned above to find out whether Kenyan law complies with Article 12 of the CRPD. The indicators flow from CRPD Committee's concluding observations after reviewing reports of States Parties to the Convention.<sup>74</sup> Under each indicator, there is a conclusion, an explanation of the precise CRPD standards and an analysis of Kenyan law and practice. Reference is also made to the personal testimonies collected during the project and which are set out in Appendix 1 of this report.

## 2. Indicator 1: Does the law recognise people with disabilities as persons before the law?

**Conclusion:** Yes, but this recognition is meaningless in practice.

**CRPD Standard:** Article 12(1) of the CRPD sets out the right of people with disabilities to be recognised everywhere as persons before the law. Any form of discrimination in the recognition of people with disabilities before the law is prohibited and disability-based discrimination violates the inherent dignity of the person.<sup>75</sup> States must prohibit all forms of discrimination and promote equality through equal protection and benefit of the law for people with disabilities and take appropriate steps to provide reasonable accommodation and ensure substantive equality.<sup>76</sup> Article 12(1) requires that if the law recognises people by possession of identification documents (birth certificates, identity card or passport) people with disabilities should be eligible for such documents on an equal basis with others and when necessary supported to gain such documents. In May 2012, the CRPD Committee urged Peru to provide identification documents to persons with disabilities including those in rural areas and to collect complete and accurate data on those that are currently undocumented and who do not enjoy the right to a name.<sup>77</sup>

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<sup>74</sup> CRPD, Article 35, sets out States' obligation to report to the CRPD Committee on measures taken to implement the CRPD.

<sup>75</sup> CRPD, Preamble Paragraph (h).

<sup>76</sup> CRPD, Article 5, on equality and non-discrimination.

<sup>77</sup> CRPD Committee, Concluding Observation of the Committee, Peru, CRPD/C/PER/CO/1, 9 May 2012 Paragraph 23.

**Analysis of Kenyan law:** The Constitution sets out that “every person has inherent dignity and the right to have that dignity respected and protected”.<sup>78</sup> It provides for the right to equality and non-discrimination and guarantees equality before the law and equal protection and benefit of the law.<sup>79</sup> Equality includes full and equal enjoyment of all rights and freedoms. Women and men ‘have the right to equal treatment and opportunities in political, economic, cultural and social spheres, but the civil sphere is not expressly mentioned.’<sup>80</sup> The Constitution prohibits direct and indirect discrimination on grounds including disability, health and age.<sup>81</sup> The prohibition extends to entities of the State (such as a government-run school and public authorities) and non-State actors (including companies, churches and private hospitals). It requires the government to take legislative and other measures including affirmative action programmes and to design policies to challenge disadvantage suffered by individuals or groups because of historic discrimination.<sup>82</sup>

**Analysis of practice:** The Kenyan government acknowledges that disability-based discrimination is entrenched in stereotypes prevailing in Kenyan societies, which portrays people with disabilities as burdens and curses, and sometimes lead to families hiding such persons.<sup>83</sup> People with disabilities remain vulnerable to discrimination and inequality despite their legal recognition as persons before the law. Social prejudices are also apparent in the way that people with mental disabilities are treated in practice by both State and private entities, as has been established in previous research.<sup>84</sup>

There is a high probability that people hidden from society will be unable to access and possess personal identification documents. The issue of someone being hidden features in the testimony of Atieno, a woman in her late 20s with an intellectual disability, who said that when she was growing up her family did not want her: “they hated me”, she said, and they locked her inside a pen in the garden. She explained how her father said that she is “a bad omen to the family”. Inside the pen the only company she had was “animals and goats, and I would get so lonely”. After neighbours reported the matter to a church group, she was rescued.

78 2010 Constitution, Article 28. Also, Article 54(1)(a) states that persons with disabilities are entitled to be treated with dignity and respect and to be addressed and referred to in a manner that is not demeaning.

79 2010 Constitution, Article 27 (1), (2) and (3).

80 2010 Constitution, Article 27 (1), (2) and (3).

81 2010 Constitution, Article 260. This interprets disability to include any physical, sensory, mental, psychological or other impairment, condition or illness that has or is perceived by significant sectors of the community to have, a substantial or long-term effect on an individual’s ability to carry out ordinary day-to-day activities.

82 2010 Constitution, Article 27(4), (5) & (6).

83 Initial report to the CRPD Committee, 31 August 2011, 13 Paragraph 47.

84 The Equal Rights Trust’s report on inequality and discrimination in Kenya portrays a failure to realise the right to equality and non-discrimination. The report described that State clearly plays a role in discriminating and creating inequality. The report also assesses the impact of poverty and ethnicity on discrimination and inequality. The Kenyan National Human Rights and Equality Commission has documented the inequality of people with mental disabilities in its report “Silences Minds: Systematic neglect of mental health systems in Kenya”, (2011).

Many people with intellectual disabilities with whom MDAC researchers spoke did not have a national identification card because no one had supported them to get one. Ndungu is a man with intellectual disabilities in his 30s, and he told us how he thought he did not have an identification card because of his disability.

Family members told MDAC researchers about Kikuyu culture<sup>85</sup> which refers to people with psycho-social disabilities and people with intellectual disabilities as “stupid or idiots”. This discrimination leads to numerous social restrictions, with the result that people with disabilities are not recognised equally in inheritance and are denied the opportunity to participate in important cultural practices such as circumcision rites which is a significant rite of passage to adulthood. This subsequently impacts on several other rights of the adult such as the right to marry and have a family.

The Kenyan government has an obligation to ensure that the recognition of people with disabilities as people before the law goes beyond legislative recognition. It is important that the government takes action to ensure that recognition translates into practice, where people with disabilities will experience substantive equality without any form of discrimination, instead of mere formal equality.

### 3. Indicator 2: Are people with disabilities enabled to exercise legal capacity on an equal basis with others?

**Conclusion:** No. Law and practices restrict people with disabilities from exercising their legal capacity on an equal basis with others.

**CRPD Standards:** Article 12(2) of the CRPD sets out that States must ensure that people with disabilities have legal capacity on an equal basis with others. There should be no barrier for adults with any kind of disability to exercise their legal capacity, which means to make decisions which the law recognises as valid.

**Analysis of Kenyan law:** Kenyans assume full legal capacity at the age of 18 years.<sup>86</sup> Yet the law allows for the full deprivation, or partial restriction, of an adult’s right to legal capacity, based on their disability. This violates Article 12(2) of the CRPD. The two main legislative culprits are the Children’s Act 2001 and the Mental Health Act 1991.

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85 Kikuyu is one of the ethnic tribes in Kenya, currently estimated at 6.5 million people, mainly located in the highlands of south-central Kenya but also constitute a substantial emigrant population in most Kenyan towns. They are traditionally agriculturalists. See <http://www.bluegecko.org/kenya/tribes/kikuyu/> (last accessed: 9 March 2014).

86 Revised 2012 Age of Majority Act of 1974 (Cap 33), Section 2 provides that a person shall be of full age and cease to be under ‘disability by reason of age’ on attaining the age of 18 years. It is worth noting that different statutes in Kenya used different ages of majority. The Children and Young Persons Act (Cap 141), Section 2 defines a child as someone under 14 years, a juvenile between 14 and 16 years, and a young person between 16 and 18 years. The Employment Act (Cap 226), defines a person under 16 years of age as a child for the purpose of being engaged in gainful employment in any industrial undertaking.

### 3.1 The Children's Act

There is a common understanding in Kenya that 'guardianship' refers only to children. Interviewees often referred MDAC researchers to the Nairobi Children's Court when seeking information about adults under guardianship.<sup>87</sup> This may be because adult guardianship is uncommon. The Children's Act defines a guardian as "a person appointed by will or deed by a parent or by an order of the court to assume parental responsibility for the child upon the death of the parent of the child either alone or in conjunction with the surviving parent of the child..."<sup>88</sup> Where a guardian is appointed only to manage the estate of the child she/he need not have custody of the child.<sup>89</sup>

The Act allows the guardianship of a child to extend beyond the age of 18 years in "exceptional circumstances",<sup>90</sup> which include circumstances where the child has a mental or physical disability or an illness that renders them incapable of maintaining himself/herself or managing his/her own affairs and property without the assistance of a guardian.<sup>91</sup> Such extension orders are made before the child's 18th birthday and an application can be made by the child, the child's parent, the guardian, a relative or the director of children services.<sup>92</sup>

The Children's Act allows the child to consent to the extension order if capable of consenting, but it fails to specify how consent will be sought and obtained, and what happens if consent is refused.<sup>93</sup> The guardianship extension order may define the duration of the guardianship measure and prescribe how it will be conducted. An application to revoke an extension order can be made by those who were eligible to submit the initial application for the order (or if the person is married, the spouse).<sup>94</sup>

MDAC attempted to obtain statistics on children under guardianship, but courts do not collect this information. A search on the case database of the Kenya National Council for Law Reporting yielded no useful results.<sup>95</sup>

Through interviews and focus group discussions we learned that some parents treat their adult offspring with disability as children when it comes to decision-making, especially those with intellectual disabilities. Some relatives presented themselves during focus group discussions and interviews as guardians even though they had not been formally appointed by a court. This may be because the Children's Act allows parents to appoint guardians through "will or deeds" or because the word "guardian" is used colloquially as a synonym for "carer".

87 Correspondence with Kenyan lawyers and ex-interns of MDAC in Nairobi, 2013.

88 Children's Act (No. 8 of 2001), Section 102(1) and Section 104(1).

89 Ibid, Section 102(5).

90 Ibid, Section 107(1).

91 Ibid, Section 107(2).

92 Ibid, Section 107(3).

93 Ibid.

94 Ibid, Section 107(4) and (5).

95 Available at <http://www.kenyalaw.org/CaseSearch/> (last accessed: 9 March 2014).

## 3.2 Mental Health Act

The Mental Health Act regulates the “care, custody and estates management for people suffering from mental disorder or mental subnormality with mental disorder”.<sup>96</sup> A person with mental disorder “includes a person diagnosed as a psychopathic person with mental illness and person with mental impairment due to alcohol or substance abuse”.<sup>97</sup> Legal capacity can be deprived under this Act either through a court process or by the director of a mental health hospital.<sup>98</sup>

### 3.2.a Restriction through a court process

A person’s relative “or any other suitable person” (undefined) may send a petition to the High Court,<sup>99</sup> which can appoint a guardian for anyone suffering from a “mental disorder”.<sup>100</sup> The court may appoint a relative or the Public Trustee as estate manager and guardian.<sup>101</sup> Where the court views that the person concerned is able to manage most areas of their lives but is incapable of managing their estate, they may decide to place these matters under the responsibility of an estate manager, leaving other areas of legal capacity intact.<sup>102</sup> The order may include provision for maintenance of the person and their dependents but need not include custody or guardianship of the person.<sup>103</sup> The Act allows the court to fix an allowance to be paid from the person’s estate to the manager or guardian.<sup>104</sup> The court order may concern any matter pertaining to the person or the person’s estates.<sup>105</sup> The government may instigate a secret court hearing about anything related to the order.<sup>106</sup>

During the course of its investigation MDAC did not observe any court hearings simply because they are apparently so rare. An MDAC researcher visited the Family Division of the High Court in Nairobi in January 2013 and was told by the registrar that there are no data on the number of guardianship cases. The registrar did, however, provide MDAC with the register of cases. MDAC reviewed the case files for the years 2010 to 2012 inclusive and picked out cases relating to the Mental Health Act or the appointment of a guardian. No

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96 Mental Health Act (Cap 248), Preamble.

97 Mental Health Act (Cap 248), Section 2.

98 Mental Health Act (Cap 248), Section 16(4).

99 Mental Health Act, Section 2 interprets the word ‘Court’ in the Act to mean the High Court. Also Article 165(3)(a) of the 2010 Constitution gives the High Court unlimited original jurisdiction in criminal and civil matters.

100 Mental Health Act (Cap 248), Section 26(1)(a) and (b).

101 Mental Health Act (Cap 248), Section 26(2).

102 This is where the court finds that a person is able to manage their day-to-day affairs, is not a danger to the public or themselves, and where they are unlikely to offend public decency.

103 Mental Health Act (Cap 248), Section 26(3).

104 Mental Health Act, Section 27(2).

105 Mental Health Act, Section 28(1).

106 Mental Health Act, Section 28(2): “the Minister, the Public Trustee or a manager may take out, as a matter of course, an application in chambers for the determination of any question arising out of the management of an estate in respect of which an order has been made.”



information was available about whether the cases were pending or decided. We identified eight cases for 2010, 11 cases for 2011 and 16 cases for 2012. These numbers should not be taken as the only cases since we visited only the court in Nairobi and there are other High Courts in the country.<sup>107</sup>

We could not interview a person deprived of legal capacity through the court process, despite asking several NGOs to identify such people. A reason for the lack of cases seems to be that the court process is used for the management of people with significant wealth, yet the majority of people with disabilities associated with NGOs are likely to be poor.<sup>108</sup>

Two reported Nairobi High Court cases illustrate the process which courts take in legal capacity proceedings: *Waiganjo v. Waiganjo*,<sup>109</sup> and *Re Francis Mwaura Kamau*.<sup>110</sup> Of particular concern from review of these cases are:

- the applicant in guardianship proceedings;
- the sufficiency of evidence to deprive a person of their legal capacity; and
- the level of involvement of the person who is subject of the proceeding.

#### *Waiganjo v. Waiganjo*

In 2012, William Waiganjo applied to the court to put his older sister Leah Waiganjo under his guardianship. He said that Leah suffered from a “mental disorder” that rendered her incapable of managing her affairs and that her two landed properties were in danger of alienation following another court’s judgment against her (in proceedings she was not involved in). William wanted to save the estate and wanted legal power to challenge the judgment (by becoming a *guardian ad litem*). The High Court relied on what he said and two medical reports from 1997 and 2012.<sup>111</sup>

There is no evidence of the judge calling the doctors to give evidence. There is no evidence of the judge ensuring legal representation for Leah or allowing her or a representative appointed by her to cross examine the doctors or present alternative expert evidence to challenge the doctors’ testimony. In June

<sup>107</sup> We have no information about High Courts in Kenya located in the 19 other administrative districts.

<sup>108</sup> This is because most if not all of the cases taken to Court involve a person with wealth/property at stake which family members/relatives want to manage. The Kenyan government attests in its report to the CRPD Committee that most people with disabilities depend on their families for economic, financial and other supports.

<sup>109</sup> From the case database of the Kenya National Council for Law Reporting: High Court of Kenya at Nairobi, *Leah Wachu Waiganjo v. William Kibera Waiganjo*, Misc 330 of 2012, 29 June 2012, available at: [http://www.kenyalaw.org/CaseSearch/view\\_preview1.php?link=52491330487458673017231](http://www.kenyalaw.org/CaseSearch/view_preview1.php?link=52491330487458673017231) (last accessed: 9 March 2014).

<sup>110</sup> High Court of Kenya at Nairobi, *Re Francis Mwaura Kamau*, Misc Civil Application no 81 (2003)

<sup>111</sup> First medical report signed by Dr. P.D Kanyuira reads “...suffers from Temporal Lobe Epilepsy and periodic depressions. She has had three episodes of acute psychosis necessitating her admission to hospital for in-patient management. She is regular on medication since 1980 and it’s necessary that she continues on the treatment. Any attempt to reduce or stop the maintenance medication she is on makes her get into confusion states of mind, loss of memory and acute psychosis of fits.” Second report signed by Dr. Mutinda states “The above is a patient on follow up in our facility for a Bipolar Mood Disorder complicated by Temporal Lobe Epilepsy. She is currently on medication but has not yet stabilised. She is unable to make sound judgment.”

2012, the (male) judge met Leah in court and described her as a middle-aged lady who appeared well-nourished and well-groomed, able to state correctly her home address and the names of her father and other relatives. The judge noted that she responded with hesitation and probing, and therefore found her incapable of making sound decisions, and not capable of taking care of her own affairs and estate. The judge appointed William as Leah's *guardian ad litem*. From that point, Leah had no rights to decide anything about her assets or to guarantee her income from them.

#### *Re Francis Mwaura Kamau*

In September 2003, Cecilia Wangari Kamua applied to be the guardian of Francis Mwaura Kamau, her husband, as he had a "mental disorder". The court relied on three medical reports that the husband was suffering from dementia, as well as testimony of the wife and their two children.<sup>112</sup> The court found Francis Kamau to be suffering from a mental disorder within the meaning of the Mental Health Act and that his "affairs and estate required immediate care and preservation". It appointed Cecilia Kamau as Francis Kamau's guardian and requested her to submit medical reports, an inventory of the properties and debts every six months. There is no evidence in the court file that Francis Kamau knew anything about these proceedings that happened without his involvement. He was given no opportunity to participate, and no lawyer was appointed to represent him.

These two cases illustrate the faults in procedures used by courts to make a determination on a person's legal capacity. They fall short of the requirements of Article 12 of the CRPD, which requires States to shift away from restricting legal capacity under substituted decision-making arrangements (such as these) and move towards providing supports for people to exercise their legal capacity. In the first case, the judge could have spoken to Leah about what she needs to be able to manage her estate as she wishes. The judge could have put in place a structure to preserve her legal capacity while making sure that her brother does not unduly influence her in investment decisions. In the second case the judge could have at the very least spoken to Francis Kamau, and asked him about his opinion, then put in place some supports which would have ensured that his finances and daily care needs were taken care of.

These court procedures lack the meaningful participation of the person with disabilities whose legal capacity is in question. The process pays no respect to the will and preferences of the person concerned. In Leah's case, her hesitation and probing in answering questions were taken as evidence of her incapacity, a finding that does not survive Article 12 scrutiny which requires efforts be made to ascertain the types of supports she may

<sup>112</sup> Medical report submitted by Professor Paul G. Kioy, a neurologist and neurophysiologist, who states "the patient's present medical condition is irreversible and treatment remains cosmetic." Affidavit was sworn by two children because the third child had been certified as severely mentally challenged.

need to forge her way through life. The Mental Health Act provides no guidance as to how courts are to judge someone's decision-making capacity, and notwithstanding the rarity of the cases coming before the courts, those that are decided by judges seem to be about restricting decision-making rights instead of putting in place access to a range of supports which preserve legal capacity.

There is the risk that several human rights are violated in such proceedings, including:

- 1 The right to be heard and present during proceedings. This does not happen as a matter of course, but rather only when the judge orders it.<sup>113</sup>
- 2 Adults are not obliged to be served notice of the application.
- 3 They have no legal representation.
- 4 They have neither the right nor the opportunity to present their own evidence (including witnesses), nor the opportunity to challenge opposing evidence.
- 5 Placing too much emphasis on a diagnosis as evidence of the supposed inability to make independent decisions (including with support).
- 6 Very little evidence is required to deprive someone of their legal capacity.
- 7 The person is not asked about the appointment of a guardian.
- 8 Appeal routes are closed for the individual concerned, who loses their legal personality as a result of the proceedings.
- 9 The person is denied the opportunity to challenge the appointment of a particular person as guardian.
- 10 Guardianship is not periodically reviewed.

The court has authority to grant powers to the estate manager,<sup>114</sup> but these powers remain unclear, beyond requiring the estate manager to provide an inventory of the property to the court and to the Public Trustee,<sup>115</sup> and to seek the court's permission to sell or lease the property.<sup>116</sup> The court gave such permission in the case *Ramesh Liladhar Shah v Joseph Kibe Mungai*.<sup>117</sup>

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113 Mental Health Act, Section 38, which provides that when a person alleged to be suffering from a mental disorder is before the court or magistrate, such court or magistrate shall sit in camera, where possible.

114 Mental Health Act, Section 27(1).

115 Mental Health Act, Section 33(1).

116 Mental Health Act, Section 27(1)(i), (a), (b) and (c). Also, Section 4 of the Revised 2009 Trustee's Act of 1982, which sets out the manner in which a trustee may invest any trust fund in his hands whether it is in a state of investment or not at the particular time.

117 High Court of Nairobi, *Ramesh Liladhar Shah v. Joseph Kibe Mungai*, Miscellaneous Application 360 (2002) of 30 October 2009, available at: [http://www.kenyalaw.org/CaseSearch/view\\_preview1.php?link=25506778468820283280940](http://www.kenyalaw.org/CaseSearch/view_preview1.php?link=25506778468820283280940) (last accessed: 9 March 2014).

*Ramesh Liladhar Shah v. Joseph Kibe Mungai*

In May 2002, the High Court at Nairobi appointed Mr Mungai as Mr Shah's guardian to manage his affairs (based on Section 26(3) of the Mental Health Act). In September 2009, Mr Mungai applied to court to sell Mr Shah's interest in the leasehold property he jointly owned with his wife. The testimony of Mr Mungai and Mr Shah's wife supported the application. The court asked two doctors to write expert opinions and the court relied on these in deciding that Mr Shah's condition had not improved since the 2002 guardianship order which stated that, "it was obvious that Mr Shah could not follow the proceedings and was totally unaware and incapable of being aware of what was going on around him". The court did not invite Mr Shah to participate in the 2009 proceedings at all. The court granted the guardian permission to sell Mr Shah's interest in the leasehold property, on grounds that this was in Mr Shah's best interests.

This case highlights the paucity of safeguards available. Article 12 of the CRPD demands that safeguards should be put in place to find out and respect the will and preferences of Mr Shah, not simply take decisions for him, while guessing what is in his supposed "best interests".

Following extensive legal research MDAC found only one case where the person whose legal capacity was in question actually challenged the application.<sup>118</sup> The judgment in this case described the issues and submissions as "unprecedented".<sup>119</sup>

*K v. K*<sup>120</sup>

A son alleged that his 78-year old father could not manage and administer his property and other affairs. In June 2009, he asked the court to declare his father to be suffering from a mental disorder under the Mental Health Act and appoint a firm of lawyers as estate managers and other people as guardians. S relied on medical and psychiatric reports and his own witness statement. His father objected. The court ruled that, "all actions by relevant authorities and applications to be made either seeking a person's admission in mental hospital or seeking such orders should be directed towards the care and welfare of the persons and preservation of their estates against wastage or plunder by greed of relatives or others".

The court was able to come out with such a strong statement because the father produced medical reports showing that he was able to carry out daily life, has good judgment and average intelligence and exhibits adequate mental capacity to continue playing an active role in his company.

118 High Court at Nairobi, K v. K, Petition 36 of 2009, 1 December 2009, available at [http://kenyalaw.org/CaseSearch/view\\_preview1.php?link=17284381570124221590243](http://kenyalaw.org/CaseSearch/view_preview1.php?link=17284381570124221590243) (last accessed: 9 March 2014).

119 Ibid, page 5.

120 Here we use initials used in the judgment.

This case raises thoughts that are worth reflecting on.

- It is clear that people subjected to legal capacity determination proceedings may be interested in challenging the process if they have the means. Means will include financial, appropriate knowledge and supports (such as a lawyer and access to legal aid).
- This case raises the obvious possibility that relatives/family members are not always driven by caring for the individual concerned but sometimes will be interested to become estate managers and guardians regardless of whether the person in question is able to exercise their legal capacity independently or with access to relevant supports.
- It also highlights how courts rely primarily on medical reports.

If there is “sufficient cause” the court can remove a guardian, and appoint a new one.<sup>121</sup> The court can restore a person’s legal capacity, “when there is reason for believing that the adult has recovered after receiving evidence by affidavit or otherwise”.<sup>122</sup> This remains only a theoretical possibility. MDAC research in the database of Kenya National Council of Law Reporting for the years 2002 to 2013 found no case where a guardian has been removed or a person’s legal capacity had been restored.

### 3.2.b Restriction by the administration

The Mental Health Act allows the director of a psychiatric hospital to restrict the legal capacity of a person by detaining them in the psychiatric hospital.<sup>123</sup> The director may also hand over a patient to the custody of the patient’s relatives or friends who agree to, and will be bound by, certain conditions,<sup>124</sup> which remain unspecified in the Act. Anyone who gives, sells or barter any commodity to an inpatient of the hospital without prior consent of the director of a psychiatric hospital is guilty of a criminal offence.<sup>125</sup> In addition, discharge of a voluntary patient at the hospital is at the discretion of the director, which limits the adult’s decision in accepting or refusing healthcare.<sup>126</sup> Article 12 of the CRPD underlines that the decisions which people with disabilities make, including those relating to healthcare, should be respected.

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121 Mental Health Act, Section 34(1) and (2).

122 Mental Health Act (Cap 248), Section 36.

123 Mental Health Act (Cap 248), Section 16(4).

124 Mental Health Act (Cap 248), Section 22(1).

125 Mental Health Act (Cap 248), Section 52.

126 Mental Health Act (Cap 248), Section 10(3).

*In practice*<sup>127</sup>

The previous section examined the extent to which Kenyan law restricts legal capacity. This section looks at what happens in practice. Although no national statistics exist, MDAC obtained the strong impression from interviews that few people are deprived of legal capacity through the courts. More commonly, decision-making is restricted by directors of psychiatric hospitals, and through informal practices within families and communities. A report issued by Kenyan disability organisations noted that three quarters of people with disabilities who were interviewed reported being denied the right to make decisions on issues affecting their lives.<sup>128</sup>

MDAC carried out 20 interviews with people with intellectual disabilities and people psycho-social (mental health) disabilities. None of them were under formal guardianship but many of them told MDAC about practical restrictions on their decision-making. In our focus group discussions a participant with a brother with an intellectual disability explained that in Kiambu (a county in the central province of Kenya having a population of 1.6 million),<sup>129</sup> guardianship is determined on customary basis. The example was given of this person's father who divided land among his four children, but placed the piece allocated to his son with an intellectual disability in the hands of another son who promised to take care of his sibling.

One parent said in a focus group that he makes decisions for his son who has an intellectual disability because there is no social protection system which would help his son rent a house, buy food and so on. The father said that parents decide where their children stay or what they eat because parents provide the money. While he would like his son to live an independent life, the lack of community-based supports scares him. He told MDAC of decisions which his son makes independently, like collecting tins and bottles to sell. Another participant of a focus group, a man with a psycho-social disability, told MDAC that he is demoralised as his relatives question every decision he makes, evidencing the way in which social stigma have a significant impact on the lives of people with disabilities more generally.

MDAC found that people with psycho-social disabilities, unlike many people with intellectual disabilities, have many opportunities for decision-making in their family and home life. This ranges from deciding where to live, daily activities, personal care, and taking part in family life. Poverty overwhelmingly affects the choices people can make, as Yusuf, Wambua and Kariuki told MDAC. For example, Kariuki a man in his early 30s explained to MDAC the reasons he lives with his family, but nevertheless that he would like to be more independent:

I find it easier to live with [them]. Firstly, because of issues to do with costs [...] At some point it might be nice to get my own place and be completely independent. I also find myself to be useful within my family, because I support them in a number of ways.

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127 The names of people interviewed in this section have been changed. You can read full testimonies from each person interviewed for this research in Appendix 1.

128 African Union of the Blind (AUB), Kenya Union of the Blind (KUB) and Centre for Disability Rights Education and Advocacy, *State of Disabled Peoples Rights in Kenya*, 2007, 11. Available at: <http://www.yorku.ca/dmpi/files/KenyaReport07.pdf> (last accessed: 9 March 2014).

129 More information available at <http://www.kenyampya.com/index.php?county=Kiambu> (last accessed: 9 March 2014).

Kariuki's mother noted how the family appreciate his support and presence.

However, Jacinta told MDAC that her father makes decisions. He even represents her in the women's group she attends. Jacinta, Yusuf, Wambua and Kariuki feel supported in making decisions in their family and at home but this is linked to the financial contribution they make to the family, as they work. Jacinta and Yusuf told MDAC that they would like to have more independence from their family, but this is dependent on financial security.

People with intellectual disabilities told MDAC that their relatives and teachers make most decisions for them, albeit with the best of intentions and with the person's future in mind. In Kenya many people with intellectual disabilities live with their relatives, so many relatives thought it was funny when MDAC asked about where their relative with intellectual disabilities lived.

It was clear that the norm for families of people with intellectual disabilities was to exclude them from decision-making on the basis that they are likely to be incapable of participating. When MDAC asked Kiprop's sister whether this was right, she responded:

Well, yes and no. Yes because he can make some decisions and no because I am his carer and I think I know what is best for him [...] To say the truth, I admit he should make his own decisions but look, he is not in a position to and that is why I make them for him.

When MDAC asks Kiprop about how he feels when someone makes decisions for him, he responded after a long silence: "Bad".

Bosire is a woman in her early 20s with an intellectual disability. Her parent hired a personal attendant who told MDAC:

We make most of her decision, me, her parents, and the teachers. You see, she may not be so much in touch with herself and that is why we make decisions for her [...] when it is time for meals [...]. I tell her when to take a bath, just the general tasks that one does.

Research in Kenya has already found that parents acknowledge the right to self-determination of their children with intellectual disabilities, but also point to their dependence, vulnerability and limited capacity to understand consequences of their actions, making parents the only ones who know how to make "good decisions".<sup>130</sup> This limits the opportunities for people with intellectual disabilities to take part in community life. They experience less freedom of movement because their relatives want them to be accompanied if they go out – with more restrictions at night outings for safety and security reasons – and are represented by relatives in community activities.

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130 Aviva Mill, Rachel Mayes and David McConnell, "Negotiating autonomy within the family: The experiences of young adults with intellectual disabilities", *British Journal of Learning Disabilities*, 38(3), (2009):194-200.

Kiprop's sister told MDAC that he "is not involved in community life", yet would love to "go out, meet other people." But in reality, his sister thought this would be impossible:

Such a thing would be really dangerous because he can just walk and not be able to come back home. So I prefer when he is just around home, then that is okay with him and with me also.

She explained her fear for his safety stems from community attitudes towards people with intellectual disabilities.

Some of these attitudes, we have very little control, because the community views him differently and fails to integrate him in mainstream activities so, yes, I can say that his right to be part of community is denied.

Ali is a man in his early 20s. His brother also explained Ali's exclusion from community activities in safety terms:

Sometimes when we are going out at night to watch movies, he is not allowed to go with us because of his condition. I think he is not happy about it but he doesn't voice his disappointment either[...] You see, at times he is so weak and if he goes outside he can fall down, so that is why we ask him not to get so much involved.

People with psycho-social disabilities, however, appear to have more freedom to participate in community life. People MDAC spoke to included a member of a church, a neighbourhood security team and a women's group. They enjoy more freedom of movement, although more significant restrictions were seen in the case of younger women. Jacinta, for example, had limits placed on her by her parents due to her disability. Onyango told MDAC that, "my mum normally tells me not to come home very late because it's risky, but I normally go everywhere I choose or wish [...] I am an adult."

Our research suggests that people who develop a psycho-social disability during education or when decisions regarding education need to be made are encouraged by their family to either quit education or change subject. Decisions are made by parents on their own initiative or prompted by teachers. Poverty and a lack of reasonable adjustments in education both seem to be factors in such decisions. A man with a psycho-social disability told MDAC during a focus group that he stopped studying for his master's degree because he experienced a mental health crisis, and he thinks that the reason that a year after the crisis he has not been scheduled by the university to present his thesis proposal was because of his disability.

MDAC found that from the people we spoke to, people with psycho-social disabilities are empowered to decide on more issues in relation to their lives than people with intellectual disabilities. Gender and age impact differently on both groups in relation to decision-making. Older people and men are more likely to be given opportunities to exercise their legal capacity than younger people and women. Githinji a man in his early 70s with a psycho-social disability spoke about how he made all his decisions in his life:



“You know me”, he said, “I am an old man who is very wise and well matured so it’s very difficult for people to make any decision for me because they respect me very much.”

This reflects cultural norms which both demands respect for elders and is a patriarchal society.<sup>131</sup> However, the daughter of Njeri, a woman in her early 70s with an intellectual disability, told MDAC that, “my mum is fit and she makes all the decisions. At times she is slow in reasoning [...] but she makes sound decisions.”

MDAC’s findings suggest a link between educational attainment, employment and decision-making authority. People who earn an income are more likely to have a say in issues that affect them, especially anything which involves finances, and shows the independence that employment and education can bring to the lives of people with disabilities. It also shows how denial of such opportunities is likely to negatively impact on the right of people to exercise their autonomy as full members of society.

## 4. Indicator 3: Can people with disabilities exercise legal capacity in all aspects of life?

**Conclusion:** No. law remains ambiguous yet impacts on how people with disabilities make decisions about their lives.

**CRPD Standards:** Article 12(2) of the CRPD sets out the obligation on each State to “recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.”

**Analysis of Kenyan law:** Several laws restrict the legal capacity of people with disabilities, sometimes in an ambiguous way.<sup>132</sup> Laws define the group of people whose legal capacity may be restricted by using the terms “mentally insane”, “people of unsound mind” and “mental defectives.” This indicator looks at whether people with disabilities are legally empowered to exercise legal capacity in the following aspects of life: political participation, work and employment, health care services, access to justice, marriage, property rights and land rights.

<sup>131</sup> African Charter on Human and Peoples’ Rights, Article 29(1) provides a duty to everyone to respect their parents at all times, and maintain them in case of need. Article 26(c) of the African Youth Charter gives young people the duty to have full respect for their parents and elders and to assist them in cases of need.

<sup>132</sup> Legislation includes the 2010 Constitution of Kenya; Mental Health Act (Cap 248); Age of Majority Act; Persons with Disabilities Act, No.14 of 2003; Civil Procedure Act (Cap 21); Criminal Procedure Act (Cap 75); Sale of Goods Act; Law of Succession Act; Traffic Act (Cap 403); Matrimonial Causes Act; Children’s Act No.8, 2001; Penal Code; Sexual Offences Act; Evidence Act (Cap 80); and the Election Act.

## 4.1 Political participation

**Question:** Does Kenyan law allow and enable people with intellectual disabilities and people with psycho-social (mental health) disabilities to make legally-binding political decisions on an equal basis with others?

**Conclusion:** No. Law prohibits people of “unsound mind” from voting and being elected into certain public offices. There is no definition of what this antiquated term means. MDAC found that those people with disabilities are only able to exercise their political rights when the following conditions are met:<sup>133</sup>

- 1 The person lives in the community (not in a psychiatric facility during voters registration or election day); and
- 2 The person is interested in politics and is supported by his or her family or an NGO to provide support; and
- 3 The polling station officer does not perceive the person to be of “unsound mind”; and
- 4 The person can physically access the polling station and can physically write, or have someone else mark an “X” on the ballot paper.

These are significant hurdles for the majority of people with psycho-social (mental health) disabilities and people with intellectual disabilities.

**CRPD Standards:** Article 29 of CRPD provides for the right to political participation for people with disabilities, without any exception. The CRPD Committee has stated that, “persons with disabilities regardless of their impairment, legal status or place of residence have the right to vote and participate in public life on an equal basis with others”.<sup>134</sup>

**Analysis of Kenyan law:** The Constitution provides for the right of every adult citizen to freely make political choices including the right to free, fair and regular elections based on universal suffrage and to freely express the will of the electors, to hold elected office, register as a voter and vote by secret ballot in any election or referendum without unreasonable restrictions.<sup>135</sup>

In reality things are more complicated. The 2003 Disability Act recognises the right of every person with a disability to participate as a voter in elections.<sup>136</sup> They are entitled to a personal assistant who follows their

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133 MDAC got this information from interviews we conducted in Kenya and from Skype communication with different stakeholders including Users and Survivors of Psychiatry Kenya, Kenyan Association for the Intellectually Handicapped and Basic Needs Kenya before and after Kenya’s Constitutional Referendum in August 2010 and the March 2013 general elections.

134 CRPD Committee, Concluding Observation of the Committee: Spain 19 October 2011, CRPD/C/ESP/CO/1. Also see the CRPD Committee’s subsequent concluding observations on Tunisia, Hungary, Peru, China and Argentina.

135 2010 Constitution, Article 38.

136 It defines disability as “physical, sensory, mental or other impairment, including visual, hearing, learning or physical incapability, which impacts adversely on social, economic and environmental participation”.

instructions to vote in presidential, parliamentary and civic elections.<sup>137</sup> The personal assistance is guilty of an offence if they fail to comply with the instructions provided.<sup>138</sup> The 2011 Election Act mandates the Election Commission to disseminate rules about facilitating the right to vote for people with disabilities and people who cannot read or write.<sup>139</sup> The Elections Regulation of 2012 mandates the person in charge of a polling station to allow such a voter to be assisted or supported by a person of the voter's choice who is not a candidate or an agent of a candidate.<sup>140</sup> The support person must be an adult who makes a declaration of secrecy: if breached this is a criminal offence, and each support person should assist only one voter and will be registered as such.<sup>141</sup>

The Constitution provides that a voter must be someone who is "not declared to be of unsound mind".<sup>142</sup> The Local Government Act 2010 sets out regulations for local elections. It expressly disqualifies a person of "unsound mind" from voting in local elections.<sup>143</sup> Similarly, the Election Act 2011, regulating national elections, also disqualifies those of "unsound mind" from voting.<sup>144</sup>

There is no clear interpretation of what it means to be of "unsound mind". Prior to the 2010 Constitutional referendum, the High Court held that the former Constitution did not exclude adult inmates in prison from voting in a referendum.<sup>145</sup> However, no such voting arrangement was made for people in psychiatric facilities. But this misses the point. The CRPD is clear that irrespective of any disability-related labels (like "unsound mind"), and irrespective of place (such as prison or psychiatric facility), everyone is entitled to vote. It is not for the State to establish a system to determine someone's electoral talents before deciding whether they are good enough to cast a vote. Kenya clearly fails this basic indicator of democracy and human rights.

In 2010 the Kenyan Society for the Mentally Handicapped (KSMH) together with other NGOs rallied against the Interim Independent Electoral Commissioner who said that adults with intellectual disabilities would not be eligible to vote in the Constitutional referendum. He then withdrew the statement and ensured that such adults could register as voters.<sup>146</sup> However, just a minimal percentage of those that registered actually voted since they faced numerous attitudinal and practical physical barriers at polling stations.<sup>147</sup>

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137 2003 Persons with Disabilities Act, Section 29(1), (2) and (3).

138 2003 Persons with Disabilities Act, 2003, Section 29(4).

139 2011 Election Act, Section 109(1)(n) and (o).

140 2012 Election (General) Regulations, Section 72(1).

141 Ibid, Section 72(2), (3), (4) and (5).

142 2010 Constitution, Article 83(1)(b).

143 Revised 2010 Local Government Act (Chapter 265 of 1998), Part V, paragraph 53(C).

144 2011 Election Act (No.24), Section

145 High Court of Kenya at Nairobi, *Priscilla Nyokabi Kanyua v Attorney General & another*, Constitutional Petition 1 of 2010, 23 June 2010.

146 Kenya Society for the Mentally Handicapped, available at <http://www.ksmh.org/ksmh-at-work/campaigning-for-rights/right-to-information> (last accessed: 9 March 2014).

147 Ibid.

### *Research findings*

MDAC asked people with psycho-social disabilities and people with intellectual disabilities whether they had ever voted. People who lived in the community participated in elections, either with support from local organisations or their families. Some face practical challenges from other people at the polling stations. Mumbi is a woman with an intellectual disability in her early 30s. She has a national identity card, but she told MDAC about her experiences when asked if she has ever voted, saying that in the line people pushed jostled and shoved her out of the voting queue and she felt bad about it.

Other interviewees were not interested in politics and did not want to vote. Some wanted to vote but could not, for practical reasons. Ndungu told us that he needed an identification card to vote, but because his family have not supported him to acquire one, he could not vote. He explained that he lacked an identification card, “because of my head”, going on to say that “my uncles say it and even I hear it from my grandmother sometimes when she is talking to people [...] I feel bad because I don’t know what they are talking about, and I don’t think there is any problem with my head.”

People with disabilities are prohibited from being a candidate for elected positions. The Constitution disqualifies a person from being elected Member of Parliament if that person is of “unsound mind”, the same phrase which again is undefined.<sup>148</sup> The Constitution allows for the President of the country to be removed if he or she becomes physically or mentally “incapacitated”.<sup>149</sup>

The National Land Commission Act 2012 allows for the removal of the Secretary of the Commission in case of inability to perform the function of the office as a result of “physical or mental incapacity”.<sup>150</sup> The Commission for the Implementation of the Constitution Act 2010 similarly can strip the Chair or a Member for “physical or mental infirmity”.<sup>151</sup> Nowhere in Kenyan law are “unsound mind”, “physical or mental incapacity” or “mental infirmities” defined.

KSMH has pointed out that the term “unsound mind” is derogatory and discriminatory.<sup>152</sup> Its view is that the Constitution must be brought in line with the CRPD, which prohibits discrimination based on any form of disability, and guarantees the right to vote and stand for election on an equal basis with others.<sup>153</sup> The “unsound mind” provision means that the quota system (5% of elected and appointed public positions to be filled by people with disabilities) will only be filled by people with physical or sensory disabilities.<sup>154</sup>

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148 2010 Constitution, Article 99(2)(e).

149 2010 Constitution, Article 144.

150 2012 National Land Commission Act (No 5, 2012), Section 21(1)(a).

151 2010 Commission for the Implementation of the Constitution Act (No 9, 2010), Section 11(1)(d).

152 This section allows for a person to be disqualified for registration as a voter at elections or referenda if the person is declared to be of ‘unsound mind’.

153 Kenya Society for the Mentally Handicapped available at: [http://www.ksmh.org/publications/doc\\_download/26-ksmh-recommendationselections-bill-2011](http://www.ksmh.org/publications/doc_download/26-ksmh-recommendationselections-bill-2011) (last accessed: 9 March 2014).

154 2010 Constitution, Article 54(2).

Mutua a man with an intellectual disability in his early 40s told MDAC that he was interested in standing for political office. He had to change his mind:

During that time that I wanted to be a politician, there was a lot of mudslinging and they could talk about me very much. I think even some other rivals said I was crazy and finally the pressure was too much so I decided to bow out [...] I would like to be a politician and that is what my dream is [...] I felt awfully bad, but there was nothing I could do.

There are examples of people with a political leadership role who, because of the stigma associate with mental health issues, do not come out in their role. Githinji is a village elder and none of his fellow villagers know about his psycho-social disability, because, as his wife put it, "they might think he will not do his work properly". Both Githinji and his wife want him to give up the role because he does not get any supports. His wife told MDAC:

You know, leadership has a lot of problems and also some people are very high tempered, so when he comes into contact with them, his stress levels become very high which is not very healthy for him [...] but since most of the people in the village like his leadership, he feels he cannot leave them just like that as his people.

## 4.2 Work and employment

**Question:** Does Kenyan law allow and enable people with intellectual disabilities and people with psycho-social (mental health) disabilities to make legally-binding decisions about work and employment on an equal basis with others?

**Conclusion:** No. Law prohibits employment-related discrimination and ensures that reasonable accommodations (adjustments) are provided. In practice, some people receive adjustments from employers, while others – especially people with intellectual disabilities – face discrimination in the workplace affecting their legal capacity.

**CRPD Standards:** Work and employment rights are set out in Article 27 of the CRPD. States must recognise the right to work for people with disabilities on an equal basis with others and create an enabling and conducive environment in both public and private sector employment. It gives people with disabilities the right to work and earn a living, to be treated fairly when employed, to choose the work of their preference, complain and join labour and trade unions, freedom from harassment, the right to receive career counselling, opportunities and vocational training, and to promote self-employment and business opportunities. This should be guided by the principles of non-discrimination and access to employment in the open market.

The State should also ensure that law provides reasonable accommodation for people with disabilities. This means providing necessary and appropriate adjustments and modifications in all employment matters including conditions of recruitment, hiring and employment, continuance of employment, career advancement and ensuring safe and healthy conditions for people with disabilities. States have an obligation to adopt positive measures to

promote employment opportunities, take measures including adopting legislation, modifying or abolishing laws, regulations, customs and practices that constitute discrimination in the work place for people with disabilities.<sup>155</sup>

As a social and economic right, the right to employment is subject to progressive realisation, which means that it can be implemented over time, rather than immediately. The CRPD Committee has specified that States should implement measures of affirmative action for the employment of people with disabilities. They are required to increase the diversity of employment and vocational training opportunities, ensure the participation of people with disabilities and their representative organisations within labour inspection offices. The also means that measures should be taken to ensure the freedom of choice of people with disabilities to pursue vocations based on their preferences.<sup>156</sup>

**Analysis of Kenyan Law:** The Employment Act 2007 prohibits direct and indirect disability-based discrimination against employees,<sup>157</sup> and prohibits employers from dismissing employees on disability-related grounds.<sup>158</sup> The Disability Act 2003 sets out a potentially far-reaching prohibition on any person from denying people with disabilities access to opportunities for suitable employment.<sup>159</sup> The Disability Act entitles qualified employees with disabilities to the same treatment, terms and conditions and benefits as those without disabilities,<sup>160</sup> accompanied with reasonable accommodation and tax relief for employers.<sup>161</sup> The National Council for Persons with Disabilities is required to recommend measures to prevent discrimination against people with disabilities,<sup>162</sup> set up schemes and projects for self-employment or regular or sheltered employment to enable people with disabilities to generate income<sup>163</sup> and to take actions to secure the reservation of 5% of all casual, emergency and contractual positions in both public and private sectors.<sup>164</sup> Despite these provisions, People with disabilities continue to face a variety of barriers to employment.

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155 OHCHR, Report on thematic study on the right to work and employment of persons with disabilities, A/HRC/22/25, 17 December 2012.

156 CRPD Committee, Concluding Observation of the Committee: Spain, Tunisia, Hungary, China, Peru and Argentina.

157 2007 Employment Act (No.11, 2007), Section 5(3)(a).

158 Ibid, Section 46(g).

159 2003 Persons with Disability Act, Section 12 (1). Kenya's initial report to the CRPD Committee says that the National Council for Persons with Disabilities is undertaking placements for persons with disabilities in Government institutions and private organisations as it forwards the CVs of people with disabilities and works to build their capacity.

160 2003 Persons with Disability Act, Section 12. However, the 2007 Amendment Bill seeks to remove the word "qualified" before "employee" in Section 7.

161 Ibid, Section 15(5) and 16(2).

162 Ibid, Section 7 (1)(I)

163 Ibid, Section 7 (1)(V).

164 Ibid, Section 13.

## Research findings

People with disabilities told MDAC that getting and holding down a job is a challenge. Community stereotypes strengthen the perception that a person with a disability cannot be trusted, and this makes potential employers (and some people with disabilities themselves) doubt their potential.

People with psycho-social disabilities reported a variety of experiences in relation to employment. Some had a job and their workplace offered them some adjustments relevant to their mental health. Kariuki told us how his boss employed him to work as a consultant, not a full-time employee:

He also allowed me to determine which hours I worked and even allowed me to work from home. This really helped me to be productive and keep my job. Once he gave me these options, I was able to work more efficiently. He even spoke to the other employees about their attitude to ensure that my environment at work was good.

Yusuf, a teacher in his early 40s told MDAC that his company didn't give him any adjustments, explaining that: "When you take medication, you feel sleepy during the day. You doze a bit and sometimes you feel you are affected by these drugs and not at your best." He explained that it affected his performance as a teacher, so he discussed it with the human resources officer. He said that other colleagues have complained that he should leave his job if he cannot perform it fully. "I wish there was an alternative where I could manage myself like in business, more flexibly", he said.

Other people told MDAC that when they experienced mental health issues family members jumped in to prevent them from going to work or urged them to resign. Jacinta's father told MDAC, "the main reason why we insist that she stay at home is because she is sick and she might not be able to work".

It seemed from talking to a range of people that women, especially married women, are questioned about their ability to make choices in relation to work, a finding which may reflect wider gender issues unrelated to disability. Many people with intellectual disabilities MDAC spoke to reported being out of a job. Some interviewees reported being employed but this was mostly manual labour. Some spoke about helping out at home, taking care of animals, working in the farms, looking for sisal,<sup>165</sup> or on dumpsites. Having been excluded from school, educational attainment is a problem in securing employment for some people with disabilities. Nekesa, a woman in her late 20s told us that house help is the only job she could do since she needs no school-leaving certificate. Others experienced limitations of their ability to make employment decisions mostly from relatives who think no one will employ them because of their disability (see Juma's story) or decide the type of manual job they engage in.

Ali told MDAC that his mother found a job for him in a sheltered workshop for people with intellectual disabilities but he would have preferred to be consulted on the decision as he did not like working there. Ndungu told MDAC:

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<sup>165</sup> Sisal is an agave-type plant with large, sword-shaped leaves which yield stiff fibres that can be used to make cord and rope.

My grandma had gone to ask them for a vacancy because she had heard that they needed a watchman, so she was told to take me, which she did [...] She did not consult me, she just told me we need to go there to get a job and that would help in getting money to buy food [...] You know, she is the one who knows best, so if she tells me something, I have to obey her [...] It was okay, only the nights were very cold, and at times no matter how I covered myself, it was too, too cold [...] But now I am laid off [...] It is because they said that I have a problem with my head [...] I don't know what that means [...] I felt very bad because that is the money that I was taking home to feed my brother and my grandmother, so when I was fired, that meant that we had to struggle for food, or go borrow from my uncles.

### 4.3 Healthcare

**Question:** Does Kenyan law allow and enable people with intellectual disabilities or people with psycho-social (mental health) disabilities to make legally-binding healthcare decisions on an equal basis with others?

**Conclusion:** No. Law limits legal capacity in relation to healthcare decisions. People with psycho-social disabilities are deprived of mental health treatment choices. Relatives and carers make healthcare decisions for people with intellectual disabilities.

**CRPD Standards:** Article 25 of the CRPD sets out the right to health, and paragraph (d) focuses on consent to treatment. The CRPD Committee has said that States must adopt measures to ensure that, “all health care services provided to persons with disabilities, including all mental health care and services, is based on the free and informed consent of the individual concerned and that laws permitting involuntary treatment and confinement, including upon the authorisation of third party decision-makers such as family members or guardians, are repealed”.<sup>166</sup> States are expected to develop a wide range of community-based services and supports that respond to the needs of people with disabilities, respecting their autonomy, choices, dignity and privacy, including peer support and other alternatives to the medical model of mental health. Article 26 of the CRPD encourages States to adopt a rights-based approach to rehabilitation and ensure that such programmes promote the informed consent of persons with disabilities, respecting their autonomy, will, preferences and integrity.<sup>167</sup>

**Analysis of Kenyan Law:** The Constitution sets out the right to the highest attainable standard of health and healthcare services.<sup>168</sup> It obliges the government to ensure people with disabilities have reasonable access to healthcare services through affirmative action programmes specifically designed for minorities and marginalised groups.<sup>169</sup> The Disability Act mandates the National Council for Persons with Disabilities to monitor the provision of healthcare to people with disabilities to ensure that services are not discriminatory.<sup>170</sup>

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<sup>166</sup> CRPD Committee, Concluding Observation of the Committee: China, 15 October 2012, CRPD/C/CHN/CO/1. See Article 25.

<sup>167</sup> CRPD Committee, Concluding Observation of the Committee: China, 15 October 2012, CRPD/C/CHN/CO/1, Article 26.

<sup>168</sup> 2010 Constitution, Article 43(a).

<sup>169</sup> 2010 Constitution, Article 56.

<sup>170</sup> 2003 Persons with Disability Act, 2003, Section 20.



### *People with psycho-social (mental health) disabilities*

People suspected of having a “mental disorder” may be involuntarily admitted into a psychiatric hospital.<sup>171</sup> Police officers are allowed to detain someone they believe to have such a condition who they perceive as dangerous to themselves or others, likely to act in a manner offensive to public decency, and those not under proper care and control, or who are being cruelly treated or neglected.<sup>172</sup> These legal criteria are extremely wide.

People are detained against their will for more than the maximum 12-month period provided by the Mental Health Act for involuntary patients.<sup>173</sup> Most people who land in psychiatric hospitals through the criminal justice system are forgotten about in the hospital.<sup>174</sup> Family members frequently coordinate with psychiatric hospitals to have their relatives admitted against their will.<sup>175</sup> One research paper found that only 12% of the study’s 226 interviewees from nine hospitals had admitted themselves into the hospital, the rest being involuntary patients.<sup>176</sup> Only 15% of the respondents reported feeling safe in the hands of their carers.<sup>177</sup>

The Mental Health Act contains excessively wide inclusionary criteria to admit patients involuntarily. Application for admission is made by the person’s spouse or relative. Anyone else can (in their absence) make an application, stating why the application is not being made by the spouse or a relative, stating their connection with the person to be admitted and the circumstances in which the application is made.<sup>178</sup> This means that a neighbour or adversary can have someone involuntarily admitted to a psychiatric hospital with ease.

Patients consider themselves to be inmates. In February 2011 the TV channel CNN showed how this was the case for people in Mathari Mental Health Hospital in Nairobi.<sup>179</sup> In May 2013, media reported that forty patients escaped from the hospital by forcing their way out and those who escaped had previously complained

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171 Mental Health Act (Cap 248), Section 16.

172 Ibid, Section 16(1).

173 Independent Medico-Legal Unit, *Traumatic Experiences and Victimization among People with Mental or Psycho-social Disabilities in Kenya Public Hospitals*, Nairobi: IMLU, 15 November 2012, 19.

174 Ibid.

175 Independent Medico-Legal Unit, *Traumatic Experiences and Victimization among People with Mental or Psycho-social Disabilities in Kenya Public Hospitals*, Nairobi: IMLU, 15 November 2012, 19. The Mental Health Act, Section 14(6) provides that involuntary patients can be admitted for six months with the possibility that the director of the facility can extend it a further 6 months.

176 Independent Medico-Legal Unit and others, *Alternative Report Submitted to the Committee against Torture and Cruel, Inhuman and Degrading Treatment or Punishment*, 13 April 2013, 11.

177 Independent Medico-Legal Unit, *Traumatic Experiences and Victimization among People with Mental or Psycho-social Disabilities in Kenya Public Hospitals*, Nairobi: IMLU, 15 November 2012, 11.

178 Section 14(1) states: “Subject to this section, a person who is suffering from mental disorder and is likely to benefit by treatment in a mental hospital but is for the time being incapable of expressing himself as willing or unwilling to receive treatment, may, on a written application under this section, be received into a mental hospital as an involuntary patient for treatment.” See also Section 14(2)(a), (b) and (c).

179 This was produced with the assistance of the Kenyan Society for the Mentally Handicapped.

about ineffective medication. The police launched a manhunt for the patients.<sup>180</sup> The majority were brought back (some by relatives and others by police), demonstrating how the decision about whether or not to be in a psychiatric hospital is made by authorities and relatives often without the pretence of gaining consent from the person concerned. This is a clear example of the way in which legal capacity is restricted in practice. Involuntary patients are required to undergo psychiatric treatment without their consent.<sup>181</sup> Therefore, patients are treated against their will, based on admission decisions made by others.

In interviews conducted by MDAC, people with psycho-social disabilities reported restrictions in decision-making because they were hospitalised during mental health crises.<sup>182</sup> Most interviewees had experienced forced admission (either being taken to the hospital by relatives, restrained with rope, or by the police) and treatment. Jacinta told MDAC that she has been forcefully admitted to hospital twice. “[My family] pushes me to go to the hospital, sometimes I’m taken by force, like when I was admitted to Mathari [psychiatric] Hospital,” she said. The situation is complex, as her father explained:

When we took her to Mathari, she was not conscious of what was going on, so we had to take her by force. She was even fighting, insisting that she did not want to go. Even now sometimes she says she does not want to take her medication because she is not sick [...]. I personally thought it was important for her to be taken to hospital to receive medical attention and that is why I took her by force since it was in her best interest.

Many interviewees wanted to be more involved in making decisions, including during periods of crisis. Yusuf told us about his experience, bringing in the role of money in how one is treated by psychiatric services:

My hands were tied from behind, and so were my legs, and I was bundled in the back of a vehicle [...]. I think they saw as if it was wastage of money when I was saying I will pay the policeman [to take me to the hospital without being tied] and they thought that the money could be used in another way. I think they were money-minded [...] and they valued that more than my freedom [...]. I felt like an animal going to a slaughter and I had no choice [...]. They should not put money in front of the sickness. You know they use a lot of money for other things. They should treat me like a human being, even if money is to be used.

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180 Global Post, available at: <http://www.globalpost.com/dispatch/news/regions/africa/kenya/130513/kenya-40-mentally-ill-patients-escape-nairobi-psychiatric-hospital> (last accessed: 9 March 2014).

181 Mental Health Act, Section 14(1).

182 People interviewed by MDAC highlighted serious concerns regarding the conditions in Mathari Mental Health Hospital, and in Ward 10 in Nyeri General Hospital. Some of the concerns included: locking several people in the same room, a lack of beds, the use of buckets since there are no washrooms, infestation by lice, clothes not properly washed in Mathari. Other concerns raised included people being locked in small rooms, injections by force making them sleep for over three days at a time, patients fighting among themselves and with intern doctors since the intern doctors were not respected due to their age on Ward 10, Nyeri. People also complained of nurses insulting patients verbally and patients being beaten by nurses.

Yusuf gave MDAC several examples of how he could have been supported:

I think if you have people who care for you and people who love you, people who will tell you 'Look here, you are sick and we are taking you to the hospital' and also give you a chance to express yourself in terms of what you want, then you will cooperate. But if you are forced, that is the time things get worse [...]. You feel traumatised, you feel the decision made was not in the right direction [...]. I think the family should be aware that when they have a sick person they have a duty to ensure that he is respected as a human being. They should also help the person to make the right decision, rather than seeing the person as a bother to them [...]. It would be good if there is a group of people with an office nearby which advocates for persons with mental disability, that when you have a problem you can go to their offices and they can assist you with decision-making other than making decisions on your own and at the time when you are sick.

Wambua explained to MDAC that many doctors ignore patients and get information only from relatives. He believes that forced treatment is counterproductive:

I remember back in year 2000 when I was taken to a certain doctor in town who put me under psychotropic drugs and later took me through ECT [...]. He did not consult me, he just informed the family and they agreed [...]. I actually did not know what he was doing and I was not consulted in any way [...]. I felt stigmatised and traumatised. I also did not like the fact that they were viewing me as a helpless person [...]. I lost my memory and I don't know what happened, because, since that treatment, I suffer from things that I cannot explain, for example, memory lapses. I don't think it's my mental health problems that messed up my emotions [...] sometimes I harbour resentment about this. They continued putting me on cocktails of psychotropic drugs which finally did not work for me [...]. [Instead] they should have first gathered enough information from me in regards to the problems that I was having, because I feel that nobody has an insight of what I was going through. They should have walked together with me and this would have helped me to make better decisions [...] It's only when I addressed my issues that I was able to get much better.

Other interviewees told MDAC about the importance of learning to understand their own mental health issues. When not in a crisis, they are able to exercise more control and make autonomous decisions, including those about healthcare and support, strengthening the need for recognition of advance planning processes. However, the cost of support services was reported as commonly limiting access to services for people with disabilities. Onyango explained that he had good relationship with his first doctor because the doctor appreciated and understood him. He told MDAC that he disliked his second doctor for not listening to him.

Roshi explained to MDAC about her mental health crises. She said that she is, "normally very difficult during such times and it's important for me to be taken to the hospital for care. I think they normally do not have a choice". Her husband finds the use of force distressing, but, "she insists that she is not sick and yet all of us, from her behaviours, we certainly see she is unwell. Unfortunately, we have to use force and tie her up [...]. I know it's no good, [but] we cannot live with her like that and I must use all means possible to take her to the hospital."

Some other people reported being beaten by their relatives or parents for refusing treatment. Others told MDAC they were given the option of accepting treatment or being thrown out of their house. See Chumo's and Wambua's stories in Appendix 1.

### *People with intellectual disabilities*

For people with intellectual disabilities, access to specific healthcare or social services seems to be severely restricted. Interviewees reported not being told about healthcare procedures and not being invited to consent to treatment decisions, which were often made on their behalf by relatives or carers.

Atieno, a woman in her late 20s, told MDAC that she was sterilised without her consent sometime after 2001:

I don't think I would get children. I will tell you something, you see here [lifts up the blouse and reveals a scar on her stomach] here I was made an operation [...]. This is contraceptive, all of us had been done like this, we cannot get children [...]. Nobody asked me [if I want it]. They should have asked me, because I love children [...]. I feel bad, but what can I do now?

Atieno said that she had not told anyone about this before. She did not report it to the police, as she believes that the religious order where she lives would have thrown her out, and she would have been destitute. MDAC asked the head of this religious order in general terms about women with intellectual disabilities having relationships and becoming parents, to which the response was: "No, that will be promoting promiscuity among young women".

## **4.4 Access to justice**

**Question:** Does Kenyan law allow and enable people with intellectual disabilities and people with psychosocial (mental health) disabilities access to justice on an equal basis with others?

**Conclusion:** No. Law restricts people's legal capacity, which as a result, restricts their access to justice. Law labels people incapable of pursuing or defending litigation, including in respect of proceedings related to their legal capacity. It fails to protect people from unwanted interference by family members in blocking access to justice. It provides no support for people to access justice.

**CRPD Standards:** Article 13 of the CRPD obliges States to guarantee people with disabilities effective access to justice on an equal basis with others. This should include procedural and age-appropriate accommodations (adjustments) to enable people with disabilities to play an effective role as a victim, a witness, or defendant in any legal proceedings. These include civil and criminal cases, and it includes not just the trial stage, but also investigative and other preliminary stages. Article 13 demands that State officials working on administering justice, including police and prison staff, be given appropriate training. The CRPD Committee has interpreted procedural accommodations to mean ensuring that people with disabilities who intervene in the judicial systems should do so as subjects of rights and not objects of protection.<sup>183</sup>

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183 CRPD Committee, Concluding Observation of the Committee: China, 15 October 2012, CRPD/C/CHN/CO/1.

**Analysis of Kenyan Law:** The Constitution guarantees the right of everyone to access justice,<sup>184</sup> setting out that any fees should be reasonable and not impede justice. Justice should not be delayed and should be rendered according to the rule of law.<sup>185</sup> The right to a fair trial and public hearing is also guaranteed.<sup>186</sup> Everyone has the right to institute court proceedings in case of a denial, violation, infringement or threat to a right as set out in the Bill of Rights.<sup>187</sup> Court proceedings can be instituted by a person acting as a member of, or in the interest of a group or class of persons.<sup>188</sup> In addition, all State organs and public officials must address the needs of “vulnerable groups” which includes people with disabilities.<sup>189</sup> The Attorney General in consultation with the National Council for Persons with Disabilities and Kenyan Law Society must issue regulations on free legal services for people with disabilities in relation to specific matters.<sup>190</sup> No such regulations have been issued. There is an unpublished draft Legal Aid Bill of 2010 which covers people with disabilities under “vulnerable group” and, the organisation Users and Survivors of Psychiatry Kenya has been engaging the drafting committee to ensure that the right to legal capacity is upheld.<sup>191</sup>

The Civil Procedure Act is the law which prescribes in detail the rules of civil litigation. It treats people considered to be of “unsound mind” as if they were children.<sup>192</sup> The accompanying Civil Procedure Rules applies to people who are found by a court to be incapable of protecting their interests when suing or being sued by reason of “unsound mind and mental infirmity”.<sup>193</sup> No guidance is given as to how a court is to establish this. If the court declares that someone in a proceeding is of “unsound mind”, it will appoint a “next friend” when the person is suing and a “guardian ad litem” when the person is the defendant in civil proceedings.<sup>194</sup> These people should be (unsurprisingly) people who are not of “unsound mind”, and they should have no adverse interest. They should be appointed by a competent authority and themselves consent to the appointment. In *Republic v Chairperson*

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184 2010 Constitution, Article 48.

185 2010 Constitution, Article 159.

186 2010 Constitution, Article 50 and 50(m).

187 2010 Constitution, Article 22(1) and 22(3)(b).

188 2010 Constitution, Article 22(1).

189 2010 Constitution, Article 21(3).

190 2003 Persons with Disability Act, Section 38(1). Other ‘specific matters’ include violation of human rights, deprivation of property and cases of capital punishment.

191 Users and Survivors of Psychiatry Kenya, Position Paper No.2: Comments on the Persons with Disabilities and the Legal Aid Bill, 2010 (Nairobi: USPK, 2012)

192 Revised 2009 Civil Procedure Act of 1924 (Cap 21) of the Laws of Kenya.

193 Ibid., Order 31 Rule 15.

194 *Credit Finance Corporation Ltd v Mahendi Abdulla Karnali*, Civil Case No 1736 of 1958. The Court of Appeal held that without a qualified guardian as provided by Order 31 Rule 3 of the Civil Procedure Rule, any decree obtained in the suit is a nullity. In case person of unsound mind institutes a suit without a next friend, it may be struck out by the Court and it requires the next friend to sign a written authority.

*Kilibwoni Disputes Tribunal & two others*,<sup>195</sup> the High Court of Eldoret stated clearly that "... it is only a Court of Law which can adjudge a person to be of unsound mind for purposes of suing or being sued."

The Court said that "if a person whether a relative or not wishes to manage or protect the estate of any person suffering from mental disorder, he must obtain the leave of the Court first". In this case, a son instituted an application as "the guardian and next friend of his adult father" alleging that the father suffers from "mental illness and psychosis" and therefore lacks legal and "mental capacity" to take proper care of himself. The son filed medical reports as evidence. The Court held that: 1) the son did not obtain leave of the Court to have legal powers; 2) no Court has adjudged the father to be of unsound mind; and 3) the doctor's letter is not premised on any law and cannot invalidate the father's voluntary acts and transactions.

Where no-one can be found to be a *guardian ad litem*, a court officer may be appointed.<sup>196</sup> Once appointed, applications or orders made in the case will be in the name of the next friend or *guardian ad litem* until (in the case of a child) the child becomes an adult.<sup>197</sup> In the case of a person of "unsound mind" the law is silent.

This system does not comply with Article 12 of the CRPD which requires States to ensure that systems provide supports for people with disabilities to exercise their legal capacity – in this case to sue and be sued. The law needs to change so that the question is not "can the person participate alone without any help in court proceedings?" but "What supports need to be put in place for the person to participate in court proceedings?" The person in question should be enabled to freely choose the support person, and a support person should not take litigation decisions like the next friend or *guardian ad litem* in the current system.

No statistics exist of the number of children or the number of people of "unsound mind" who have had a next friend or *guardian ad litem* appointed. Reported cases do, however, exist. An example is *Kariuki v. Mwangi*,<sup>198</sup> where the applicant applied to the High Court to be appointed *guardian ad litem* of Kariuki, who is said to have become "insane" and who opposed the application on the basis that a transaction in dispute was concluded long before the alleged "mental incapacity". The judge allowed the application.

### *Research findings*

MDAC's interviews show that people either go to the police in urban areas or to the chief and village elders in rural areas. In these domains they face challenges in seeking justice. These range from relatives preventing a matter from being reported to the police, the police not pursuing allegations and the unaffordable financial costs associated with legal proceedings.

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195 From the case database of the Kenya National Council for Law Reporting, High Court of Eldoret, *Republic v Chairperson Kilibwoni Disputes Tribunal & 2 others*, Misc. Civ Application 74 of 2009, 21 May 2009, available at <http://www.kenyalaw.org/caselaw/cases/view/55534/> (last accessed: 9 March 2014).

196 Republic of Kenya, Civil Procedure Rules, Order 31 Rule 15.

197 *Ibid.*, Rule 12(1) and (2).

198 High Court at Nairobi, *Wambui Kariuki v. Kamau Mwangi*, Civil Case No 526 of 1993, 29 May 2003. Found from the website of Kenya National Council for Law reporting. <http://www.kenyalaw.org/CaseSearch/> (last accessed: 9 March 2014).

People with psycho-social disabilities gave MDAC numerous examples of barriers to exercising their legal rights. Jacinta told MDAC how she withdrew a case she filed with the police against a neighbour who had beaten her in order to comply with her father's demand that the case be withdrawn because the perpetrator was a neighbour and close relative. Jacinta's father went further and told police to be careful in the way they deal with Jacinta because she is unwell, which implies a link between Jacinta's police complaint with her psycho-social disability.

Chumo had contracted HIV and told MDAC how this probably happened because she was frequently raped on the streets when she was homeless:

Some men would come and agree with the watchman that they would sleep with me during the night, though I have asked God to forgive them. I was being forced by the watchmen [...] They were saying it was a way of welcoming me to the town [...] [If I would refuse them] I would be battered by them and also the watchmen.

Chumo reported this to the police and claims she was not taken seriously because of her psycho-social disability.

I was very sick at that particular time; I would go to the station screaming instead of talking to them in a soft voice so they would say that I am mad. They would just calm me down and tell me that they will warn those particular persons [...] some of the policemen would give me some money and tell me to forgive the perpetrators since I am a Christian and I go to church. I would come back, start crying and screaming within the town. People would think that I am pretending and some of them would even mock me, telling me to remove my clothes[...] Most of the men [who raped me] were drug addicts and if you take that kind of action against them they can even beat you up. I would be very scared of what they would do to me.

People with intellectual disabilities may also need a variety of supports to access justice. Out of the five women with intellectual disabilities MDAC interviewed, Atieno, Mumbi and Nekesa experienced sexual abuse. Eight of the 10 people with intellectual disabilities MDAC interviewed had suffered some form of domestic or community violence. Apart from Mumbi who was satisfied that the person who raped her was sent to jail, Atieno was unable to access justice after being a victim of sexual violence and Ndungu serves a prison sentence he considers to be unfair particularly as he was unable to access legal advice.

Some people are unaware of their right to pursue matters through the justice system because of rumours and disinformation in their communities. A man with a psycho-social disability who participated in a focus group discussion told MDAC how he thinks that he can only access the court through a third party because of his disability even though he has not been legally adjudged by a court to be of "unsound mind". He sees this as direct denial of access to justice.

## 4.5 Marriage and divorce

**Question:** Does Kenyan law allow and enable people with intellectual disabilities or people with psycho-social (mental health) disabilities to get married and divorced on an equal basis with others?

**Conclusion:** No. Kenyan law does not comply with the CRPD. Legislation limits the right to marry of people who have been labelled of “unsound mind” and those who have been found “insane”. In practice, families restrict the marriage rights of their relative with disability. Some people with disabilities marry if they can find spouses that accept or are unaware of their disability, while some marriages break up because of a spouse’s disability.

**CRPD Standards:** Article 12 of the CRPD sets out the right to legal capacity in all areas of life. Marriage is recognised as an ‘area of life’, and this is confirmed in Article 23 of the CRPD which recognises the right of persons with disabilities of marriageable age to marry and found a family base on free and full consent.

**Analysis of Kenyan Law:** The Constitution recognises the family as the natural and fundamental unit of society,<sup>199</sup> and leaves it to various laws to regulate marriage itself.<sup>200</sup> Article 45(1) of the Constitution gives every adult the right to marry a person of the opposite sex, based on free consent with equal rights at the time of marriage, during and at the dissolution of marriage.<sup>201</sup> Lesbian, gay, bisexual and transgender people with disabilities in Kenya are discriminated against in this regard, not because of their disability but because of their sexuality. Disability-based discrimination is as rife in the area of marriage as it is other areas of life. In *Wairimu v. Karira*,<sup>202</sup> the Endoret High Court held that marriage is a civil contract that requires “mental capacity” and consent from the parties for it to be valid. The Court said it is commonly presumed that adults of marriageable age are “sane” and capable of making a valid marriage contract until their incapacity is alleged and proved.

A finding of “unsound mind” or “recurrent fits of insanity or epilepsy” is enough to render a marriage null and void.<sup>203</sup> The unhappy spouse must prove that he or she was unaware of the unsoundness of the proposed spouse when the marriage took place, and these proceedings should be initiated within one year from the marriage.<sup>204</sup>

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199 2010 Constitution, Article 45(1)

200 These primarily include the Revised 2008 Marriage Act of 1984 (Cap 150 of the Laws of Kenya). Along with this there are customary laws regulating family life within the various ethnic/cultural groups. These include the Revised 2008 Hindu Marriage and Divorce Act of 1984 (Cap 157 of the Laws of Kenya), based on Hindu Law and governing adherents of the Hindu faith; the Revised 2008 Mohammedan Marriage, Divorce and Succession Act of 1984 (Cap 156 of the Laws Kenya), based on Islamic law and governing adherents of the Islamic faith; the Revised 2008 African Christian Marriage and Divorce Act of 1977 (Cap 151 of the Laws of Kenya), governing people who choose to marry under the formal law regardless of their cultural or religious background; and the Revised 2008 Matrimonial Causes Act of 1941 (Cap 152 of the Laws of Kenya) which consolidates the law relating to matrimonial causes.

201 2010 Constitution, Article 45(2) and 45(3).

202 High Court at Endoret, *Wairimu v. Karira*, Civil Appeal No 37 of 2002 (Appeal of Divorce Case No 16 of 2001 delivered on 19 April 2002).

203 Matrimonial Causes Act, Section 14(1)(f) (Cap 152, revised 2008) 1941.

204 Ibid, Sections 14 (1)(i) and (ii).



In *Wairimu v. Karira*, the Endoret High Court also held that the one year limitation period to initiate proceedings can be extended by the Court.

Divorce can be granted on the basis that one of the spouses is of “unsound mind” and has been receiving treatment for at least five years immediately preceding the petition.<sup>205</sup> In *NKG v. ASM*,<sup>206</sup> Mombasa High Court ruled that the five year requirement is irrelevant when a spouse fails to disclose their mental condition prior to the marriage, and that this amounts to psychological cruelty to the other spouse. Also, detainees who are considered to be “criminal lunatics” in institutions are deemed to be under treatment.<sup>207</sup> A court can dismiss a request for divorce if the spouse asking for a divorce is guilty of wilful neglect or misconduct that has contributed to the other spouse having an “unsound mind”.<sup>208</sup>

Under Kenyan customary law, the mere presence of a psycho-social (mental health) disability or an intellectual disability do not restrict the right to marry in themselves and are not grounds for divorce. However, very high levels of stigma around madness and disability mean that it is difficult for some people with disabilities who are ‘out’ about their disability to get married.<sup>209</sup> Many families prevent their relatives with disabilities from getting married, and it is also common that restrictions can be placed on non-disabled relatives from marrying those who have disabilities.

### *Research findings*

In MDAC’s focus group discussions participants shared their experiences of love and marriage. Five out of the ten people with psycho-social disabilities whom MDAC interviewed were married. They told MDAC about how some of their spouses provided care and emotional support while others did not. Only one person out of ten interviewees with an intellectual disability had been married, and her husband had died. A 29-year-old woman with a psycho-social disability reported that a man wanted to marry her and he knows about her disability but her parents stopped the relationship because they feared that she could harm him. A 22-year-old woman with an intellectual disability told MDAC that she would like to get married and have a family like other people but her relatives told her that she cannot take vows at the church or at the District Commissioner’s Office. A parent of a boy with an intellectual disability told MDAC about how her son loved a girl with an intellectual disability and wanted to marry her, but the girl’s parents were reluctant to allow the marriage. A 25-year-old woman with a psycho-social disability explained how her husband, on learning about her mental health condition, took their children to his village home. She told MDAC that there is nothing she can do because the husband has her medical documents which he can use to win a case if she were to initiate a parental rights case at court.

205 Ibid, Section 8(1)(d).

206 High Court at Mombassa, *NKG v. ASM*, Divorce Cause 53 of 2008, judgment 27 May 2009, available at: <http://www.kenyalaw.org/caselaw/cases/view/58097/> (last accessed: 9 March 2014).

207 Matrimonial Causes Act, Section 8(2).

208 Ibid, Section 10(iv).

209 Kenya initial report to the CRPD Committee, 36.

In MDAC's interviews, Mutua, a man with an intellectual disability, explained how his wife left with their two children:

She left me because some women of the village told her that am retarded [...] You see, sometimes we would quarrel in the house and then she would blurt it out she would say no wonder I am a foolish man, and that she has confirmed what she was told by a certain woman, that her husband is retarded [...] I would just keep quiet because at times if I respond to her she would hit me with whatever she is holding[...] [When she would hit me] I would not do a thing, just keep to myself[...] I would feel very bad because even one time she injured me so badly with a knife. I had a deep cut here (shows the mark on his arm)[...].

#### 4.6 Right to property

**Question:** Does Kenyan law allow and enable people with intellectual disabilities or people with psycho-social (mental health) disabilities to make legally-binding decisions about their property and assets on an equal basis with others?

**Conclusion:** No. Kenyan law does not comply with the CRPD, as it restricts people of "unsound mind" from using their own money and property.

**CRPD Standards:** Article 12(5) of the CRPD obliges States to ensure that people with disabilities have an equal right to own or inherit property and that those who do own property are not arbitrarily deprived of it.

**Analysis of Kenyan Law:** The Constitution provides that every Kenyan citizen can acquire and own property in any part of Kenya.<sup>210</sup> Laws must not arbitrarily deprive a person of their property, or their interest in or rights over a property, or limit in any way the enjoyment of any related rights on any of the grounds where the Constitution prohibits discrimination, which include disability.<sup>211</sup>

The Law of Succession Act adopts the position that people of "unsound mind" lack the capacity to make wills.<sup>212</sup> A person making a will is of "sound mind" unless he or she is in a state of mind arising from mental or physical illness, drunkenness or from any other cause that makes the person unaware of what they are doing.<sup>213</sup>

The High Court can deal with the property of people with psycho-social (mental health) disabilities.<sup>214</sup> When Courts manage property of people with disabilities in a way that goes contrary to their will and preference, the

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210 2010 Constitution, Articles 40(1)(a) and (b).

211 2010 Constitution, Article 40(2). Grounds on which discrimination is prohibited under Article 27(4) include race, sex, pregnancy, marital status, health status, ethnic or social origin, colour, age, disability, religion, conscience, belief, culture, dress, language or birth.

212 Revised 2008 Succession Act of 1984, Chapter 160, of the Laws of Kenya.

213 Ibid, Sections 5(1) and (3).

214 Mental Health Act, (Cap 248), Section 29.

effect of this is to deprive them of their right to own and enjoy their property. It is more difficult for people labelled as being of “unsound mind” to challenge violations of their property rights, since they are not allowed to initiate complaints themselves; they must go through someone else to complain for them.

Financial gain is the primary reason why people file petitions to become the estate manager or guardian of people with disabilities. A person with a psycho-social disability told MDAC at a focus group discussion how his wife went to court and claimed that he would sell their property because he has a mental health issue. The Court ordered him to be examined at the Mathari psychiatric hospital, and as a result transferred his assets to his wife. She then sold their house and two plots of land and disappeared.

A parent of an adult with an intellectual disability told MDAC of cases where guardians steal the property of the person with a disability. He worried about the future of his child when he dies. Another person told MDAC that once a person is labelled with a psycho-social disability their property is lost automatically. Others told us about how families do not consider people with psycho-social or intellectual disabilities as being capable of inheriting property. And if by chance a person does inherit assets, the person is seen as incapable of managing them and the property is therefore highly likely to be placed under the custody of another relative.

## 4.7 Land rights

**Question:** Does Kenyan law allow and enable people with intellectual disabilities or people with psycho-social (mental health) disabilities to make legally-binding decisions about their land on an equal basis with others?

**Conclusion:** No. Kenya does not comply with the CRPD in allowing people with disabilities access to their land and lacks safeguards to ensure access to trust lands held under customary law.

**CRPD Standard:** Article 12(5) provides for the right of people with disabilities to own and inherit property, and this includes land.

**Analysis of Kenyan Law:** Management of land in Kenya is so important that the Constitution lays down principles for its management. Equitable access to land, security of land rights and elimination of gender discrimination in law, custom and land practices are all covered.<sup>215</sup> Land is an important means of livelihood for many people in Kenya. Three quarters of the country’s population lives in rural areas and rely on agriculture for livelihood, and among the poorest in rural areas are persons with disabilities.<sup>216</sup> Land law reforms took place

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<sup>215</sup> 2010 Constitution, Article 60.

<sup>216</sup> International Fund for Agricultural Development, “Enabling poor people to overcome poverty in Kenya” July 2011, 1.

in 2012,<sup>217</sup> before which the rights and obligations of land owners were regulated in various laws.<sup>218</sup> This was problematic for people with psycho-social disabilities and people with intellectual disabilities because the eligibility to own land was subject to contract law,<sup>219</sup> which considered the “insane” or “people of unsound mind” as lacking the capacity to enter into valid and enforceable contracts (except for contracts entered into during lucid moments and contracts for the supply of necessities needed for survival such as food, shelter and clothing).<sup>220</sup> Some of the recently-repealed land laws provided that where a person disposes of land in the form of a gift while under disability it may be repudiated on cessation of disability,<sup>221</sup> and a guardian may make any application, do any act or be a party to any proceedings on behalf of people of “unsound mind” in any dealings in land.<sup>222</sup>

The Land Registration Act 2012 did not make substantial changes. A person “of unsound mind” is treated as a child.<sup>223</sup> Both are prohibited from dealing or having an interest in land.<sup>224</sup> Guardians can act on behalf of a person deprived of their legal capacity.<sup>225</sup> A person of “unsound mind” or a minor, who is registered as an owner of land or a lease, which he/she acquired as a gift and is still in possession of, has a period of six months to reject the gift after he/she ceases to be of “unsound mind” or become an adult.<sup>226</sup> However, the person’s rejection is only valid when the land or lease is transferred to the donor, who is obliged to accept it and when the transfer has been registered.<sup>227</sup>

Under customary law, trust land is land that was held communally (community land) which is now governed by the Trust Land Act.<sup>228</sup> This vests trust lands in the county council where the land is situated and requires the

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217 2010 Constitution of Kenya (Article 60-68); the 2012 Land Act (No 6) which repeals the Land Acquisition Act (Cap 295); and the Land Registration Act of 2012 which repeals the 1882 Indian Transfer of Property Act; the Government Lands Act (Cap 280); Registration of Titles Act (Cap 281); Land Titles Act (Chapter 281) and the Registered Land Act (Cap 300).

218 These include Government Lands Act (Cap 290) of the Laws of Kenya; Trust Land Act (Cap 288) of the Laws of Kenya; Survey Act (Cap 299) of the Laws of Kenya; Agricultural Act (Cap 318) of the Laws of Kenya; Land Control Act (Cap 302) of the Laws of Kenya; Land Planning Act (Cap 303) of the Laws of Kenya; Land Consolidation Act (Cap 283) of the Laws of Kenya; Land Adjudication Act, (Cap 284) of the Laws of Kenya and Land Acquisition Act (Cap 295) of the laws of Kenya.

219 Revised 2009 Law of Contract Act of 2002 (Cap 23), of the laws of Kenya that apply English common law of contract to Kenya with certain modifications.

220 Revised 2012 Sale of Goods Act of 2003 (Cap 31) of the laws of Kenya, Section 4(1).

221 1882 Indian Transfer of Property Act, Section 127, which applies in Kenya as a statute of general application and the Registered Land Act, Section 115.

222 Revised 2010 Registered Land Act of 1989 (Cap 300), Section 114.

223 2012 Land Registration Act (No. 3 of 2012), Section 2. It defines “legal incapacity” as “a person of unsound mind or a person under the age of eighteen years”.

224 Ibid, Section 47(2).

225 Ibid, Section 48(3).

226 Ibid, Section 49.

227 Ibid.

228 Trust Land Act (Cap 288), of the laws of Kenya.

council to manage the land in a way that complies with the rights and interest under customary law of the people connected with that land. These rights are vested in any tribe, group or individual, subject to the right of the government to alienate the land for public purposes. Courts apply customary law in civil matters including land held under customary tenure, intestate succession and administration of estates,<sup>229</sup> and Magistrate Courts have jurisdiction over questions on land tenure under customary law.<sup>230</sup> Lands held under customary tenure may be converted into individual tenure through processes set out under the Land Consolidation Act,<sup>231</sup> and the Land Adjudication Act.<sup>232</sup>

These processes may result in the deprivation of people with disabilities (especially people with psycho-social or intellectual disabilities) of their right to land. The responsibility to safeguard their claim and interest in ancestral land rest with families and relatives because laws fail to protect their land rights, for which they may require access to support that respects their choices and preferences during litigation. The repealed Registered Land Act made it difficult to secure a rectification once first registration of land is procured,<sup>233</sup> and first registration may not be defeated even if it was obtained, made or omitted by fraud or mistake.<sup>234</sup> This fails to protect people who can easily be deprived of their land because of lack of support by members of society in a more advantageous position. In *Kasuve v Mwaani Investments Limited & others*,<sup>235</sup> the Court of Appeal at Nairobi held that a person may apply to the High Court for an order that he/she be registered as the proprietor of land claim by adverse possession. The claimant must prove open and exclusive possession of the land and as of right without interference for 12 years after dispossessing the owner or after the discontinuation of possession by his own volition.

Therefore there is a great need for care to prevent shrewd individuals from exploiting this legal provision by seeking to stay on the land of people with psycho-social disabilities and people with intellectual disabilities until the point that they are able to submit a claim for title by way of adverse possession. These provisions should be brought in line with Article 12 of CRPD that sets out the State obligation to ensure that people with disabilities have and enjoy the legal capacity to own, inherit and dispose of land.

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229 Judicature Act (Cap 8), of the Laws of Kenya, Section 3(2) and Magistrate Courts Act (Cap 10), of the Laws of Kenya, Sections 2, 5(2) and 9(a).

230 Magistrates Court Acts, Section 5(2) and 9(a).

231 Land Consolidation Act, Chapter 283 of the Laws of Kenya. The main purpose of the Act is to consolidate fragments or pieces of land into economically viable units. It requires significant co-operation of land owners who after adjudication of titles surrender old plots which are taken up conveniently by another in exchange for a single plot with a similar aggregate acreage.

232 Land Adjudication Act, (Cap 284) of the Laws of Kenya.

233 Registered Land Act, Section 28.

234 Ibid Section 143(1).

235 Civil Appeal No. 35 of 2002.

### *Research findings*

Among the people with disabilities MDAC interviewed, only Githinji mentioned that he owns land which he inherited from his father before he developed a psycho-social disability.

A participant of a focus group told MDAC that she saw guardianship as something that allows people to grab the land of people with disabilities. A female carer who participated in a focus group discussion explained how her brother developed a psycho-social disability when he was already married with five children and how this led to another relative enticing him to sell the land. The relative would give her brother food, clothes and money for alcohol and one day chased her brother and the five children from their land, saying that the relative had bought the land.<sup>236</sup> When elders were called to resolve the matter, they ruled that her brother had sold the land and that the decision could not be reversed. Her brother lacked money to pay a lawyer, so could not challenge the sale in court.

Another female carer who participated in a focus group explained that her father had divided land among the siblings including her brother with a psycho-social disability whose portion of land was placed in the custody of another sibling. Although the sibling promised to look after her brother with disability, the land was later sold. Since their father had died there was no way to challenge the sale of the land.

A male participant at a focus group discussion told MDAC how his mother ran away when his brother was born with Down syndrome. His father remarried and before he died, the father ordered that his brother with Down syndrome should never be made to suffer and the family should take care of the piece of land he allocated for his brother with Down syndrome. The step-mother later chased his brother with Down syndrome away from the house and sold the piece of land allocated to him, a decision which was not able to be challenged.

In a focus group discussion with people with psycho-social disabilities a woman explained that she runs a small business in a rural suburb and wanted to buy a piece of land with some of the money she saved, but was told by relatives that she cannot buy it in her name. The evidence from MDAC's focus groups reflects findings in another study in Kenya which found that people with disabilities are deprived of their land solely because of their disability.<sup>237</sup>

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236 There is some evidence to suggest that this is a issue in other countries in the region too. MDAC has heard similar stories from three people with psycho-social (mental health) disabilities in Uganda.

237 Equal Rights Trust, Report on Discrimination in Kenya, 136.

## 5. Indicator 4: What kinds of supports are available for people with disabilities who may need them in exercising their legal capacity?

**Conclusion:** Kenya does not comply with the CRPD as it fails to guarantee access to supports for people to exercise their legal capacity.

**CRPD Standards:** Article 12(3) of CRPD requires States to ensure that law provides access to support to people with disabilities who may need it to exercise their legal capacity. Support is not something which can be forced on the person. There should be safeguards to prevent abuse in the support relationship to ensure that the will and preferences of the person with a disability are respected.

As discussed above, supported decision-making is a cluster of different methods which give primacy to the person's will and preferences. It may include a specific support agreement or a representative agreement where the person with a disability chooses an individual or group (a friend or a relative) to support him/her in forging their way through life. The support can come from a community-based organisation or take the form of advance planning with safeguards that protect the individual's rights to autonomy and right to be free from ill-treatment.

States should also create regulatory frameworks to address situations where, after all efforts are made, an individual's wills or preferences cannot be ascertained. In these rare cases of last resort, there should be an option for facilitated decision-making (appointing an outside decision-maker) when supports have been exhausted (i.e. after creative communication techniques, building relationships, accessible information). Facilitated decision-making is only to be used where there is no information which can be used to determine the person's likely decision, will or preferences, or where these cannot be unambiguously ascertained and where the person has no previously-expressed will (e.g. evidenced in a planning document). Even in such circumstances, the process should be based on protection of the rights, will and preferences of the person concerned, and should only be used for the minimum period necessary and with the sole purpose of augmenting their ability to make decisions through supported decision-making. In this way a person's legal capacity is preserved to the maximum extent possible.

The CRPD sets out the State's obligation to take appropriate measures to provide access to such supports for people with disabilities. Article 12(4) of the CRPD obliges States to ensure that there are safeguards to prevent abuse and to guarantee that supports respect the rights, will and preferences of people with disabilities. It also mandates that support mechanisms are free from conflict of interest and undue influence, are proportional and that they are tailored to the person's individual circumstances. They should be in force for the shortest time possible and be subject to regular review by a competent, independent and impartial authority or judicial body. In addition Article 16 of the CRPD mandates States protect and prevent people with disabilities from abuse, violence and exploitation and ensure that all instances of violence, abuse and exploitation are investigated and when necessary prosecuted.

**Analysis of Kenyan Law and research findings:** Only the Sexual Offences Act provides an example of access to support, as it allows a court to communicate with victims of sexual violence who have a disability through an intermediary.<sup>238</sup> In such cases, people who have an “intellectual, psychological or physical impairment” can apply to the court to be a “vulnerable witness”.<sup>239</sup> The intermediary helps the person understand questions, informs the court when the witness is tired or stressed and can ask the court for a break.<sup>240</sup> However, it is unclear whether the person with a disability can choose the intermediary, in conformity with the CRPD.

Supports required by Article 12 of the CRPD are much wider than court proceedings dealing with allegations of sexual crimes. The Constitution fails to provide for access to support to people with disabilities in exercising their legal capacity even though all people are recognised as persons before the law. The Persons with Disabilities Act 2003 provides for the rights and rehabilitation of persons with disabilities, equal opportunities, the principle of non-discrimination and so on,<sup>241</sup> but is silent on the exercise of legal capacity and access to supports. There is a need for one law to set out regulations for supported decision-making.

Among the people MDAC interviewed, two women with intellectual disabilities said they had been raped several times. Mumbi benefited from the kind of support envisaged by the Sexual Offence Act: she informed her mother about the rape, and the mother reported it to the police. When the suspect was arrested, Mumbi was invited to identify him. Some time later, she was raped again by a man who confessed to the crime and was sentenced to imprisonment.

Atieno is another woman who told MDAC she had been raped by the watchman in the parish where she lived. She reported it to the nun in charge, and no action was taken, to keep the crime quiet.

Lack of effective remedies for rape cases seems to be a systemic problem in Kenya. In a now famous case,<sup>242</sup> 11 children went to court to challenge a police failure to investigate and prosecute alleged rape cases. The High Court held that the government was responsible for failing to ensure an effective investigation and therefore failing to bring a prosecution. In this judgment, the High Court found that such failures create a climate of impunity, causing psychological harm to the children. The court went further by finding that this amounted to a violation of

238 2006 Sexual Offence Act, Section 31: intermediaries may include a parent, relative, psychologist, guardian, counselor, social worker, etc.

239 Ibid, Section 31(2)(b). Section 2 defines ‘person with mental disability’ as “a person affected by any mental disability irrespective of its cause, whether temporary or permanent, and for purposes of this Act includes a person affected by such mental disability to the extent that he or she, at the time of the alleged commission of the offence in question, was – (a) unable to appreciate the nature and reasonably foreseeable consequences of any act described under this Act; (b) able to appreciate the nature and reasonably foreseeable consequences of such an act but unable to act in accordance with that appreciation; (c) unable to resist the commission of any such act; or (d) unable to communicate his or her unwillingness to participate in any such act.”

240 Ibid, Section 31(7).

241 Persons with Disability Act 2003, Preamble, and Section 15 of the Act prohibits discrimination and provides for reasonable accommodation in the area of employment.

242 High Court of Kenya, *C.K. (A Child) through Ripples International as her guardians and next friend) and 11 others v Commissioner of Police/Inspector General of National Police Service and 3 others*, petition 8 of 2012, 27 May 2013.



the rights of the children concerned, including their right to special protection as members of a vulnerable group. As such, the failure of authorities to act in this case breached the children's rights to equal protection and benefit of the law, to non-discrimination, and to dignity and security of person.

Some people with psycho-social disabilities and their family members told MDAC about positive examples of being supported to make decisions. Yusuf's wife explained how she supports her husband to make family decisions:

He likes to be in the company of other people so that he can cool his mind during daytime when he is not working. For example, when we are with him, we keep on communicating and even discussing what we can do as a family. I know that through talking he becomes more settled and we are able to come up with ideas together [...]. He is normally very troubled when we are having family issues, for example, on finances. During that particular time I like sitting down with him so that I can understand what he is going through and support him accordingly. If we don't look for solutions he is likely to be affected more and even get sick[...] When he makes family decisions I normally support him as much as possible and even when the decision is not very good, I try to explain to him on the need to adjust or change a couple of things in that particular decision.

Githinji's wife explained how she helps her husband when he forgets things: "We have employed someone to assist him as he does his work around the compound, I think he would really suffer if he did not have people by him throughout the day to help him in the course of the day, especially because he is very forgetful. It would be very difficult for him to do anything meaningful in his life."

Majani is a member of a local women's group and said that she felt supported by them: "They know about my condition and they take me just like any other person. They normally even give me the opportunity to express my views. They listen and take my opinions seriously."

Chumo's friend explained how she is supported to prevent being hospitalised and to ensure that doctors listen to her:

When she starts becoming unstable, she becomes abusive like, when you tell her she is smart she will sometimes abuse you for the whole day, but she is not violent in any way. We normally talk to her and advise her to be calm when she is spoken to by people during such a period [...]. She is very active when it comes to going to the hospital. I have known her for over 10 years and in that period she has never been admitted, and I was even requesting the doctor to give Chumo a card which contains her specific details so that she can be able to produce it to all the doctors, so as to avoid any misunderstanding.

On the whole, support seems more likely to be given if the person with a psycho-social disability is a man and if he is living with either his wife or children or with his mother.

For people with intellectual disabilities, Mutua explained how he seeks support from his friend and nephew: “At times, I feel what I am doing is not what I am supposed to do, I ask them and they tell me what to do. It is not so much encouraging, but if it is a good opinion or suggestion, I just say it is okay.”

Ali’s brother explained how Ali was supported to take the bus to the workshop rather than walking to work: “We could put exact money for bus fare in each of the two pockets. Then he would give the money to the bus conductor while on his way to the workshop. Then on his way back he could give out the money from his other pocket.”

## Appendix 1 – Life stories

In this part, we set out a distilled version of each of the interviews we held with people with disabilities. We spoke with 10 people with intellectual disabilities and 10 people with psycho-social (mental health) disabilities. In their stories, we also incorporate testimonies from the relevant family member. To preserve the anonymity of people we spoke to, we have assigned each interviewee a Kenyan name different from their own, and removed information that may identify interviewees. The life stories contain information about education, poverty, violence, abuse, exploitation, participation in community activities and access to justice. Life stories of people with intellectual disabilities are presented first, followed by the life stories of people with psycho-social disabilities.

### The lives of people with intellectual disabilities

#### Kiprop – A man in his late forties from Nairobi

Kiprop and his sister both live at a compound they inherited from their parents. He noted how he doesn't have any friends and his sister is the only person with whom he interacts. They have two other siblings who, according to Kiprop's sister, have little interest in Kiprop and his wellbeing. As Kiprop's sister explains – "I'm his blood sister, who else can take care of him? We cannot afford to hire a carer." She finds that a lot of their choices are limited by poverty.

As a child, Kiprop attended a nursery school but did not complete it. As Kiprop explains – "My mother was told by the teachers that I need to go to special school, for people like me, but she did not have money to take me there."

Kiprop has never worked and just helps at home. He spends his days looking after chickens his sister bought for him to look after and finding ways to feed them.

*Kiprop:* You see all these food courts? I go to each one of them and tell them to keep for me any leftover food. Then I go collecting and I bring it home to my chicken, sometimes it's a lot and other times it is little. Some of the [food court owners] are good to me, but the others are so harsh to me, they don't want to see me and I feel bad.

Kiprop's sister explained that he used to work as a handyman, "like fixing the fence, nothing formal, but he doesn't do it anymore. He lost interest and just started staying at home. He also started keeping to himself[...] When he's not looking for food [for chickens] he is just in the compound, walking around and resting."

Kiprop went on to explain that his sister keeps the money from the sale of the chickens. His sister expressed a different opinion – "Now that he is not employed he does not have money as such. When he sells chicken, he gets money though he gives it to me. I let him keep some[...] Once in a while, he goes to the shop to buy bread and he even knows how much it costs."

He is not involved in community life, yet would love to “go out, meet other people”. Kiprop’s sister, however, is concerned for his safety – “You know such a thing would be really dangerous because he can just walk and not be able to come back home. So I prefer when he is just around home, then that is okay with him and with me also.” She explained that this fear for his safety and lack of inclusion in the community stems also from community attitudes towards people with intellectual disabilities – “Some of these attitudes, we have very little control, because the community views him differently and fails to integrate him in mainstream activities so, yes, I can say that his right to be part of community is denied.”

Kiprop also mentioned how he was once “beaten and locked in a room, all alone[...] They didn’t want me to go anywhere”, but did not want to share with the interviewer further details as to who did this and when.

When discussing community attitudes to people with intellectual disabilities, Kiprop’s sister noted: “There is this time I had to lock him in his house because he was wandering and at some point he had been beaten by villagers. He was so angry but not to an extent of suing me. But he surely felt confined.” Kiprop’s sister noted that the beating was not reported to the police, but “next time it happens, I will [report it]”.

She was not sure whether making decisions for Kiprop is the best course of action she takes – “Well, yes and no. Yes because he can make some decisions and no because I am his carer and I think I know what is best for him[...] To say the truth, I admit he should make his own decisions but look, he is not in a position to and that is why I make them for him.” Although he appreciates her support, Kiprop noted that he would like to have more opportunities to make decisions in his life.

*Interviewer:* Do you think your sister should ask you before making decisions?

*Kiprop:* Yes

*Interviewer:* What I’m asking is, do you feel good or bad when someone makes decisions for you?

*Kiprop:* (Long silence) Bad.

## **Ali, a man in his early 20s from a provincial town**

Ali lives with his mother, three siblings and his cousin who also sometimes looks after him. His father works in another town, while his mother works in his hometown. He attended primary school until Standard 8. According to Ali, it was his mothers’ decision for him not to continue to secondary school, although he would have preferred to stay in education. His brother confirmed it was because Ali “didn’t do well at school” and the fact that there was no special school close to their township.

When Ali left primary school, he worked in a workshop for people with intellectual disabilities for almost a year. His mother found this work for him and decided that it was the right job for him. In the interview, Ali disclosed that he would have preferred to be consulted on the decision, as he didn't like working there. He also described a time when a co-worker at the workshop attacked him. He didn't disclose the incident to anyone and said he wouldn't know where to seek help. However, his brother knew about his incident – "there is a time he was bullied at the workshop by another man[...] We did not know where we would have been helped [if we reported it]. Again we thought he would easily be bullied by those who do not understand his condition."

To his brother's knowledge, Ali wasn't paid at the workshop. His brother explained – "We did not know why [he didn't get paid] because he stayed for long without being paid and mother went to find out. Most times they were saying that he had not mastered the art of making beads so did not warrant payment." Although Ali did not like working there, he did like working with beads and would like to work "putting beads on the wire, to make beads." In general, Ali said he'd like to do more for himself. He likes visiting his relatives who live in Nairobi and would like to live there someday. However, his family prefers him to be at home – "For us we would like him to stay close to us, work nearby so that we monitor him and be with him." (Ali's brother).

Ali: [Instead of working] I stay in the house[...] fetching water, I go with my brother, [...] I watch citizen TV[...] I like Papa Shirandulla and Inspekta Mwala.

He would like to have pocket money to "go to the shop[...] [buy] clothes". However his brother stated that he doesn't get pocket money as "he does not know currency". When Ali used to work at the workshop, he'd occasionally be given money to take a bus, rather than walk. In such instances, Ali's brother explained "we could put exact money for bus fare in each of the two pockets. Then he would give the money to the bus conductor while on his way to the workshop. Then on his way back he could give out the money from his other pocket."

He also goes to church each morning, although he'd prefer to "stay in the house". But if he doesn't go "my mother will quarrel with me... I am not happy". His brother explained – "My mother is very religious, so maybe that's why she tells his friends to take him. We have never asked him [if he likes to go there]." Ali also likes visiting his neighbours, but is not allowed to do so at night, which he's not happy about.

Ali's brother: Sometimes when we are going out at night to watch movies, he is not allowed to go with us because of his condition. I think he is not happy about it but he doesn't voice his disappointment either[...] You see, at times he is so weak and if he goes outside he can fall down, so that is why we ask him not to get so much involved [in community life].

Ali likes living at home, but is not always happy there, because: "Sometimes they shout at me[...] my mother, or my brother, [...] I feel very bad[...]. I am not happy about it[...] [I'd like for them to talk to me] without shouting, quietly." His brother noted that his family also ties him up to handle Ali's behaviour that they perceive as violent, despite knowing that this breaches his rights.

*Interviewer:* How else do you think his rights are violated?

*Ali's brother:* Sometimes he gets so angry and he can get violent and at such times, then he is always tied with ropes, because he is too violent. He does not it, he kicks around and gets very angry. [But] it's the only way that calms him.

## **Juma, a man in his late teens from a provincial village**

Juma lives with his mother and uncle in one of Kenya's provinces. His father left the family when his younger brother was born. In Kenya, people often live with their family members, so asking about choice of where to live, particularly for young people, may sound funny. Juma's mother answered: "That is a funny question. Who decides for him where he will live? This is where he lives, I am his Mother, where else would he live?" Juma's mother is his primary carer and decision maker: "both then [growing up] and now she still makes decisions for me."

His younger brother now lives at his aunts' compound, where he helps with the cattle. Juma would have liked to go and help with his brother, but was not allowed.

*Juma:* She did not ask for me, my Mother said that she asked for my brother[...] She said because I am sick, I should stay at home[...] Sometimes I get convulsions, so that is why[...] I was not happy when she said that[...] I was not asked, you see, I was just told I could not go.

His mother viewed the decision differently.

*Juma's mother:* (Laughs) They can't go the two of them, who will keep guard the house, when they both go?[...] I know he would have wanted, but you see, because of his condition, it would not be appropriate. I like him being close to where I am[...] You see, Juma gets convulsions and he started getting them when he was nine years old, so I am the only one who knows how to handle him, that is why I would not want him to go and live far. Sometimes, when he falls, he gets cuts and bruises on his head, and I am perhaps the only one who would know how to go about it.

Juma however says that he takes medication for his epilepsy and manages it himself "because if I don't take, then I will get convulsions[...] I know where they are kept, so I just take when it is time."

Juma's mother stressed how she, too, had to accept limitations to her options, due to her son's disability.

*Juma's mother:* You see, even me, I can't go far from where he is, like going to a place where I will have to spend the night because of him. So it is for his own good that I don't allow him to go. You see, he is my son, I love him so, and were it not for his condition, he would do all that he wanted to do, with little supervision.

Juma went to secondary school – and “liked it very much[...] playing with friends[...] buying sweets and biscuits[...] in the school canteen (smiles), Swahili, science.” However, Juma was taken out of school after he beat up another pupil.

*Juma:* Headmaster said I should pack my things and go[...] I beat a boy with kicks and blows... we used to sit next to each other[...] He stole my money. He stole my 100 bob, which is why I beat him. He was a thief, that is why I decided to beat him[...] I know it was him who stole my money, he was sitting next to me, and that's why I know he was the thief. [I kept my money] in my desk, and then he took it[...] My mother [gave it to me], it was mine[...] The teacher, my class teacher took me to the headmaster [silence] and when he was told that I had beaten someone, he did not listen to me.

Juma never got the money back. His mother explained how the situation could have been worse for Juma:

*Juma's mother:* Actually, [he was only expelled] because the Headmaster knows his condition, otherwise it would have been a legal issue[...] The parents to the other boy who was beaten wanted to forward the matter to the authorities like in a police station, but the Headmaster talked to them and convinced them otherwise. He told them that [Juma] had a mental condition, and that is why they did not forward the matter.

Juma now spends his days looking for sisal at the dumpsites and selling it to the women working at the market for a small fee (20 Kenya Shillings for 1kg of sisal). His mother is not happy about him earning his money this way. Both of them said that Juma gets skin rashes working at the dumpsites. His mother does, however, ask him for the money he earns “to buy food or anything else needed in the house”, which Juma doesn't like. Juma said I would prefer “to buy my own things[...] like my shoes.” His mother said she only takes money from him occasionally “when maybe I do not have money[...] to buy groceries[...] I really don't take time to ask him [if he's happy with that], because he will eat the food we buy with that money, isn't it?”

Beyond looking for sisal, “I just stay at home”, both Juma and his Mother confirmed. He also has friends that he likes to go and visit. However, his mother and uncle forbid him to socialise at night:

*Juma:* There is this one time my friends were going to watch a movie and they asked me if I wanted to go, of course I wanted to go but my mother refused[...] She said it was late, I could not go[...] I was not happy[...] even if it was at night, I wasn't walking alone.

His mother said she forbids him only because she fears for his safety.

Juma doesn't like that he's not in school anymore and would like to go back. He told his mother about it – "she said she would go and talk to the Headmaster[...] she tells me to wait[...] [I want to] go back to school." His mother is aware of this, yet explained the difficulties due to both his intellectual disabilities and the discipline issues because of which he was expelled. She only wants him to have a "Form Four Certificate" so that she could send Juma to a vocational college. She hasn't discussed these plans with him:

*Juma's mother:* No you cannot ask him, because he will not know, so I will just take him[...] the way I see him, he would do well in carpentry[...] it is good for him, I am his mother and I know what is best for him.

Juma's dream for the future is to be a policeman, "so that I can arrest bad people". He hasn't shared this dream with anyone. His mother thinks he would not be able to gain employment.

*Juma's mother:* I am almost sure that he would never get employed in this condition. So the only other thing he can do is starting his small business of carpentry.

### **Atieno, a woman in her late 20s from a provincial town**

Atieno lives in a Church parish. She moved there from her hometown because of the abuse and neglect she experienced in her family.

*Atieno:* You know, when I was growing up, my family did not want me, they hated me[...] they even used to lock me in another place, where I was just alone[...] My parents, especially my father[...] when I was young he used to say that I am a bad omen to the family, and that is why I was being locked inside a pen[...] And I never used to have people around me, only animals, goats, and I would get so lonely[...] The neighbours reported the matter to the Church[...] And then these people from the Church came and rescued me.

[...] I have siblings but they are at home with my parents, you see, they are more loved, so they stay at home. I doubt they are mistreated like the way I was[...] I remember I used to be all alone and I could only see my siblings when they are bringing food to me, and at times in that place I could peep and see my siblings playing with their friends and I was just locked up, and I hated every one of them[...] I felt so lonely; many times I was wishing I would die, and I would cry so much[...] I don't like going there [home], it reminds me of all those things I went through when I was young so I don't like going[...]



You know you can only miss people when you were close to those people, but if you are not, then you cannot miss them, isn't it? [...] [I was] just a young girl, I would not remember age, maybe around puberty stage[...] Sometimes [I miss them], and I ask myself why they hate me that much[...] I would really like to know because if I have done something bad to someone, then I will say sorry.

The Parish Sister we spoke to during the study explained that the Church where Atieno now lives is “a missionary church funded by the missionaries and one of our programmes is to rehabilitate abused women and give them skills so that they can empower themselves[...] we believe they are the backbone of any society so we help them empower themselves.” The Sister also explained how they identify the women who live at the Parish:

**Sister:** Most of our cases are referred by the villagers. Then we go for a fact-finding mission. You find villagers and neighbours coming to us for help in rescuing the women[...] that is how we learnt about Atieno[...] You know around here there is a belief that if you give birth to a child with disability, then it is a curse from the ancestors, so such children find themselves shunned by the society[...]

Some members of this church came and reported to us that there was a girl who had a mental disability who had been shunned by the parents and lived in a goat pen. We were concerned and decided to go and for sure we found that it was true, the poor girl was secluded and locked up. So we called the Chief [local administrator] and we decided that the missionary would be a perfect place to rehabilitate the girl.

The Church did not press charges against the parents. The Sister told us “no, in the villages such things are rampant, so we just told the parents that we would take Atieno and take care of her. They gladly accepted us to take her and that is how she ended up being here.”

The Sister explained what happened when Atieno was rescued from her home:

**Sister:** [She was a] big girl, almost 15 years, but because of the circumstances that she lived in, she looked quite young, and emaciated. She was a very scared child [...] When she came here, she was not talking coherently and I think because of trauma, too, she was very withdrawn, but with constant company around her from the other young women, she has now picked up and is doing well.

While she was kept at the family pen, Atieno was also sexually abused.

**Atieno:** There was a man who used to come and force himself on me[...] He was I think a neighbour, he was a big boy, and he knew my name[...] [He would come] many times, and nobody cared about me. I think when there was nobody around, he was coming[...] I felt very bad, I hate that man.

Atieno reported this to the Sister at the Parish but doesn't know whether any action was taken about it – "I did not talk to her [Sister] about the experience again". The Sister confirmed that Atieno told her about the abuse, but that nothing was done as, "it has been long and we did not have proof so we just thanked God that Atieno was now in safe hands, in our custody".

She likes living at the church, because "at least I have friends here and am not lonely, there are also girls like me, who are my friends[...] I am very happy here, they even give us food and they buy us shoes. It is nice here." Her mother used to come and visit her once she started living in the Church "but recently she does not visit me, so now I am just on my own". The Sister confirmed this, explaining that "she [the mother] was doing it behind her husband's back, she did not want the husband to know. But I think now she is too old to move, maybe that is why she does not come".

Atieno never attended school and wishes she had.

*Atieno:* I feel bad, I cannot read, and writing I also don't know, but it is fine, since God is still blessing me, so I am happy the way I am.

*Sister:* By the time we brought her here she was over the age to attend school, she lacked the basics in speech and we kind of engaged her in conversational moments till she became coherent in speech.

At the Parish, Atieno started a vocational course.

*Atieno:* I have attended a dressmaking course, where I have learnt how to do tailoring and make dresses. We have teachers who come and teach us how to sew. It is the course they offer girls, so I just got involved in doing it[...] I like it.

During the day, Atieno makes dresses. The dress she was wearing was "from well wishers who come to visit us" and the dresses she makes "are for sale, so that is why we are not allowed to wear them[...] We make very beautiful dresses and at times I would like to wear one of them." Atieno hasn't shared this wish with anyone at the Parish. Apart from working as a seamstress, she also helps at the Parish – "In this place we plant our own vegetables and go to the farm to cultivate, we also have cows that we look after." She and other women also attend mass.

*Atieno:* I wake up – actually, we are woken up by the Sister – and we go for a morning mass, then we later go and take breakfast[...] After breakfast I go to clean[...] just at the front of the dormitory, I mop there every day. We call them duties and everyone has her own duty of cleaning somewhere[...] I like it because it is making our compound clean[...]. Then I go to the workshop[...] I like making those things[...] [after workshop] we go for lunch and then we relax, we make hair and some other people sleep[...] After the evening mass, we take our food, by that time it's evening, isn't it? So we go to watch TV in the common room[...] We don't watch every day, we watch TV on Sundays mostly, other times we have teachers teaching us[...] I [also] wash my clothes, we have a day for washing them.

Atieno also has time for free time activities.

*Atieno:* Oooh, didn't I tell you that I sing in the choir?[...] Ahhh, I go to practice songs, because I love singing in church on Sundays.

Atieno and the Sister confirmed that Atieno doesn't get paid for any of the work she does, but she doesn't mind.

*Atieno:* You cannot be given money for doing something for yourself. It is our food that we cultivate and also the cows give us milk[...]. [The dresses we make] are sold and that is how we get money to buy our things that we need, things like food[...]. That is what Sister tells us, that the money we get from making dresses is for our own good.

While she is both grateful that the missionaries saved her and enjoys her days at the Parish, Atieno doesn't like it every day.

*Atieno:* Sometimes it is very cold and I don't feel like waking up, but I have to wake up because it is for my own good.

She never mentioned it to the Sister: "You cannot say, you will make her angry[...] because it means not going to the mass, and that is very bad." However, when asked what she'd do if she could choose what she'd do, Atieno confided: "[Looks around and almost in a whisper] Sleep a bit more." If she could choose what to do she would "just go to the workshop, only."

*Sister:* In Atieno's condition previously, we made all the decisions for her; we would take her to the bathroom, help her with bathing and make her bed, literally everything for her. But now, she does most things without being told.

When asked if there is still a need to make decisions for Atieno, the Sister laughed and said:

**Sister:** I don't know; you know, here we have a schedule that we follow, so it is up to these women to fit in it. Since this is a missionary church, we always go for a morning mass, and you find that some girls do not want to wake up. Atieno has a problem waking up and since it is a rule, then we have to ensure she is awake and that she attends the mass[...]. It is a rule and it has to be followed, isn't it? It is part of help for the girls, spiritually.

Unfortunately, Atieno has experienced sexual abuse at the Parish, too.

**Atieno:** I was just walking around near the Parish and then there is a man who used to greet me[...] And he would give me sweets and such things[...] He was working here, as a cook or a watchman, I don't know, but was a worker here. So one day he called me through the fence, and when I went, he dragged me in the nearby bushes and forced himself on me[...] I did not want him[...] He said if I screamed he would do something bad to me, like kill me, but you see, he was holding my mouth also[...] I was hurting and was feeling so bad [quivering].

Atieno reported it to a Parish Sister, who, according to Atieno's recollection, said she would look into the matter. However, that didn't seem to be the case:

**Atieno:** I have seen him even after that day, around here, and I told Sister again, so I doubt he was arrested[...] I felt very bad, because he did something bad to me, he should be punished.

**Sister:** Sometime back, when she had stayed here like three years, she reported to me that our watchman had raped her[...] I did my follow-up and talked to the watchman who denied the allegation.

When asked if Atieno was taken to the hospital to check if she was raped, the Sister replied:

**Sister:** No, we do not have those kinds of facilities here[...] There is a clinic at the other end of this compound, a basic one that has painkillers[...] The District Hospital is far from here, and we do not have resources to undertake such expenses[...] I am sure if we had the means, we would have taken her.

Beyond that, nothing else was done about the Atieno's allegations. However, when talking about Parish policy regarding any rape allegations, the Sister noted: "Well, that would be a police case, I would report to the authorities".

There is also limited support available to women about the experiences they had. The Sister explained: “Well, we talk to the young women quite extensively, so as we talk we also counsel them. In addition, they are welcome to talk to us whenever they have a problem.”

*Atieno:* When something like that happens to you, you don’t want to remember, but sometimes it keeps coming to your head and you feel very bad. If it were you, how would you feel?[...] I think I would beat the man or even kill him, now I am a strong woman and would fight with any man[...] Even if you report nothing will be done, so I even see that there is no point in reporting.

At the Parish, Atieno was also sterilised without her consent.

*Atieno:* I don’t think I would get children[...] I will tell you something, you see here (lifts up the blouse and reveals a scar on her stomach) here I was made an operation[...] This is contraceptive, all of us had been done like this, we cannot get children[...] The other women were talking and I was there when they were saying that we cannot get children, or even get pregnant, because there was an operation that was done to stop us from getting children[...] Nobody asked me [if I want that] [...] They should have asked me, because I love children[...] I feel bad, but what can I do now? [...] If I knew before, I would have refused to go for that operation. I would have ran away from here and would not have wanted the operation[...] [I haven’t discussed this with anyone] and the sisters would be very angry if they know that we know. They think we don’t know, so we only talk about it ourselves[...] [I cannot report it to the police] because they will kick me out of this place and I will have nowhere to go. So I cannot report them.

The Sister didn’t disclose such practices when asked whether the Parish undertakes any measures to prevent pregnancy among women who live there: “No, no, that would be promoting promiscuity among young women, so we have not put any measures to ensure they don’t get pregnant.” However, Atieno showed the interviewer the scar on her stomach and neither Atieno nor the Sister noted any other health issues that would have warranted Atieno to have had a medical intervention resulting in such a scar.

Atieno also experienced bullying behaviour in the local village.

*Atieno:* When we go to the shopping centre, and there are these young men, they start shouting those names[...]; they say I am retarded or foolish and I don’t like it[...] I am not happy and I think that is why my father said I should be locked up because I am bad omen[...] [I feel] very discriminated because I think am a human being like any other[...] I get so angry, but now there is nothing to do.

The Sister confirmed that the women go to the village and the shopping centre for walks, but did not mention bullying by the villagers.

Atieno also spoke about her dreams.

*Atieno:* [I would] like to be a teacher[...] to teach the little children, to play with them, that is what I would like[...] [I haven't discussed this with anyone] because I fear it will make her [Sister] very angry so I just keep to myself.

The Sister finds it difficult to see that Atieno and her peers will easily be integrated back into the society.

*Sister:* You see, like in the case of Atieno, the parents do not show any interest, these women they don't have relatives, they do not have people to go back to, that is why integration would be difficult[...] Until they can stand on their own, start a small business, then they can continue with their life. Of course when they feel they can be on their own, we don't keep them, actually there are some who have left and they are doing very well on their own.

### **Mumbi, a woman in her early 30s from a provincial town**

Mumbi lives with her older sister and her sisters' family in one of Kenya's provincial towns. Her father died when Mumbi was still a baby. Following the death of her mother while she was still in primary school, Mumbi moved to live with her aunt. She was the one who eventually decided to move to her sister's house.

*Mumbi:* Because, at my aunts, things were not so good[...] I think I was not happy, and I was doing so much work there, and my cousins were mean to me[...] I told my sister one day that I would like to live with her and then she accepted. You see, she had completed her university and got married, meaning she had her own house now, so that is why I wanted to live with her.

Her sister added how she was pleased that Mumbi asked to live with her.

Mumbi stopped her education in Standard 8. She did not proceed to secondary school.

*Mumbi:* I had not performed well in my primary school. I did not get good grades[...] I think [the death of my mother] also affected my performance and contributed to poor grades[...] My aunty told me I would not go to secondary school since I failed my Class 8 exams that would have enabled me to join a secondary school[...] I felt very sad, you know, most of my friends in primary school all joined secondary school and only I was left, it was very devastating[...] I think if she [my aunt] wanted me to join, she would have done everything in her capability to enable me to do so. But she was hesitant, I don't know why.

*Mumbi's sister:* I remember my aunt mentioning that she could not find a school for her[...] When Mumbi was in primary school, she would get seizures and I think it affected her schoolwork, since she was not performing well.

Mumbi now manages her epilepsy herself. Both Mumbi and her sister noted that “she knows which day she is supposed to go to the clinic and since it is not far, she takes herself and brings herself home” (Mumbi’s sister).

While Mumbi still lived with her mother, she was raped. Although she was at university at the time, Mumbi’s sister confirmed that their mother told her about the rape.

*Mumbi:* One man came to our home and cheated me, because I was young and he was old and he tricked me and then he slept with me[...] I did not know him[...] [It happened] just one time[...] He gave me some money and then he told me he would give me more money if I accepted to sleep with him, so even before I replied, he took me by force. [...] I wanted to tell him I was not interested because I know it is wrong[...] My mother kept on telling me that I should not allow a man to touch me here [points below her stomach][...]

I felt very bad and very dirty. [...] I told my mother and then my mother went and reported to the police[...] The police carried their investigations and then the man was arrested[...] I went and I identified him.

This was not Mumbi’s only experience of rape.

*Mumbi:* There was another one time and a different man forced himself and raped me[...] I was still staying at home with my mother, but my mother had gone out, I don’t know where to, then a man came and he raped me[...] I knew him, he was staying in the neighbourhood, sometimes he used to come and fetch water for us or just help with menial jobs[...] With this second time, it happened more than once[...] That man used to wait until when there was no one around and then he would rape me[...]

I did not want what he was doing to me, actually, both of those people, I did not want them. First I was afraid to say, you know, like report it to anyone, and then later I decided to tell my sister because it happened many times. [I did not report immediately because] sometimes if I say, my mother maybe could not have believed me[...] especially on just the normal things and she never seemed to listen or to be keen on what I always told her.

*Mumbi's sister:* At first I did not believe her, but when I told my mother about it she was so mad and stormed into that boy’s home. Apparently when the boy was confronted, he confessed to sneaking in and raping her. Well, he was taken to the police then later to court and was jailed.

After reporting both rapists, Mumbi was taken to the hospital – “both times by my mother. You know, they had to check where the baby passes if it was okay.” Mumbi was happy that both men were arrested and jailed: “When they were arrested I was happy because they had done to me something bad, so they were to pay for that.”

Mumbi is currently unemployed, but used to work as a saleswoman in a shop and at the market, selling vegetables. Both were informal jobs. Mumbi’s sister confirmed this, explaining “since she does not have substantive education, she cannot get a good job so she only worked informally.”

*Mumbi:* The shop belonged to a friend of my aunt. So one day, the friend came and asked my aunt if I could go and help her at the shop. So my aunt told me to go and help[...] I was selling small things[...] like hairclips, hand lotion, earrings, belts, necklaces, such things[...] but sometimes people were not coming to buy so I was laid off.

Mumbi received a salary for her work at the shop and enjoyed having her own earnings.

*Mumbi:* I was buying for myself things, many things I wanted[...] soda, sweets, perfume[...] I was deciding for myself, and some of it I was giving to my aunt[...] She was asking for it and I was giving her[...] I would have wanted to use all the money on myself[...] I was not happy [giving her money] at all.

[At the market] I was just helping my aunt, but right now I am not, am just staying at home. She just told me she needed me in the house, then she got another woman to help her at the market[...] I used to like very much helping out at the market.

Although Mumbi wasn’t happy that she had to stop working at the market and asked her sister about it, “I can’t even remember what she said.” Mumbi’s sister said Mumbi had stopped working at the market because of her temper.

*Mumbi’s sister:* I have a store at the market place and I used to have her helping me[...] I then realised she has a bad temper at times. At times she just shouts or gets angry and can be very adamant. Even when you talk to her she will just look down and won’t move an inch. So when I realised that, I was so sure that I would lose customers I employed a lady to help me out and told my sister to be staying in the house, as she helps out with household chores.

At the house, Mumbi feels she is “just like a housemaid [...] I wash utensils, then I make beds for the children, then I mop the floor”, but her sister doesn’t pay her for the work, as “I am not employed, she has not employed me, so I don’t get paid[...] I don’t mind, because once in a while she gives me a little money.” Her sister confirmed: “I give her pocket money, because, you see, she is a young woman, she may want to purchase some things, so I give her a small stipend.”



Mumbi likes looking after her baby niece: “I like holding her and feeding her. And she likes me, sometimes when she is crying, I hold her and she stops crying.” However, Mumbi is not sure if she herself would like to get married and have children one day.

*Mumbi:* I fear being beaten or someone can make me sick with a bad disease[...] I was beaten by the one who was forcing me to sleep with him, so that I don’t report him.

When talking about Mumbi’s experiences of rape, her sister noted “I don’t know if she was traumatised, but she never speaks about it[...] I think she does not like men from her previous experiences.”

Because reporting resulted in arrests in the past, if someone would infringe Mumbi’s rights, she would report it again: “Like now, I can tell someone, like my sister, because she is the one I am with.” Mumbi’s sister confirmed – “I think I would go get that man who would try to touch her and report him to the police, and maybe follow up the case to see that he is imprisoned.”

In her free time, Mumbi visits her friends and goes to church, but she doesn’t go out at night: “I think my sister is scared something bad will happen to me, so she says no going out[...] I am scared, too.” Her sister confirmed she is scared for her safety.

Mumbi has hobbies, too.

*Mumbi:* I love knitting cardigans, we were taught in primary school and I still love knitting. So I knit cardigans and baby socks. I make them for my baby niece and nephew.

Mumbi’s sister thinks knitting can be more than a hobby.

*Mumbi’s sister:* I even encourage her, you see she likes knitting she could easily go to a vocational centre and be trained on how to knit for commercial purpose. I have even mentioned it to her, but she was not so keen, so I decided I will still go with a plan of taking her to a vocational training centre[...] I won’t ask her, now that I know she is good at knitting and that she likes it, I will just take her there to learn more skills and to polish whatever she knows[...] It is good consulting her, but you work with what you have, isn’t it?

Mumbi said that, in her life, “I make most decisions”, but dreams of more independence and getting her own house. Her sister, however, finds that she make a lot of decisions for Mumbi.

*Mumbi’s sister:* But it is always in her interest, you see, like now I am telling you that I want to take her to a vocational college. She would not make such a decision so at such times I come in. I just decide. I guess that is life, not everything goes the way we want it, right?

When asked what work she'd like to do in future, Mumbi replied: "Well, I have never thought about it... I don't know, maybe I would have to think about it, [...] I don't think I can think about it now."

Mumbi's sister said that she has national identity card and has voted once but with an unpleasant voting experience.

*Mumbi's sister:* Yes, I remember she went to vote once and she came home complaining. She thought the people had mistreated her and she vowed she would never go voting again because the people had jostled and shoved her out of the queue and she felt bad about it.

*Mumbi:* Yes, only once [I voted], but my sister can't agree me to go, you know when we are queuing, and someone comes and pushes me. That time I voted, I was queuing and then it was very sunny so I went under the shadow then the people passed me, and they would hear none of it that I had just gone to sit under a tree for shade. So you see even sometimes where there are many people, even if you want to buy something you can't buy, because people just push me.

### **Ndungu, a man in his late 30s who lives in a remote village**

Ndungu lives with his 83-year-old grandmother and his cousin at the family compound, as both of his parents died, as did his cousins. His sister is married and lives in another village. Four of his uncles and their families also live at the compound. The atmosphere between families is not always amicable, particularly because of poverty.

*Ndungu:* One day, my uncle chased me away from his house with a panga [machete] and he told me that I was an old man who should fend for himself, that I should not go to borrow food from his wife[...] I felt so bad, I felt unwanted and I reported it to grandma[...] she just told me to leave other people alone and to keep to myself[...] I would have wished he just gave me the food I was borrowing, 'coz I was so hungry.

Ndungu's grandmother is concerned about such incidents and discrimination Ndungu faces in the community on a regular basis.

*Ndungu's grandmother:* Even my sons who are the uncles of the children, sometimes I see them not treating him well. And it is even worse with the wives, you see they shun the two boys, they shout at them and I get so depressed but I know God will take care of them even when I am not around them.

Ndungu dropped out of education whilst still at primary school, during Standard 6.

*Ndungu:* You know, my grandma came to school and abused the Headmaster, and then the Headmaster chased me away[...] I am not sure [why] but I think it is because the Headmaster kept beating me in school because I was always in the last position. One day he beat me so badly that I fainted, and when I went home I informed my grandma, who got angry and went to insult the Headmaster[...] I was not happy for dropping out of primary school.

*Ndungu's grandmother:* The teachers were mistreating him in the sense that they could beat him senseless when he failed his arithmetic, you know the corporal punishment, yes, that is what those teachers were subjecting him to every day, so I thought that is not the life I wanted him to live, of being called names, so I withdrew him from school.

Despite his bad experiences, Ndungu would have preferred to complete his education. He is worried that lack of education prevents him from finding work.

*Ndungu:* I think education was very hard, so I was performing poorly in all subjects[...] I did not want to tell teachers to repeat [what they explained] because I thought I would be disturbing the them[...] I would like very much to go back to school so that I can get a good job because, you see, now if I would be having education, I would be having a good job[...] I had told even my uncle that I want to go back but they never took me seriously, because if they took me seriously, then they would have taken me to school.

Ndungu's grandmother tried to explain to Ndungu the reasons why she pulled him out of education and never enrolled him in another school.

*Ndungu's grandmother:* I told him and very slowly made him understand why I would not want him to go back to that school, which he accepted and that is how he stopped attending the school[...] At first he was determined to still attend school, but I was so persistent until he gave in and now he stays with me at home[...] I had already decided for him and that was the best for him at that time.

And something else, he would not have been in a position to know what was right for him, so that is why I thought of not asking him anything[...] [Having looked for a new school] I had lost my patience and I thought all schools would mistreat him so I decided that he would just stay at home with me. Besides, the teachers thought he would never achieve anything academically so it was good for him to stay with me.

During the day, Ndungu helps his grandmother at the family compound. In the past, he used to work as a night watchman in a nearby home – a job that his grandmother found for him.

*Ndungu:* My grandma had gone to ask them for a vacancy because she had heard that they needed a watchman, so she was told to take me, which she did[...] She did not consult me, she just told me we need to go there to get a job and that would help in getting money to buy food[...] You know, she is the one who knows best, so if she tells me something, I have to obey her[...] It was okay, only the nights were very cold, and at times no matter how I covered myself, it was too, too cold[...] but now I am laid off[...]

He was dismissed due to his disability.

*Ndungu:* It is because they said that I have a problem with my head[...] I don't know what that means[...] I felt very bad because that is the money that I was taking home to feed my brother and my grandmother, so when I was fired, that meant that we had to struggle for food, or go borrow from my uncles.

For a while, Ndungu also worked at a construction site, but now works at the market carting groceries for the shoppers for a small fee, as "it's much less tiring". He explains, "my uncle told me to do it, so that I can get some money". The money he earns go to the grandmother: "I don't spend even a single coin[...] she buys for us food with the money, so am happy to give her all the money." Ndungu's grandmother confirmed that this is their only income.

*Ndungu's grandmother:* We only survived with the little that he brings home[...] and gifts from well-wishers[...] he has a very good heart, actually, were it not for his condition, he would be a very responsible person.

Ndungu doesn't have an identification card.

*Ndungu:* [I don't have an ID] because of my head[...] my uncles say it and even I hear it from my grandmother sometimes when she is talking to people[...] I feel bad because I don't know what they are talking about, and I don't think there is any problem with my head.

Talking about this, Ndungu spoke about how he was twice incarcerated.

*Ndungu:* You know, even another time when I was in the prison they said my head had a problem so I was released[...] You see, I have been in prison two times. One day, I was just walking around and went near the town centre. And then I came across some students of a certain primary school. Actually, I think as I was walking, I then entered a school and saw a girl I thought I knew. Then I went to where she was and wanted to greet her. So as I was trying to say hello to this girl, by handshaking her, then suddenly I was surrounded by other students who started screaming and shouting at me. They came up to where I was and they started attacking me. So they started beating me and hitting me until I collapsed, and you know I thought I would die because of how they beat me. They were hitting me with stones and sticks, and it hurt so much.

His grandmother explained that, at the school, Ndungu “held a girl’s hand and told her that he would like to marry her” which triggered the violence from other pupils.

*Ndungu’s grandmother:* By the time I was called I thought he was just about to die[...] I never thought he would live to see the next day and I did not even have hope that he would survive.

From the school, Ndungu was taken by the police to the hospital and then incarcerated.

*Ndungu:* They said that I wanted to rape the girl and I could not do such a thing to her[...] I used to tell them [police officers] almost every day [that I’m innocent] but they could not listen to me, sometimes they would beat me, saying that I was a child molester and that was not true. [Silence, almost in tears] I could never do such a thing.

[...] Only my grandmother used to come and visit me[...] I was very happy [to see her] and every time that she was going away I could get very sad, I always wished I would go home with her[...] [I stayed there] a very long time, I think almost two years[...] [I had no lawyer], it is the second time [I was in prison] that grandma hired a lawyer for me.

Ndungu’s grandmother noted that “the girl’s mother heard of the incident and was so furious, she insisted on the imprisonment of Ndungu[...] he was put in remand for almost one year and then he was later released due to lack of evidence.” Ndungu’s grandmother confirmed that she could not afford a lawyer.

This was not the only time Ndungu was imprisoned.

*Ndungu:* [On the second occasion] I felt very bad, and was wondering why this entire curse had to befall me[...] I was near the shopping centre and was seated next to other young men. They stabbed somebody, stole from him and then threw the knife near where I was, so when people came they thought I was among the gang that had robbed and killed the man. They frogmarched me to the police even with my pleads that fell on deaf ears. The police came and I was put in the cells[...] I tried to explain [to the police] but nobody was listening.

And, you see, it was Charge 2 that I was charged with. Charge 2 is murder because the person had died. So I was put in the cells where I really suffered[...] I was beaten up so many times and the place was infested with lice and bugs. I stayed for almost three years, and I really suffered because I was taken to a prison and the conditions there were so unbearable[...] The food was not palatable at all, it had more water than vegetables and the bedding had lice and bugs. There wasn’t any toilet in the cells so we were helping ourselves in a bucket that was at the corner of the room.

The prison wardens were brutal to us and I hated that place[...] My grandmother paid the lawyer, I think she had borrowed some money from her friends and maybe had sold some of her cattle. I tried to tell the lawyer that I was innocent, good thing is they said I had a problem with my head so I was taken to Mathare mental hospital[...] I did not want to go because I was being given medicines that used to make me feel dizzy and I would sleep all day[...] Nobody was asking me if I wanted to go to Mathare but you know what, it was like a blessing in disguise, because there was good food at the hospital and also conditions there were better than the prison[...] I was then taken to the court for mentioning, but the person who was suing did not show up even once, so my lawyer told the court. [...] Then I just had to go home, and that is how I went home[...] It was such a good feeling.

His grandmother corroborated Ndungu's story.

Because of these experiences, Ndungu's grandmother tries to limit where and how much he leaves from the compound, but Ndungu disregards her requests.

*Ndungu:* [She] makes noise to me, all the time she says that if I just walk aimlessly just like that, that I would get into trouble.

However, Ndungu still finds that "my grandma makes decisions for me[...] I like it". When asked if he would prefer to make decisions about his life, Ndungu just noted that he would like to decide about how to spend the money he earns.

*Ndungu:* I would not tell her [that] at all[...] I don't know[...] I don't feel good about it, I am a big man, would like to be deciding things myself[...] there isn't anybody I can talk to about it.

Both Ndungu and his grandmother would like for him to continue his education. However, they have different plans. Ndungu's grandmother would like him to attend a vocational school.

*Ndungu's grandmother:* I have a plot that I bought when I was working and I have been looking for a buyer. Once I sell it, then I will take both boys to a vocational centre. That is the only thing that they can inherit from me; survival skills[...] I would like Ndungu to learn masonry now that he has worked in a construction firm[...] I haven't asked him but I am sure he will like it.

Ndungu mentioned this plan, too, noting that he is not keen to attend a vocational school, explaining, "because I don't even know which course I would learn, I don't know what is taught, so why would I want to go to such a school?"

One of the key reasons Ndungu would like to go back to school is to pursue his dream career.

*Ndungu:* I would like to fly airplanes; you see like the ones that fly on air, I would like to be inside one of those, directing it[...] I have told this to her [grandmother] many times, but I think because she does not have money, I think she cannot take me to school[...]. She never took any action, she just listened.

### **Nekesa, a woman in her late 20s from a provincial town**

Nekesa has a two-month-old baby boy. She is the oldest of five children. Her two brothers and two sisters live with her mother. Her family disowned Nekesa because of her decision to keep the child without a father, “because there was no way I could provide for the baby”. She didn’t want to get pregnant.

*Nekesa:* I was using family planning pills. I had been using them for a long time because I was cautious not to get pregnant. So I don’t know if I had confused the days or the pills backfired, I don’t know.

Nekesa met the baby’s father while working as a house maid. Although she trusted him, he sexually abused her.

*Nekesa:* I thought he was a good person, so one day he told me he had found for me another job. So I was interested and that is when he forced me to sleep with him. It was somewhere outside, like in a bush. It was in the evening and there weren’t people passing [...] I felt so bad because he had taken advantage of me. It was the first time that he did that to me. I told my mother [about it] and she took me to the chief [local administrator] and reported the man who had done that to me. The chief told me to look for him and once I get him, I go back to the chief and report his whereabouts and then he would be apprehended[...] He must have learnt that he was being looked for, because he later moved and I never saw him again.

Despite what he has done, Nekesa would still like to stay with her baby’s father, but cannot find him. “I don’t even know where to start the search for him so it is like I am easily giving up.” Nekesa’s cousin doesn’t think Nekesa was raped: “I heard rumours from friends of hers that she was having a man friend, who was a watchman, who was promising her a job at the house he was guarding.”

Because of her family’s decision not to support her, Nekesa now lives with her cousin. However, Nekesa’s cousin perceived her invitation differently to Nekesa:

*Nekesa’s cousin:* When her mother threw her out I sympathised with her and told her she could stay with me for a few days before she planned her next move. But she has now stayed for almost a month.

Because of that, Nekesa and her cousin are finding it difficult to live together.

*Nekesa:* [My cousin] sees me as a burden[...] When I got pregnant she offered to give me money to abort but I refused. Then after I came home with the baby she told me that I should throw away the baby, again I refused, so that is why she does not like me. And that is also the reason that she mistreats me by not buying food in the house.

Nekesa's cousin explained that she finds it difficult to discuss and agree on issues with her.

*Nekesa's cousin:* [Nekesa] just keeps quiet when I ask her anything[...] You know, it can be very annoying to talk to somebody who is not responding, so nowadays I just talk to her when it is extremely necessary.

As she cannot find work while caring for a small child, Nekesa feels she has to resort to begging. Her cousin suspects that Nekesa begs.

*Nekesa's cousin:* One of my neighbours told me that she saw Nekesa on the streets begging from motorists. When I asked her she denied ever begging.

Nekesa feels her family should be more supportive.

*Nekesa:* You see, I am not the one that wanted to get pregnant, it was an unfortunate incident that led to the pregnancy so I would like to be supported, not demonised[...] At times, I get no one to help me so I am forced to sleep hungry[...] Such times, the baby also goes hungry because I can't produce milk[...]

I would have wished the people around me understand my situation and give me support in bringing up my baby. When I was working, I could manage to pay my rent, and I was not a burden to anyone. Only now I am not working because I cannot manage to work with the baby. Again, I have no money to hire a babysitter, so I just stay without looking for a job and am forced to beg.

Nekesa's cousin views the situation quite differently.

*Nekesa's cousin:* [Nekesa can be] very arrogant and rude and she does not take any advice from anybody including her mother, and that is why the mother does not want to see her[...] Previously, I would not have minded her living with me, if she did not have a baby, but now she went to make herself pregnant and now she wants everyone to shoulder that burden with her. Again I think she is not a good person, she likes acting a lot.



In education, Nekesa only reached Standard 8. Both her cousin and Nekesa confirmed that this was due to her family not being able to afford sending both her brother and her to secondary school.

**Nekesa:** I repeated several classes until he caught up with me, so when we sat for the Class 8 exams, he was given priority[...] He was brighter than I was, so I thought it was a good thing he was paid to join a secondary school[...] [although] I would have wanted to go to secondary school.

Had she completed her education, Nekesa would have loved to be a secretary.

**Nekesa:** I like the way they dress, nice skirts and wearing heels. Also, I would like to be working with a computer. When I was working as a house girl, Madam would send me to big offices. When I go there, I see the secretaries working with computers and I really admire them.

Nekesa started working as a house help once she left school: "That is the only work I could do since it needed no certificate." The home where she met the father of her baby was the second home she worked. She was sexually abused in her first post, too.

**Nekesa:** The man of the house used to touch my body when the wife was not around[...] I was not happy and did not want anything to do with him, but he still used to insist on touching me[...] I told the wife who was the Madam of the house. I think she fought with him, but the next day I was kicked out of the house and I just went back to my mother's house.

I felt bad because, had I done any mistake? [...] I think they thought I was a bad girl so that is why I was kicked out of the house[...] I felt betrayed, because I trusted them so much and I was feeling like they are part of my family[...] If I kept quiet, I am sure I would not have been kicked out.

Nekesa was paid for her work but was not asked to return. After she was fired, Nekesa found another job as a home help, but she chose not to stay with her employers "in case I get another man who would try to touch me." She was laid off from that job once she fell pregnant.

**Nekesa:** I felt so bad because now I was exposed to abject poverty and with a baby on the way. I knew it would be miserable for me.

Her cousin is planning to move and Nekesa is worried about this.

**Nekesa:** If she goes, I won't get a place to sleep. I am sure she will not take me with her. I feel bad, because I am a human being also. And her doing that to me is not fair, but it is okay, I am sure I will pull through.

*Nekesa's cousin:* She has the option of going to the village to stay with grandmother. One day I asked if she can go there, and I was even willing to pay for her bus fare, but she did not respond. Actually it is like she was not interested so I have never brought the conversation up again[...] I just think she is being difficult. I am tired, you see, I pay the house rent and yet it is like she does not appreciate what I do for her, so now I want to move out.

### **Mutua, a man in his early 40s from a remote village**

Mutua lives with his friend and his nephew at the family compound that he and his two brothers inherited from their parents. He enjoys the company of his friend and nephew, but doesn't get on well with his brothers who also live at the compound, "because they say that I like spreading gossip about their families... Each of us minds his own business and we hardly interact... I would like to be close to them, though." His sister married and moved to another province: "At times she comes here to visit me, because this was our parents' home... she also comes to check on me to see how I am faring on."

Mutua explained how his disability developed during primary school:

*Mutua:* I kept having falls[...] Sometimes the convulsions would occur so many times that I really thought someone had bewitched me[...] I went to church then they prayed for me and they said I had a mental disorder or illness of some kind.

He has been seeing Western medical doctors, too, but is not happy with how they treat him.

*Mutua:* He just says that I will be fine, he does not explain to me anything. Even I would like to know, but still I don't have an answer. I hear the nurses talk about it, as they refer to me, so I know what medication I use.

Despite his health concerns, Mutua finished secondary school and went on to college, first attending an accounting course, then journalism. However he did not finish either course as a man who promised him work after college left Kenya. He was an Italian catholic priest who lived in Kenya and sponsored Mutua to finish a special school initially, as his teachers in regular school "were harsh". The priest promised Mutua that he would take him to Italy, "but he just left without me". Mutua's friend spoke about the grave effect this had on Mutua.

*Mutua's friend:* When the priest went without him, I think he got depressed and started hallucinating. At times he would say he is hearing things, yet we could not hear what he was hearing.

Around that time, Mutua decided to get married.

*Mutua:* I was working as a messenger in an office that the [the Italian priest] helped me get, so I had some money. So it was then I decided to marry and went to my home where my parents were staying.

Mutua got married to a woman from his village and has two young children (five and seven years old). However, his wife left him with the two children. During the course of their marriage, she abused Mutua.

*Mutua:* She left me because some women of the village told her that I am retarded [...] You see, sometimes we would quarrel in the house and then she would blurt it out, she would say no wonder I am a foolish man, and that she has confirmed what she was told by a certain woman, that her husband is retarded[...] I would just keep quiet because at times if I respond to her she would hit me with whatever she is holding[...] [When she would hit me] I would not do a thing, just keep to myself[...] I would feel very bad because even one time she injured me so badly with a knife. I had a deep cut here (shows the mark on his arm)[...]

I came home and she asked me for money to buy necessities for the house and I only had 50KES [approx. 50 euro cent] in my pocket that day. So when I gave her the 50 bob note she hit me with it as she asked me what she would do with that kind of money. She then went to the kitchen and came out brandishing a knife and as I jerked, it scratched me on the arm. The children were playing so it was just two of us at the house[...] I wasn't scared, I know it's because she was unhappy that she used the knife on me, but I don't think she would have killed me[...]

I did not share this with anyone, I just decided to keep it to myself[...] If she knew I told anyone, she would have been infuriated, I'm sure[...] I just tied a cloth on it to stop the bleeding and few days later it was healed[...] she looked remorseful, but she didn't say she was sorry[...]

People did not know what was happening in the house. One time I tried to hold her and she got so, so angry, so because I love her I just let her be[...] I feel so bad, because I loved her very much and even now I wish she would come back to me[...] She just says that she will come to me one day[...] but she now has a complete new lifestyle. Before she was a house maid in another home. Then when she moved to town, she started selling beer in a pub and the customers tip her, so I know she is making a lot of money and maybe she now thinks I am a poor man.

Mutua doesn't discuss his thoughts and feelings about the separation with anyone.

*Mutua:* I just keep quiet to myself: I don't want to keep telling people about my affairs.

Both Mutua and his friend think that his brothers' wives contributed to the divorce.

*Mutua's friend:* You see when Mutua was staying with the wife, the children would at times stay hungry and such times the brothers would chip in and help Mutua's wife with food[...] I think they were not happy and decided to incite the wife[...] She was told that the husband is retarded and that she is the laughing stock of the whole village.

His friend and nephew moved in with him once his wife left. Mutua enjoys their company and support, including support when making decisions.

*Mutua:* At times, I feel what I am doing is not what I am supposed to do, I ask them and they tell me what to do[...] It is not so much encouraging, but if it is a good opinion or suggestion, I just say it is okay.

During the day, Mutua does odd jobs in the village and at the compound.

*Mutua:* I work with the donkey at times, fetching water or carrying luggage, or at other times I help in cultivation and help people in tilling their gardens[...] I get around 30KES per trip to fetch water[...] I don't mind because I get some money from that and am able to survive, purchase items that I would have otherwise not afforded.

However, his friend thinks that Mutua is not paid well for his work.

*Mutua's friend:* People give him peanut pay because they say he doesn't know so much about the value of money. You see, he is one of those people who are born when they are a bit slow. And people tend to take advantage of them. I like him, he is a very good man, he likes helping when he can with or without pay, so people take advantage to use him.

Mutua didn't face abuse just at home. In the past, his neighbours used to beat him up, too. Mutua said: "It doesn't happen anymore since I decided to keep to myself." He reported this to the police, but this had no impact.

*Mutua:* They would just record the statement but did not take any action against those who have assaulted me[...] People say I am ailing from an illness or that I have a mental disorder[...] I don't think I have such a big complication[...] It feels bad when people of this village say that I take long to understand things, I don't even know why they say that[...] I think I am just like everybody else. I would want people to stop talking about me, you know, and to treat me just like anybody else.

*Mutua's friend:* You know how things are here: this is not America where things are so smooth. Here you have to be strong and persevere challenges.

The prejudice and abuse Mutua has faced also became a problem when he decided to stand as a representative for his village.

*Mutua:* During that time that I wanted to be a politician, there was a lot of mudslinging and they could talk about me very much. I think even some other rivals said I was crazy and finally the pressure was too much so I decided to bow out[...] I would like to be a politician and that is what my dream is[...] I felt awfully bad, but there was nothing I could do.

### **Njeri, a woman in her early 70s who lives in one of the slums**

Njeri has nine children, “seven girls and two boys and so many grandchildren[...] They all have their own homes. And they have children who also have children, so I am a great grandmother.” She now lives with one of her daughters and her children. Njeri’s husband passed away a few years ago, but she added: “I am not lonely, I get to have someone to talk to and my grandchildren always keep me busy.” However, Njeri’s childhood wasn’t always as happy.

*Njeri:* Before, when I was a young woman, I could have so many disagreements with people, especially women. I had a problem with my speech and I could not communicate well, so I would attract a lot of criticism[...] even my siblings somehow always distanced themselves from me, they really did not want me to hang out with them or with their friends and since I am the last born I could go and cry to my mother and she would really console me[...] My mother was always very understanding and she would tell me to leave people alone and work hard in my life.

She didn’t attend school, however this was not due to her disability.

*Njeri:* In those days, girls hardly attended school[...] we mainly looked after our siblings, went to the river to fetch water and firewood and only waited to get married[...] I did not see the need to attend school.

Njeri moved from the province where she grew up to Nairobi because of work opportunities. She was a babysitter for almost 12 years, until all of the children in the family grew up and she met her husband and decided to marry – “He was a gardener in a next home, and we were friends[...] I wanted to get married so I was happy to marry him.” Once married, Njeri continued to work as a housekeeper, but would go back home each evening, rather than live with her employers. Njeri’s relative looked after her children while she was at work.

When he retired, Njeri’s husband built a few houses around their own, which they started renting. When her husband died, Njeri took over from him responsibilities to collect rent and manage the family business. Njeri spoke about the time before she was widowed:

*Njeri:* My husband would make decisions in the house, concerning our children. I did not mind, because he was my husband. Let me say that most of what he decided was good and I had no problem with his decision-making.

Njeri likes how and where she lives and makes all the decisions in her life, from where and how she lives, management of her finances, to her medical care needs, as she has a bad back.

*Njeri's daughter:* My mum is fit and she makes all the decisions. At times she is slow in reasoning[...] but she makes sound decisions.

Her daughter appreciates Njeri's support, which includes financial support for the grandchildren's school fees.

In her free time, Njeri goes to church "and my friends visit me once in a while." She also goes to visit her other children, but finds the journeys increasingly tiresome. Njeri feels well regarded in her community.

*Njeri:* They appreciate me, even the children of the villagers as I pass they greet me as cucu [grandma], and if I have any ripe bananas or fruits I give them.

Among other reasons, Njeri attributes her position in the community to her financial stability and security.

*Njeri:* You know there is nothing as good as being financially stable, because most of the people will not see you as a beggar. But if you do not have money, no one will want to have anything to do with you[...] I am very happy, and I always encourage young women to work hard and not entirely rely on their men, because these men you see, today they are here, tomorrow elsewhere, so it is good for a woman to have a source of income, however little.

## **Bosire, a woman in her early 20s from Nairobi**

Bosire, the youngest of three children, lives with her parents and siblings. The family employed a servant to look after Bosire and help at the house. The servant noted, "you see, I am like her mother, because her parents are very busy looking for money, so we are very close."

Bosire stopped her formal schooling at Standard 5, but would like to go back to school.

*Bosire:* When my siblings are going I say that I want to go to school with them but they don't accept[...] I feel bad because I would also like to go to school or to college like my sister[...] she is learning how to make baskets for selling to the white people. I would like to be like my sister, making baskets then selling them. I always tell her [this], she just says that she will teach me how to do it, but she hasn't done it yet.

Although Bosire did not mention this, the servant explained that Bosire receives private tuition. Bosire said that, each day “I just stay here in the house...sometimes I watch TV and sometimes I go to the neighbours place to visit my friends.”

Bosire likes spending time with her siblings.

*Bosire:* Sometimes, my sisters brings me chocolate[...] when she comes home and then my brother is teaching me how to ride a bicycle.

But Bosire doesn't travel or visit many different places as her parents demand that she is accompanied everywhere.

*Bosire:* [It's] okay, only sometimes when I want to visit my friends and everyone is busy[...] I have to wait[...] then I am not so happy[...] My parents would be very angry if I said that to them, because every time they caution me not to go anywhere unaccompanied.

The maid noted how she knows that Bosire is unhappy about such arrangement, but that it's her parents who made such a decision. She added that this is the case in regards to most of Bosire's life.

*Bosire's maid:* We make most of her decisions, me, her parents, the teacher. You see, she may not be so much in touch with herself and that is why we make decisions for her[...] when it is time for meals[...] I tell her when to take a bath, just the general tasks that one does.

## **The lives of people with psycho-social (mental health) disabilities**

### **Jacinta, a woman in her late 20s from Nairobi**

Jacinta lives with her parents and five siblings, although she finds this difficult at times.

*Jacinta:* Sometimes I am not happy due to the way that am treated while other days are okay. I would like to stay on my own. Even at home I like staying alone so that I can read novels[...] [but] I don't have a job for now so I might not be able to support myself.

*Jacinta's father:* The main reason why we insist that she stay at home is because she is sick and she might not be able to work.

Jacinta finished secondary school, but didn't proceed with her studies.

*Jacinta's father:* When she was in school she was not sick and she was a very bright student[...] [but] her grades were not good enough to be admitted to university and we were not able to raise the money for college education since I work like a casual labourer. She speaks about how she would like to go back to college and study more.

Once she left education, Jacinta was "employed as a house help." She is currently not working.

*Jacinta:* My father told me [working as a home help] was not the right job for me so I had to leave it and look for something else to do[...] The way I am feeling right now, I might not have energy to do it." When she worked, "part of my income was for supporting my parents as I am the oldest child in the family, because they have never had good jobs[...] and I also had a fee balance to clear [from my education].

These were her secondary school fees that her father was unable to afford. Contributing money to the family is seen by both Jacinta and her father as her obligation.

*Jacinta's father:* You know it is good for a child to give something small to their parents.

As she is not working, Jacinta spends her days helping out with some of the house chores and talking to her family members. She enjoys reading and listening to the radio. While Jacinta is also a member in a self-help group, her father attends on her behalf.

*Jacinta:* It is my father who represents me in all the affairs of the group.

Jacinta's father stated that Jacinta had only went to the group meeting herself once and that the rest of the time he attends on her behalf.

*Jacinta's father:* When she is asked questions about the issues of the group she was able to answer them well, without any mistake, but nowadays she says she is not feeling well and hence does not attend the meeting. So it is difficult for me to know what the problem is.

Each month, Jacinta attends a clinic at the local hospital, but is not happy with her treatment.

*Jacinta:* I have been telling my family and the doctor that I don't feel as if I am getting better, but am hoping with time that I will [...] I was taking medication for depression although I felt as if they were not treating me for the right condition and because of this I think that is why my condition is getting worse[...] [The doctor] does not listen or take my opinion seriously[...] most of the time the [the doctor] talks to my father but not me.



Jacinta finds that her family “pushes me to go to the hospital. Sometimes I am taken by force, like when I was admitted to Mathare [psychiatric] Hospital.” To date, Jacinta has been admitted to the psychiatric hospital twice, and both times by force.

*Jacinta’s father:* When we took her to Mathare, she was not conscious of what was going on, so we had to take her by force. She was even fighting, insisting that she did not want to go. Even now sometimes she says she does not want to take her medication because she is not sick[...] I personally thought it was important for her to be taken to hospital to receive medical attention and that is why I took her by force since it was in her best interest.

Jacinta feels her only source of support is going to church.

*Jacinta:* I am very prayerful and my parents are also very religious so it’s the only place that I have been able to get support.

In general, Jacinta noted how her parents help her in decision-making.

*Jacinta:* I think I make my own decisions, but my parents also help me in making decisions. For example, there is a time I did not want to go to the hospital and I did not want to take medications, but my parents took me to the hospital. They really pushed me and made that decision for me.

Jacinta’s father stressed that such support is highly relevant for Jacinta.

*Jacinta’s father:* For now, let me say she is sick and might not be able to make decisions. She can say she will be able to do a certain task and then later she does not deliver on it. The most important thing for her now is that she might require our support and assistance in making decisions[...] Like when we were taking her to Mathare [psychiatric hospital]. In such situations we feel that she is not conscious enough to make her own decisions.

Despite appreciating their support, Jacinta also finds her parents’ support restrictive and her options limited.

*Jacinta:* Let me say that I find the day to be very boring and I feel as if there is something lacking in my life. I would like to go out more with my friends, but my family members sometimes say that I am unwell to do so.

A further example of family members making decisions was an incident when Jacinta was beaten up by a neighbour.

*Jacinta:* I filed the matter with the police, but my father forced me to withdraw it since she was a neighbour and also a close relative.

Her father thought it would be best to drop the case as it concerns a relative.

*Jacinta's father:* I also explained to them [police] that they should be careful when dealing with her since she is unwell.

### **Kanyonge, a man in his late 30s from Nairobi**

Kanyonge lives with his mother in the capital city. Due to family problems, the family moved a lot as Kanyonge was growing up. His father abandoned the family when he was young. "This is something which has disturbed me for many years", Kanyonge noted.

While at first grade of a boarding secondary school, "the company I was keeping was not good". He started chewing Khat and smoking Bhang, taking Miraa or drinking Changaa.<sup>243</sup>

*Kanyonge:* I was also taking some other hard drugs[...] That is where my mental health problems started.

Kanyonge noted how he knew that his mother was not happy with his friends.

*Kanyonge:* I was feeling on one side that she was right, but on the other hand I was feeling a bit bad because I did not have other people who I would call friends.

This eventually led to his first hospitalisation, which Kanyonge resisted.

*Kanyonge:* My mother would bring policemen who would come with their vehicle and take me to the hospital or sometimes we would use a taxi although my mum would not tell me where we are going, but upon realising where we were going I would become rebellious. My mother would then go and call the CID who would get hold of me and take me to the hospital where I would be injected to calm down and thereafter admitted to the hospital. The medication would start working immediately, but I was misusing it by giving it away to my friends instead of taking it so that I could get better[...] The only problem was that I was wondering whether I was going to be taking the medication all the time, but I also knew if only I could stop using the hard drugs I would be able to concentrate on my education.

Kanyonge's mother clarified that she made treatment decisions for him only in limited circumstances.

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243 These are all illicit substances, and alcoholic drinks.

*Kanyonge's mother:* When he was confused and even when you speak to him you would notice that he is not hearing or understanding anything. So in such situations I would normally seek help by sometimes even calling the police.

Despite not seeing it that way at the time, Kanyonge stressed how his mother helped him a lot.

*Kanyonge:* My mum was very caring because she received me the way I was, took me to the hospital where I came to know some doctors[...] They were giving me medication that was making me stable[...] I was admitted to the hospital because I was in a very bad condition. I was not able to stay with my mother at the time because we were always quarrelling. At that time, I did not understand that my mother was assisting me, but afterwards I got saved and left all the bad things I was involved in at that particular time[...] I also did not have friends who would have advised me and showed me that my mother was assisting me and even make me realise that going to the hospital was for my own good.

His mother decided to move to one of the provincial towns so that she can remove Kanyonge from bad company and afford his school fees so that he could finish secondary school.

*Kanyonge:* My mother was asking me what kind of a life I wanted and I would tell her that I wanted to live a good life, a life that would enable me to be productive and help myself. Have at least something that I am doing with my life. Like now I have taught myself to look after livestock, you know.

Currently, Kanyonge works as a casual labourer: "When I get a job and earn some money I share it with my mother."

His mother explained that Kanyonge gains such employment through a government-funded programme to create employment for youth. Kanyonge and his mother make joint household decisions and Kanyonge helps with any household chores. His mother noted "if he was living alone that would be different, but because we are living together we must discuss and agree on issues."

In his free time, Kanyonge likes going to the local church "so that I can listen to the preaching like on how the youths should be engaged in productive living and also not to be involved in bad things."

Kanyonge feels supported and likes listening to advice from people around him and applying it to his life. He still appreciates his Mother's advice.

**Kanyonge:** Even now she normally tells me not to keep the company of certain people. Sometimes I tell her the way some people I was with were talking so that she can advise me[...] I take that seriously you know she is an adult, older and also wiser. She has also seen different aspect of life so I humble myself before my mother and I do not ignore what she is saying.

He also attends a counselling service, and a local clinic where he appreciated the advice of the doctor.

**Kanyonge:** You know they are talking to us about certain issues that can make a person to develop a mental condition.

Even the doctor was telling me that if I want to be successful it is good for me to be busy. It is not a question of taking medication and expecting to get well.

Kanyonge makes all his healthcare decisions nowadays.

**Kanyonge's mother:** Now, because he is better, he is the one to take his clinic card and remembers he is supposed to be going to the clinic on a specific date.

In the future Kanyonge "would love to reach a point where I can say that I have improved, continue taking medication and also take care of myself."

### **Yusuf, a man in his early 40s who lives in a provincial town**

Yusuf lives with his second wife and child. He works as a secondary school teacher. He initially studied Agriculture.

**Yusuf:** I was helped to choose a course which I did not know much about[...] But one month later I started having emotional problems adjusting to university life and therefore chose to change the course to Bachelor of Education.

Once Yusuf finished university, he obtained a job in one of the provincial schools. Although he didn't want to work there, he found that he had no option.

**Yusuf:** I never wanted to go and work there because it was far away from the town. When I went to the employer they told me either to go to work there or leave and if I left I was not going to get employed anymore by the Teachers Service Commission." After three years, "I had a mental breakdown and went to stay with my brother. During my stay there, I kept going to the TSC for a transfer and eventually I was transferred [closer to my family].

Yusuf didn't experience reasonable accommodation in his work.

*Yusuf:* When you take medication, you feel sleepy during the day. You doze a bit and sometimes you feel you are affected by these drugs and not at your best. It affects my lessons and I had to go to the Human Resource Officer to complain about it. I was given a letter to take to school so that I could start my lessons from 10am[...] Sometimes they give me a duty which starts at seven and I have to arrive at school before seven, which am not very comfortable with, but there is nothing I can do about it[...] When you complain some of the workers come in and say that if you are not able to work you should leave the job[...] I wish there was an alternative where I could manage myself like in business, more flexibly.

His wife explained the difficulties with giving Yusuf early morning duties.

*Yusuf's wife:* He looks as if he is much stressed[...] This affects him in a significant way[...] the medication is still much active in his body.

She noted how he had more understanding when he worked under a Principal who changed the previous term.

Yusuf was married before and has two children from his first marriage. His former wife restricts the contact he has with children and breaks arrangements.

*Yusuf:* You can do nothing about it. For example, there was a day the kids were on an outing and I went all the way to [see them], but she broke my phone and told me she did not want me near them[...] She thinks I am not supportive of them and I don't give them enough money. She is always demanding for more money from me and when I don't give her she becomes very aggressive.

Many of the decisions Yusuf makes are driven by finances.

*Yusuf:* I do not have money, that is why I ended up staying in the rural areas, because it's cheaper than the town.

When he tried to take a loan to address some of his financial difficulties, Yusuf experienced discrimination.

*Yusuf:* They said I was sick and I could not manage the money. They had approved the loan but when I went for the money they refused it. The manager was actually told about my condition by someone, that's why he changed his position about the loan[...] I had to apply for another one with another branch of the same bank, where they did not know me. I started by applying for the loan afresh after which they gave me the money[...] [Had they known about my condition]

I strongly believe they would have behaved like the other branch[...] I thought they were not doing the right thing because I was supposed to access the loan just like any person[...] The loan was secured against my salary and I had worked with the TSC for more than 10 years[...] If they were not asking security from other people, why were they saying that my condition was not good? This was not explained to me as a pre-condition in the loan agreement.

It is relevant to note that one of the key reasons why Yusuf wanted the loan was to afford better healthcare.

**Yusuf:** Part of the money [was to pay] for my medication. I wanted to go to a good hospital and see that I am taken care of properly, but when they denied me the money I ended up in Mathare [psychiatric hospital] and had to survive in hard conditions there.

Yusuf is concerned about the conditions of hospitalisation he has experienced to date.

**Yusuf:** You feel like you are in the wrong place at the wrong time. You feel as if you are not in the hospital. You feel as if you have come to suffer.

His wife is also concerned about the conditions in the hospital and aims to help avoid Yusuf's hospitalisation.

In general, Yusuf has varying degrees of control over his healthcare decisions.

**Yusuf:** When am not very sick I make my own decision on when and where I will go to the hospital, but sometimes when the illness is very high and I am not cooperating, then I am taken to the hospital by force, mostly by my brothers.

Yusuf likes having control over his support and any treatment offered, but finds that such information is not readily shared in different hospitals. Equally, his family members don't always respect his wishes. In such instances, rather than being offered information, he finds he is treated in a manner that doesn't comply with his wishes and strips him of his dignity.

**Yusuf:** The second time I volunteered to go to Mathare [psychiatric hospital]. [It happened at the school and] I told the teachers to be taken to the police station[...] when I waited long for my brother to come and I was so sick, I saw that I was becoming too much for the school[...] so I requested them to take me to the [police] cell because I was becoming a nuisance[...]

When my brothers came, I requested to be taken to the hospital together with a policeman[...] There was a time I was in Mathare and I saw people being brought by policemen instead of being tied up. The policemen were guarding the person but

when I requested to even pay him for the service [of taking me to hospital...] I was told no. My hands were tied from behind and my legs and I was bundled to the back of a vehicle[...] I think they saw as if it was wastage of money when I was saying I will pay the policeman and they thought that the money could be used in another way. I think they were money minded[...] and they valued that more than my freedom[...] I felt like an animal going to a slaughter and I had no choice[...] They should not put money in front of the sickness. You know they use a lot of money for other things. They should treat me like a human being, even if money is to be used.

Instead, Yusuf wishes to have support and be listened to.

*Yusuf:* I think if you have people who care for you and people who love you, people who will tell you 'Look here, you are sick and we are taking you to the hospital' and also give you a chance to express yourself in terms of what you want, then you will cooperate. But if you are forced, that is the time things get worse[...] You feel traumatised, you feel the decision made was not in the right direction[...] I think the family should be aware that when they have a sick person they have a duty to ensure that he is respected as a human being. They should also help the person to make the right decision, rather than seeing the person as a bother to them[...]

It would be good if there is a group of people with an office near which advocates for persons with mental disability, that when you have a problem you can go to their offices and they can assist you with decision-making other than making decisions on your own and at the time when you are sick.

His wife confirmed how she tries to support him in a way her husband finds comfortable and adheres to his will and preference, even at the times of a crisis.

*Yusuf's wife:* He is just like anyone else and should be allowed to make decisions just like any other person[...] We have never reached that kind of a situation where we had to use the police. Even in times like that I would use a different approach[...] I normally involve his best friend who he can listen to. So that would be my first option before involving the police or even other persons to take him by force to the hospital. He normally listens to him and once they sit down and speak he settles down and he is able to make his own choices in a better way[...]

One time he started by getting angry[...] I asked him that time whether he wanted to go to the hospital and he decided he would like to go to Mathare and stay there. We even started preparing for the journey, but we started arguing about going to the hospital and I realised this was getting worse off because of the argument. You know, he wanted

to go to Mathare and people are not normally treated well there, so I did not want him to go, although he was insisting on it. He had explained all these things to me about the situation in Mathare when initially he started getting sick. I did not want him to go and live in those kinds of conditions. I told him to go and wait for me in our neighbours' place, who is like our mother. After talking to her for about one hour, he came back into the house when he was completely okay. I also showed him that I was supporting him in anything that he wanted at that particular time and this cooled him down.

She uses the same approach in relation to family decisions.

*Yusuf's wife:*

He likes to be in the company of other people so that he can cool his mind during daytime when he is not working. For example, when we are with him, we keep on communicating and even discussing what we can do as a family. I know that through talking he becomes more settled and we are able to come up with ideas together[...]

He is normally very troubled when we are having family issues, for example, on finances. During that particular time I like sitting down with him so that I can understand what he is going through and support him accordingly. If we don't look for solutions he is likely to be affected more and even get sick[...] When he makes family decisions I normally support him as much as possible and even when the decision is not very good, I try to explain to him on the need to adjust or change a couple of things in that particular decision.

When you live with your husband most of the decisions are made by him, for example, on where to live. He also takes responsibility as a husband and also the man of the house[...] although he cannot do anything before consulting with me.

She stressed that her husband would have far less control and wouldn't be treated as well if he wasn't working.

*Yusuf's wife:*

You know, naturally when you have money you are perceived like an important person within the society, but a person who has nothing is treated in a bad way by other people. The same thing would apply to him because he would not even be able to stay in his current condition. I think if he did not have a job he would have committed suicide due to high levels of stress.



## **Chumo, a woman in her late 30s who lives in a provincial town**

Chumo is the oldest of six siblings. When she was growing up, she experienced abuse at home, as she had a psycho-social disability from young age.

**Chumo:** There was one time I refused to take medication for one month and I was beaten up by my father[...] He had a very bad temper. He also used to beat me up when I would refuse to go and take care of the goats[...] I was feeling very bad but I would not tell him anything because he is my father.

Her family also used to lock her up in the house: "They were saying it's because I was too sick and getting out of control."

Chumo finished primary school, but struggled to complete it.

**Chumo:** I was not performing well so I had to repeat Standards 4, 5 and 6. When I was in Standard 7, I started hallucinating and was very sick. My parents did not understand and because I was very young they thought that I did not want to go to school or maybe I was pregnant and that I was pretending to be sick. When I was in Class 8 I took some poison and that is when my life was ruined completely[...] The poison I had taken had really affected my brains[...] I decided not to proceed to high school because I was not feeling well[...] I was collapsing a lot even during the parade and also during class time.

Despite not proceeding to secondary school, Chumo still wanted to proceed with her education: "I requested them [my parents] to take me for a course because I had always decided to be a tailor and I was also thinking about my future life[...] My parents separated at that point and my mother went to another town".

Chumo was taken in by a benefactor who "was a very staunch Christian and even took me to Tanzania so that I could be prayed for[...] so that I could get healed and also to find a job." Chumo liked this as she wanted to feel better and to see another country.

Once she returned from Tanzania, Chumo started working at the local hospital, where she was given a proposal of marriage.

**Chumo:** I met a watchman[...] who told me that he had a brother with a mental health condition and that we could live together with him as husband and wife[...] I did not exactly want to get married but I wanted to be with a person who could pray for me and this guy was a born again Christian and that is why I was listening to him[...]

I had doubts but I did not have a place to live. We started living together and I would help in the farm and other household chores, but what made me scared and run away was they wanted to circumcise me. The family told me that I could not continue staying with their son if I was not circumcised and that's when I decided to run away[...] I realised that was also a bit risky and anything could happen to me.

After running away from the family, Chumo got to the town she now lives in, but was homeless.

*Chumo:* I used to sleep in the streets. I would get into a sack and sleep since I did not have a place to live[...] I feared that my family and relatives would reject me because I was taking medication for my mental health problem and also the ARVs.

Chumo doesn't know how she contracted HIV and suspects that it happened when she was raped – something that happened frequently when she was living on the street.

*Chumo:* Some men would come and agree with the watchman that they would sleep with me during the night, though I have asked God to forgive them. I was being forced by the watchmen[...] They were saying it was a way of welcoming me to the town[...] [If I would refuse them] I would be battered by them and also the watchmen.

She did report the violence to the police, but they didn't take her claims seriously due to her psycho-social disability.

*Chumo:* I was very sick at that particular time; I would go to the station screaming instead of talking to them in a soft voice so they would say that I am mad. They would just calm me down and tell me that they will warn those particular persons[...] Some of the policemen would give me some money and tell me to forgive the perpetrators since I am a Christian and I go to church. I would come back, start crying and screaming within the town. People would think that I am pretending and some of them would even mock me, telling me to remove my clothes[...] Most of the men [who raped me] were drug addicts and if you take that kind of action against them they can even beat you up. I was scared of what they would do to me.

Chumo has had several hospitalisations, but now just attends the local clinic. Her friends now help her prevent hospitalisation, by helping her identify any early warning signs of a mental health crisis.

*Chumo's friend:* When she starts becoming unstable, she becomes abusive like, when you tell her she is smart she will sometimes abuse you for the whole day, but she is not violent in any way. We normally talk to her and advise her to be calm when she is spoken to by people during such a period[...] She is very active when it comes to going to the hospital. I have known her for over 10 years and in that period she has never been admitted.

Her friend also helps her to be able to talk to the doctors and ensure she is listened to.

*Chumo's friend:* I was even requesting the Doctor to give Chumo a card which contains her specific details so that she can be able to produce it to all the doctors, so as to avoid any misunderstanding.

Chumo had a difficult time coping with her psycho-social disability. At times during the interview, she referred to herself as “the mad lady” as that is what she used to be called in the town where she lives.

*Chumo:* It's because there was a time I was removing clothes and walking naked in the streets[...] I felt bad [when they called me a mad lady] because they are not treating me like a person sometimes. I even started abusing them with very tough words.

Chumo's friend acts as her carer and aims to help protect her from any abuse, to ensure that all such issues are addressed. Chumo noted: “[She says] I should try and address the issue by telling her first, so that she can talk to that particular person.” This is relevant as Chumo feels that “some of the adults [in the community] are very hostile and unfriendly.”

Despite such experiences, Chumo takes part in community life. In her free time, “I like participating in church activities very much [...] I normally like going to fundraisings very much and also weddings.”

Chumo now lives alone and does occasional work at the town she lives in. Her friend helps her with the work.

*Chumo:* I am sometimes sent by business people to bank money for them [...] and then am given a small fee. People here trust me a lot and that is why they like sending me [...] I mostly sell clothes on a commission basis.

*Chumo's friend:* When she is doing this I normally assist her in managing the transactions by taking stock of what she is given at the beginning of the day and also we reconcile everything with her at the end of the day to determine what she will take home as her pay and also the amount that is owed to the dealers. This is mostly so when she makes large financial transactions which might be confusing her[...]

Some people tend also to take advantage of her when they realise this but she is very much aware about how much she sells every product[...] So I can say that in terms of work she is able to do it effectively and also she chooses to do the work that she enjoys most, like selling clothes and being sent to the bank.

Chumo likes her home and her circumstances and feels settled.

*Chumo:* It's a small house but I like it very much[...] I am currently very happy where I am living right now. You know the neighbours and also the landlord is very friendly. They even take care of me when I am not feeling well, that is why I would not like to go to a different place.

Chumo's friend stressed how both the community and the government need to change their attitudes and support offered to people with psycho-social disabilities.

*Chumo's friend:* The government should be able to provide support to them [people with psycho-social disabilities] so that they are productive like the way Chumo is being supported by our community[...] The community should love these people and also show them that they are human beings just like any other person and we should not refer to them by the use of bad words. People should know how to communicate and deal with people like Chumo.

### **Githinji, a man in his early 70s who lives in a remote village**

Githinji lives with his wife and children on the land he inherited from his father, explaining "I really enjoy living here". He did not develop a psycho-social disability until he was nearly of retirement age.

*Githinji:* I was working in a shop that was selling spare parts. I also had a side business of making sculptures. But later on, towards the year 2000, I started having severe headaches, a very bad temper and also problems with my sleep, so I decided to resign from my work the following year and came back home. I was feeling quite unwell and felt I could no longer cope with my job. Sometimes I was using a bicycle to make deliveries and also collect money, so I thought it was a bit risky when I was also not feeling well.

He tried initially to discuss his feelings with the employer, who didn't show much understanding.

*Githinji:* So instead of quarrelling with him, I decided to just resign from my job and gave them my notice. The only problem is that they were refusing to pay me my benefits[...] I was assisted by a lawyer who used to work for the government in getting me my money[...] because he was feeling that my rights had been violated.

While he sought healthcare for his psycho-social disability, Githinji has had mixed experiences to date.

*Githinji:* When I go to private hospitals they are more interested in my money not anything else[...] I normally go to a hospital where I have my own personal file. There is one doctor who comes from Nairobi and normally he is very good. He sits down with me and reads my file after which we discuss things with him.

However, this doctor was replaced and the new one put Githinji on medication with strong side-effects: "I told him [about the side effects] but he did not take it seriously. He told me to either take them or leave them." His wife explained that problems only occur if he cannot access healthcare "due to charges associated with the service, because of a lack of resources[...]. He got very worse and even started forgetting a lot."

Githinji spends his days doing "a lot of work around the farm. In fact, he is very hardworking" (Githinji's wife). Githinji is also the village elder.

*Githinji:* I am normally involved in a number of things within this community. Although I really want to leave the job [as the village elder], but my people keep on insisting that I should stay[...]. It is only that I want to bring change to the community and people also like me very much.

Githinji's wife would also like for him to quit this role.

*Githinji's wife:* You know, leadership has a lot of problems and also some people are very high tempered, so when he comes into contact with them, his stress levels become very high which is not very healthy for him[...]. But since most of the people in the village like his leadership, he feels he cannot leave them just like that as they are his people.

None of Githinji's fellow villagers, however, know about his psycho-social disability. Githinji's wife feels that if they would, "they might think he will not execute his work properly".

Githinji noted how he makes all the decisions in his life.

*Githinji:* You know me, I am an old man who is very wise and well matured so it's very difficult for people to make any decisions for me because they respect me very much.

His family aims to assist him, particularly with his forgetfulness.

*Githinji's wife:* We have employed someone to assist him as he does his work around the compound. I think he would really suffer if he did not have people by him throughout the course of the day, especially because he is very forgetful. It would be very difficult for him to do anything meaningful in his life.

She added how the manner in which Githinji is supported is very important.

*Githinji's wife:* You must know how to tell him so that you don't look disrespectful. You know, as the man and also as the head of his family you might tell him something and he perceives it as if you are belittling him. This is challenging in its own way, but since it's me who handles him most of the time, I know how to address him so he does not get angry or agitated in any way, as my husband.

### **Majani, a woman in her late 30s from one of the provincial towns**

Majani lives on her husband's homestead with her child and mother-in-law. She was the youngest of five children in her family. Majani only finished primary school as her parents couldn't afford the secondary school fees. However, her older siblings "were men, so all of them were taken to high school". Hence, Majani thinks her gender is the key reason she wasn't given an opportunity to continue her schooling.

*Majani:* Of course, they were thinking I am going to get married sooner or later[...] I felt bad but even when I spoke to my parents they insisted they could not afford [to send me to school] so I also felt I did not have any other choice other than to get married.

Prior to having her baby, Majani had two miscarriages: "I think he [husband] indirectly blames me for it." It was his subsequent decision not to have more children, contrary to Majani's wishes. He didn't share her desire to have more children with him.

*Majani:* [My husband] normally assaults me very much so I would never like to get into an argument about it. I feel bad [about it] but there is nothing I can do.

Majani spends her days looking after her baby, the homestead and her mother-in-law who is has a disability. She would also like to work, but her husband doesn't allow it.

*Majani:* He just says that I should stay at home and watch the homestead[...] I told him [I'd like to work] but he became very aggressive and almost beat me up [despite] not even providing enough to support us.

Majani's husband works in another town and brings other women home. When she asks about why he does that, "normally he starts beating me up." Her mother-in-law appreciates Majani's support and feels "it's like my son has abandoned us." However, she thinks that Majani is "very happy living here[...] I think [their relationship] is okay but they have their own challenges just like any other family."

Majani doesn't feel she can change her situation, although if she were able to work she would gain greater respect.

*Majani:* Sometimes I want to go back to my family but they also live in abject poverty so I don't have any other choice but to stick around with him. I think [my husband] treats me badly because I have nothing and am from a very poor family.

Majani visits the clinic at the local hospital and is happy with the support she gets from the doctors. She is also a member of the local women's group and feels supported by them.

*Majani:* They know about my condition and they take me just like any other person. They normally even give me the opportunity to express my views. They listen and take my opinions seriously.

Her mother-in-law noted "she likes interacting with other women in her group in this village[...] they even bring some of their meetings here, at our home." However, Majani doesn't share with them what happens in her home life.

### **Roshni, a woman in her early 50s from a remote village**

One of eleven children (six girls and five boys), Roshni only finished primary school up to Standard 7 "because of a lack of school fees[...] I felt bad, but there was nothing I could have done about it." Her parents were able to send some of her siblings to secondary school and the decision wasn't based on gender, but on whether they could afford their children's education at the time: "my parents used to treat us all the same and all of us were able to get education on an equal basis."

Roshni lives with her husband and three teenage children on their homestead. She spends time looking after her home, farming and knitting. She sells her knitting in the village. Roshni would like to set up a business but feels she lacks capital for that.

*Roshni:* We don't have enough money to buy the materials required for me to constantly engage in the activity.

However, her husband noted that the villagers like her knitting so much that "some of them even pay her in advance, especially when she says she does not have the capital to buy the materials required, so that she can purchase them and start knitting."

Roshni started experiencing mental health problems when she was in her late 30s. It was her husband's decision to take her to the hospital.

*Roshni:* There are times that I completely lose myself and am not even conscious of what is happening. In those circumstances, I normally refuse that I am sick and don't even want to eat, bathe or even go to the hospital. In such situations, my husband is the one who makes the decisions for me.

[At such times] I am normally tied up with ropes, taken to the hospital and given an injection after which I start feeling better, though it has not happened in a long time. I am normally very difficult during such times and it's important for me to be taken to the hospital for care. I think they normally do not have a choice.

Roshni's husband finds this distressing, too, but feels that is the only option.

*Roshni's husband:* She insists that she is not sick and yet all of us, from her behaviours, we certainly see she is unwell. Unfortunately, we have to use force and tie her up[...] I know it's no good, [but] we cannot live with her like that and I must use all means possible to take her to the hospital.

This hasn't happened for a long time, because Roshni's and her husband are able to recognise early warning signs of her distress and agree together what they will do.

*Roshni:* My husband is able to identify when I am getting very sick early enough. In such instances, he normally discusses it with me, then we go to the hospital together and we are able to avoid a serious crisis[...] He is the one who takes care of me so he understands me very well.

Roshni's husband also helps her advocate with the doctors at the hospital outpatient clinic, such as when Roshni experiences negative side-effects of the medication she is provided.

Roshni's husband explained how he learned to support her.

*Roshni's husband:* I even went for counselling so that I could learn how to live with her[...] It was in the church and mainly we were being taught on how to understand the person that you are married to and how to live with them. It was very helpful[...]

I try to love her as much as possible. She can even tell you that I even cook for her when she is not feeling well[...] We support one another as a family[...] The first thing is that we need to get close to her so that we can understand her needs as a human being and also so that she can understand us. After this, it will be easy for you to communicate with each other and even share in case there are problems.



Indeed, when not in a crisis, Roshni feels supported and confident to make her own decisions and contribute to the family life.

*Roshni:* When I am not very sick I can make decisions for myself, although I have to consult my husband since we are a family, but when I'm in a crisis, my husband normally makes them for me because am not in a position to[...] I prefer my husband to take care of me in such circumstances.

Roshni also feels supported by her villagers, who have knowledge of her psycho-social disability.

*Roshni:* They love me and my work very much[...] They feel very bad, especially when I was sick[...] They would come looking for me to wish me a quick recovery and also to say that they miss my work.

However, Roshni's husband is concerned that not all villagers provide her with the same level of support.

*Roshni's husband:* It depends, people are very different. Some will refer to her as a mad person, but others will sympathise and make her know that she is just like any other person. The majority of them say that she is mad, especially when they see her passing. They say this despite the fact that she has never done anything wrong or even abused them, even when she is seriously sick.

Her husband encourages her to take part in the women's group for additional support, which Roshni enjoys, too.

*Roshni's husband:* When she goes to the women groups, by the time she comes back she is very happy and in a very good mood. But when she just sits around in the house, you can see that she is sometimes lost in thoughts. So I encourage her to interact with other women as much as possible. When she is here she might be thinking a lot about the [financial] challenges here at home, but when she goes out, they talk about general things and in the process of talking out issues, I think she feels better[...]

They do love her very much and mostly they keep on reminding her that she is a very nice person. They normally tell her that they would be very happy to have a home like her own. That makes her appreciate herself and realise that she might not have as many challenges like other people. This influences her mood positively.

## Onyango, a man in his late 20s from a provincial township

Onyango lives with his parents. He started experiencing difficulties in Form 1 of secondary school: "I started having behaviour problems and also being in bad company, so eventually I was expelled from school." His mother explained that in Form 2, Onyango was "also taking drugs [...]" and due to this he was having a lot of problems."

Despite this, Onyango continued his education. Based on his father's wishes, he started an IT course at the College. He did not complete it as, in the end, "I found the course to be challenging and difficult so I dropped out."

Onyango now has a sponsorship for a course to become a car mechanic. Again, he wanted to do another course, "but the sponsorship was only for a technical course[...] I would have liked to do something like medicine." He was even advised not to undertake the course by the doctor and his family.

*Onyango's mother:* Because of his mental health condition[...] the doctor was saying that the course would be very difficult, but eventually he was able to go through the course and even pass his examination.

He now works as a casual labourer. With the money that he earns, he gives some to support his family.

*Onyango:* This makes them appreciate me very much[...] People tend to respect you more when you are bringing something home.

Beyond his education, Onyango makes all of his decisions, "though sometimes I drink alcohol a lot". His family is not happy about it. However, he does feel that his family restricts his movements, although his mother spoke of the way in which she wants to guide and support her son.

*Onyango:* My mum normally tells me not to come home very late, because it's risky, but I normally go everywhere I choose or wish[...] I am an adult.

*Onyango's mother:* The only thing we do is to advise him not to be staying very late because of security reasons[...] I normally tell him he can invest his money, for example, in rearing chickens or goats, because this will help him to grow in life. He is normally very positive about it. I normally advise him to tell us what he wants to do so that we can support him. You know, at his age, it is very difficult to make choices for him.

Onyango attends an outpatient clinic each month and likes the relationship he has with his current doctor.

*Onyango:* [The doctor] is very good, I even have his telephone number. Sometime when I don't go to the hospital, he will even call me up to ask how am doing and why I did not go to the Clinic...I [then] feel very good, because he really loves and appreciates me.

His mother noted that he appreciates the treatment, “though sometimes he refuses to go, especially when he does not have money. You know, he cannot be treated without the cash, since it’s a cost sharing programme[...] The other problem is that he refuses to take the medicine due to the side-effects.”

Onyango doesn’t like the side-effects of some of the medication he was given when treated by force.

*Onyango:* They [two men] just came at home and told me that they were policemen who wanted to take me to the hospital. I told them I did not want to go for the injection but they took me into a vehicle by force. When we reached the hospital, I was injected by force[...] They should have listened to me. There is another doctor in another hospital who works with a drugs agency who came and taught us about drugs and we discussed my problems [with side-effects], after which he gave me a prescription and I was doing very well.

When I got sick again, I went to a different doctor who started injecting me without even referring to the notes from the previous Doctor. He also gave me injections for other things, for example, he was saying that I was using hard drugs, which was not true[...] the previous doctor had certified that. This really made me feel bad.

Such experiences cause Onyango to lack trust in doctors and in his family: “the only people that I share with are my friends because they understand and listen to me.” His mother explained how she felt that the family had no choice but to force Onyango to have medical treatment.

*Onyango’s mother:* When he was very sick, he used to refuse, you know, this is normal for most people with mental health issues, but later on he started getting well, and we have not had any problem with him[...] I have no idea [if arranging forced treatment was a good choice] but maybe we could tell him to agree to go to the hospital on the promise we will do something that he likes[...]

We normally encourage him to express himself, especially in what he would like to do in his life, so that we are able to support him[...] We would not like to make choices for him, since he is a grown up, because we might tell him something which he does not want to do.

## **Kariuki, a man in his early 30s who lives in Nairobi**

Kariuki lives with his family.

*Kariuki:* I find it easier to live with my family. Firstly, because of issues to do with costs[...] At some point it might be nice to get my own place and be completely independent. I also find myself to be useful within my family, because I support them in a number of ways.

His mother said the family appreciate Kariuki's support and presence.

He experienced difficulties all throughout his primary and secondary school education, which finally resulted in his first hospitalisation.

*Kariuki:* In primary school I was very withdrawn and felt like it was a prison sentence, so I used to look forward for the classes to end so that I could go home[...] I did not share this with my parents, I was a very reserved person, more like an introvert[...] I think they did notice and mostly thought that I was a shy person and again in school we were very many, so the teachers could not pay personal attention to all of us.

In high school it was pretty much the same thing[...] I did not talk much. I did not know how to express myself, so it was difficult for those around me to know and understand what I was going through[...] While I was in Form 3, I was taken to a psychiatrist, since I was a loner and not socialising with other students. That was the first time I was admitted to hospital[...] It was a joint decision by the doctor and my dad, since my mum was away from home. This decision was reached mostly because one of my brothers had committed suicide and my parents did not want it to happen again in the family[...] I was not involved in the decision, but I was physically present.

The doctor did not talk to me directly, he only talked with my dad and they both decided that the best course of action was for me to be admitted[...] I think because I was a very withdrawn person, I was used to decisions being made for me, and consequently I did not see anything wrong with this. And again, I was still relatively young[...] I also think since I was in a very deep depression, I did not have the capacity to say yes or no. Maybe because of my personality or the illness – I just went along with these decisions without any objection at all.

Kariuki subsequently completed a degree of his choice. He changed his programme of study, as "in the first university I fell sick before the end of the first semester and I was hospitalised. I decided not to go back, because I had to disclose why I was in hospital and people started treating me differently." His parents supported his decision to change universities, as they realised "they would be putting me in an environment that would make me sick again."

Kariuki mainly spends his day at home or working.

*Kariuki:* To some extent, it's my personal choice, but it's mostly because this is the only natural choice and I don't have any other alternatives[...] I think I have limited myself, since I get offers to even attend parties, but am simply not an outgoing person. I limit myself maybe because of self-stigma, or maybe the way I perceive myself.

In his free time, Kariuki attends a peer support group and his mother noted that they "really help him, even when he's low."

He also finds that his current employer accommodates for his psycho-social disability.

*Kariuki:* He employed me to work as a consultant, not a full-time employee. He also allowed me to determine which hours I worked and even allowed me to work from home. This really helped me to be productive and also keep my job. Once he gave me these options, I was able to work more efficiently. He even spoke to the other employees about their attitude to ensure that my environment at work was good.

He now manages his own treatment with support from the outpatient clinic.

*Kariuki:* I talk to my Doctor regularly[...] What I have come to understand is that I have to take responsibility for my own condition. I have also seen the adverse effects of not taking my treatment, not just on myself, but also the other members of my family.

To date, Kariuki has experienced four hospital admissions. The last one was 5 years ago. Kariuki's mother stressed that "he has understood his condition" and hence can manage it himself. The family no longer makes treatment decisions for him. He has never been treated by force, which he explains is due to his personality.

*Kariuki:* I have never really put any kind of resistance. Once they have said that I am not feeling well and not fit to be at home, then I would just comply and agree to go to the hospital[...] It might be different now, but at the time, I did not see anything wrong with it, since I did not know anything better. I would say that I don't want to go to the hospital, but on the other end, I realise that they were not comfortable with my situation[...] That is an issue of trust. That they could see it and I couldn't see that I was unwell. I simply trusted them.

He found that he did not get consulted while in hospital, due to a lack of understanding by staff in respect of his psycho-social disability.

*Kariuki:*

The hospital simply assumes that you are not capable of understanding anything. The nurses would also make some funny comments, saying that we are very young to get depressed. This was very offending to me, since it made me feel guilty that I was just wasting my family resources [to pay the hospital bills].

At that particular time, I had not really developed my personhood, so it did not matter to me who made the decisions for me, since I just wanted to get out of the hospital[...] I just felt like I was in prison[...] So I would do whatever they wanted. I think I did not have my voice, therefore I could not appreciate the distinction between the ability to make my decisions and my rights. The illness made me feel as if I was a lesser person and I had agreed with that faulty perception and this limited my ability to make choices in life.

Kariuki feels he would now react differently and take more control over his life.

*Kariuki:*

Right now, it would be very different, because I would not agree to be hospitalised by force. I would only accept it if evidence was shown to me that I needed to be admitted. I think it's the whole process of personal empowerment. Firstly, I have been able to do some thinking for myself, like completing my degree and also being able to work. I have taken loans and have been able to repay. This has helped me to realise I can be able to make choices for myself. I am no longer the lesser person I used to take myself to be.

### **Wambua, a man in his late 30s who lives in a slum district**

Wambua lives with his wife on the outskirts of Nairobi. He has a degree in engineering and works on contracts. He started experiencing mental health problems and misusing substances while studying at university. The choice of the degree was his father's.

*Wambua:*

He said this is an opportunity he has gotten for me to better my life. At some level I protested about it, but all he said was that I can't quit[...] I felt like it was some sort of blackmail, since I did not have any support of my own[...] I lost my esteem and felt powerless.

Due to his substance misuse and psycho-social disability, his family made a decision to send him to a rehabilitation centre without his consent.

*Wambua:*

They would just tell me that its either I go to the rehab or vacate this place. This left me with no choice and I had to comply with their wishes since I did not have any other place to go and was dependent on them.

He found the forced treatment has had a negative effect on him.

**Wambua:** I remember back in the year 2000 when I was taken to a certain doctor in town who put me under psychotropic drugs and later took me through ECT[...] He did not consult me, he just informed my family and they agreed[...] I actually did not know what he was doing and I was not consulted in any way[...] I felt stigmatised and traumatised. I also did not like the fact that they were viewing me as a helpless person[...]

I lost my memory and I don't know what happened, because, since that treatment, I suffer from things that I cannot explain, for example, memory lapses. I don't think it's my mental health problems that messed up with my emotions[...] Sometimes I harbour resentments about this. They continued putting me on cocktails of psychotropic drugs which finally did not work for me[...]

[Instead] they should have first gathered enough information from me in regards to the problems that I was having, because I feel that nobody has an insight of what I was going through. They should have walked together with me and this would have helped me to make better decisions[...] It's only when I addressed my issues that I was able to get much better.

His family also wanted to make decisions as to whom Wambua should marry.

**Wambua:** I would refuse, since it was not my own initiative, but they were doing it to suit their own interests[...] This was giving me a lot of pressure, because it was not out of my own will.

He is now married to a wife who is "100% my choice." While his family was initially apprehensive, "later on, after realising I made the right decision, they have been very supportive."

Wambua is a member of the security team in his neighbourhood and attends the local church. His wife added that he values attending a support group for people with psycho-social disabilities. In relation to the community where they live, Wambua's wife added "people are very different; some will treat him well and others might not want to associate with him."

Wambua finds that his work peers are supportive of him, despite knowing of his psycho-social disability. However, he would like to have another job, as his pay is low. Wambua thinks that his options in that respect are limited as, "I am not very good at taking risk and it's not very easy to get a job nowadays."

While he now manages his own finances, Wambua did note that he used to spend most of his money on alcohol. He now finds the best kind of support making decisions with his wife.

*Wambua:* [We] set out the priorities and see how we can spend what we have.

However, Wambua's wife she was of opinion that "sometimes he consults me, although most of the time he decides on his own[...]. Since he works he is the one who decides how to spend his money."

Due to limited resources, Wambua is also unable to move home, yet "would prefer to live somewhere better."

Beyond financial limitations, Wambua feels his main problem is that his family made most of the decisions in his life for him.

*Wambua:* But since I discovered myself, before I get into something, I normally ask myself is this my own initiative or am I being compelled by another person? This has really helped me in making my own decisions.



## Appendix 2

### Study Methodology

#### Phase One: Legislative compliance and data collection

Part One was an analysis of all relevant legislation and policies. This identified how issues related to and impacting on legal capacity were covered by national legislation including through:

- assessment of the legal procedures for initiation or termination of guardianship and the rights of the parties in such procedures, as well as the areas of law which remove rights to related to the exercise of legal capacity (e.g. property rights, voting rights, family rights, etc);
- examining the evidentiary standards in guardianship proceedings;
- documenting issues related to the human rights of persons alleged to lack capacity throughout the guardianship process;
- assessing the various legal determinations of incapacity;
- analysing the power and authority of guardians, their accountability and how they are monitored, as well as the processes, if any, for bringing complaints against guardians and resolving disputes between guardians and people under guardianship; and
- assessment of appeal and review proceedings on determinations.

The analysis was conducted through review of legislation, policies and procedures as they apply or may apply to people with intellectual disabilities and people with psycho-social (mental health) disabilities in Kenya. Assessments on the basis of human rights standards were conducted by a senior lecturer from Moi University, Kenya and MDAC's Legal Officer.

From 20 April 2011 to 18 June 2011, prior to the primary qualitative research discussed below, the lecturer from Moi University conducted structured interviews with two judges, two magistrates, eight lawyers, five community leaders, three psychiatrists, two police officers, two officers at the Kenyan National Human Rights Commission and one official each from the Ministries of Health, Education, Social Protection, Education and the Public Trustee's Office to explore their understanding of the right to legal capacity under Article 12. He also held focus group discussions with 10 family members of people with psycho-social (mental health) disabilities, 10 family members of people with intellectual disabilities, and with 10 adults with intellectual disabilities.

## Phase Two: Primary qualitative research

### *Data gathering*

Data gathering was conducted through semi-structured interviews and through focus groups. Semi-structured interviews were carried out from 2 April to 31 May 2012 by Anne Wambugu (MA Social Work; experience of working with people with intellectual disabilities) and Michael Njenga (Head of Programmes for the survivor organisation “Users and Survivors of Psychiatry Kenya” - USPK). MDAC prepared an interview guide and the researchers were trained on how to use it and provided with regular supervision.

This part of the study included 10 interviews with people with psycho-social (mental health) disabilities, 10 interviews with their family members/carers, 10 interviews with people with intellectual disabilities and 10 interviews with their family members/carers (40 interviews in total). The semi-structured interviews followed preliminary focus group sessions conducted between 8 April and 18 June 2011, conducted by George Otieno Ochich, Senior Lecturer at Moi University School of Law.

### *Sampling*

The sample for the interviews was a purposive one and generated with consideration for gender, age, ethnic, cultural or religious diversity and whether they were placed under guardianship (see tables below for a summary of key sampling issues and how these were considered and addressed when preparing a study sample).

Participants were identified and approached with assistance of contact persons who are community-based workers with DPOs and other voluntary organisations working in the disability and health sector in Kenya (namely, Users and Survivors of Psychiatry in Kenya, BasicNeeds Kenya and Africa Mental Health Foundation). Such contact persons were important in establishing a rapport with potential participants, due to their understanding of local dialects in the specific regions and to provide support to research participants following the interview (if relevant, considering the nature of some of the questions that explored potential experiences of abuse).

The age range of participants is between 18 and 80, with an average age of 35 for both people with intellectual disabilities and people with psycho-social (mental health) disabilities. There was a gender balance between participants with disabilities, but most of family members were female and were mainly mothers, daughters or spouses of people with disabilities who took part in the study (but some were also other female family members or female friends who act as carers or main support persons). This highlights how caring/supporting roles within families and households are mainly female in Kenya, just like in many other countries around the world. None of the participants were ever under formal guardianship.

**Tables 1 – 4****– Sample description, breakdown in terms of gender, age, location and religion**

Sampling issue – age	Number of participants			
	People with intellectual disabilities	Family members – PwID	People with psycho-social disabilities	Family members – PwPSD
18-25	2	1	0	1
25-30	3	2	2	0
30-40	2	1	5	2
40-50	2	2	1	0
50-60	0	1	1	1
60+	1	3	1	6
TOTAL	10	10	10	10

Sampling issue – gender By default - no scientific technique In case of influx 50:50	Number of participants			
	People with intellectual disabilities	Family members – PwID	People with psycho-social disabilities	Family members – PwPSD
M	5	3	5	2
F	5	7	5	8
TOTAL	10	10	10	10

Sampling issue – Location	Number of participants			
	People with intellectual disabilities	Family members – PwID	People with psycho-social disabilities	Family members
Nairobi – Kibera	2	2	2	2
Nairobi Region – Nairobi	2	2	2	2
Eastern Region – Kibwezi	2	2	2	2
Rift Valley region – Eldoret	2	2	2	2
Central region -Nyeri	2	2	2	2
TOTAL	10	10	10	10

Sampling issue – Religion	Number of participants			
	People with intellectual disabilities	Family members – PwID	People with psycho-social disabilities	Family members – PwPSD
Protestant	3	3	4	5
Roman Catholic	2	2	2	2
Other Christian	2	2	1	1
Muslim	1	1	2	2
Other	0	0	0	0
No religion	2	2	1	0
TOTAL	10	10	10	10

In order to capture the above-noted diversity across Kenya, the plan was to conduct the research in five different regions across the country: Nairobi, Central, Eastern, Rift Valley and Nyanza province. However, it was not possible to conduct the study in Nyanza because the contact persons were not able to identify any participants willing to take part in the study. Translators were used in two regions: Eastern (eight interviews were translated from Kamba to Swahili) and in the Rift Valley (eight interviews were translated from Kalenjin to Swahili). In Central Kenya, the researchers translated six interviews from Kikuyu to Swahili since they were conversant with the local dialect and two other interviews were conducted in English since participants could express themselves in English. Except in Central Kenya, the Community Health Workers acted as translators as they had a good rapport with the study participants and were knowledgeable about the relevant terminology.

### *Ethical issues*

In order to ensure informed consent by all research participants, they were provided with a brief information sheet about the study and asked to sign the consent and confidentiality form, guaranteeing that the interviews and any information disclosed would be used solely in relation to the present study. For any issues that were disclosed where interviewees shared experiences of violence or other forms of ill-treatment, they were offered guidance on further support available to them, including access to legal remedies. The information sheet and the consent and confidentiality forms were also made accessible for people with intellectual disabilities. This was ensured by an accessible information organisation run by people with intellectual disabilities themselves.<sup>244</sup> All interviews were conducted in a space where interviewees felt safe and relaxed and at a time which suited them, and were recorded. Interview transcripts were checked and shared with the interviewees.

244 MDAC used EasyRead services at Inspired Services Publishing Ltd to produce easy to read versions and a Makaton version of the interview guide. For their services on this project, Inspired Services were presented with an Accessibility Award for Innovative Practices in early 2014 during the Zero Project conference.

### *Data analysis*

Data analysis was done by one of the researchers and the MDAC Research and Monitoring Director using manual data analysis (through the use of sensitising concepts related to legal capacity). Findings from the interviews with family members with and without a disability were used to corroborate particular findings.

### *Study limitations*

The study does not capture the nature of limitation of legal capacity under the criminal justice system in Kenya, as it focuses only on determination of legal capacity under the civil procedure. Our researchers were unable to observe the process of determination of legal capacity by a court or an administrative officer due to the absence of such processes during the research period and the inability to identify research participants who have been placed under guardianship. After consulting organisations of people with psycho-social (mental health) disabilities such as Users and Survivor of Psychiatry Kenya, and the Kenyan Association for the Intellectually Handicapped, as well as visiting the Courts to review case files on legal capacity determination, we were unable to identify relevant cases and where consent could be obtained for inclusion into the study.

In parallel, researchers encountered language barriers in remote rural areas like Kibwezi, where respondents were not fully conversant with either English or Kiswahili. The researchers had to use the services of an interpreter when conducting the interviews – but the interpreters were not experienced in discussing disability-related topics.





