

**THE KENYA NATIONAL COMMISSION ON HUMAN RIGHTS AND THE OPEN
SOCIETY INITIATIVE FOR EASTERN AFRICA**

**HOW TO IMPLEMENT ARTICLE 12 OF CONVENTION ON THE RIGHTS OF
PERSONS WITH DISABILITIES REGARDING LEGAL CAPACITY IN KENYA: A
BRIEFING PAPER**

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¹African Union, 'The 21st Ordinary Session of the Assembly of the Union Appoints Members' <<http://summits.au.int/en/21stsummit/events/21st-ordinary-session-assembly-union-appoints-members>> accessed 10 June 2013. (At the time of interview, Commissioner Lawrence Mute had not yet been appointed member of the African Commission on Human and Peoples' Rights).

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Glossary of terms

Guardian - One who is legally responsible for the care and management of a minor or of a person or property of a person who has been legally declared 'incompetent'.

High support - means that support, which may be needed by individuals who require ongoing intensive support for activities of daily living; independent and informed decision-making; accessing facilities and participating in all areas of life including education; employment; family and community life; treatment and therapy; recreation and leisure.²

Intellectual disability - It is characterized by significant limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social and practical skills. Conditions associated with intellectual disability include autism, cerebral palsy and Down syndrome. A person with intellectual disability has life-long supports needs, they must be individualized which will lead to improved personal outcomes that may include more independence and enhanced opportunities.

Legal capacity –includes both the capacity for a right to recognition everywhere as persons before the law ('legal recognition') and the capacity to 'exercise' those rights.

Psychosocial disability - refers to the interaction between psychological and social/cultural components of disability. The psychological component refers to ways of thinking and processing experiences and perceptions of the world. The social/cultural component refers to societal and cultural limits for behaviour that interact with those psychological differences as well as the stigma that society attaches to the label of disabled.³

² Capacityrights.org, 'The Rights of Persons with Disabilities Bill 2011'
<<http://capacityrights.org/uploads/3/1/8/0/3180011/draftbill-pwd.pdf>> accessed 26 May 2013

³ World Network of Users and Survivors of Psychiatry, 'Implementation Manual for the UN Convention on the Rights of Persons with Disabilities' (2008)
<http://wnusp.rafus.dk/documents/WNUSP_CRPD_Manual.pdf> accessed 5 December 2012

Respite care - the provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home.⁴

Self advocacy - is about people with disabilities speaking up for themselves, making their own decisions⁵ and taking control of their lives. It does not preclude support but emphasizes that the fact that the person with a disability is the one in charge of their life.

⁴ Wikipedia, 'Respite Care' <http://en.wikipedia.org/wiki/Respite_care> accessed 25 May 2013

⁵ Inclusion International, 'About Self-Advocacy' <<http://www.inclusion-international.org/self-advocacy/about-self-advocacy/>> accessed 25 May 2013

List of Abbreviations

ACHPR – African Commission on Human and Peoples’ Rights

ATM – Automated Teller Machine

CRPD – Convention on the Rights of Persons with Disabilities

CDF - Constituency Development Fund

DPOs – Disabled Peoples’ Organizations

EKLR – Kenya Law Reports online

ECT – Electroconvulsive Therapy

HIV – Human immunodeficiency Virus

HTC - HIV Testing and Counselling

IEBC – Independent Electoral and Boundaries Commission

KAIH – Kenya Association of the Intellectually Handicapped

KNCHR – Kenya National Commission on Human Rights

KRA – Kenya Revenue Authority

NGOs – Non Governmental Organizations

MOJNCCA – Ministry of Justice, National Cohesion and Constitutional Affairs

SFK – Schizophrenia Foundation of Kenya

USP-Kenya – Users and Survivors of Psychiatry - Kenya

PO – Personal Ombudsman

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1. Background and methodology

This section provides the background of the paper, following which the methodology used in developing the paper is laid down.

1.1 Background

Kenya ratified the Convention on the Rights of Persons with Disabilities ('CRPD' of 'the Convention') in 2008. By dint of Article 2 (6) of the Constitution of Kenya 2010, the Convention now forms part of the laws of Kenya.

Even following adoption of the Convention in 2006, legal capacity remains incredibly difficult as an area of rights to implement. Kenya's policy makers and implementers have not understood the full implications of Article 12 of the Convention. Post-2010 as much as pre-2010 legislation fails to incorporate the principles of legal capacity established in Article 12 of the Convention. Court decisions on cases that touch directly on Article 12 also fail to take the Convention into consideration. A result of this is the fact that persons with disabilities in Kenya still do not enjoy the benefit of being able to exercise their rights on an equal basis as their non-disabled peers: many laws still assume that persons with disabilities merely because of their disability hold lesser rights and cannot act to exercise their rights on an equal basis with others.

It is necessary that clear guidance is provided to policy makers, legislators and those who exercise administrative procedures on how to implement Article 12 of the Convention.

This paper sets out basic information and suggestions which the country should consider as it seeks to implement Article 12 of the Convention. It defines legal capacity as a concept and norm. The paper then establishes the Kenyan policy and legislative environment relating to issues of legal capacity. It then shows the situation of persons with disabilities in Kenya with regard to Article 12 of the CRPD,

highlighting local good practice models on implementing the right to legal capacity. This section also highlights the dilemmas in implementing Article 12 in the Kenyan context. The paper then presents international good practice on implementing Article 12. It then makes suggestions on the process as well as the content which should be included in policy, law and procedures to effect Article 12 of the Convention.

1.2 Methodology

The purpose of the briefing paper: to detail the situation of the right to legal capacity in Kenya, best practices from other jurisdictions and recommendations on how the right to exercise legal capacity can be enhanced in Kenya.

The objectives of the briefing paper:

- a. To provide initial basic information on the meaning and practice of legal capacity to state agencies, professional bodies, human rights actors and persons with disabilities;
- b. To identify gaps and opportunities with regard to the right to legal capacity in Kenya; and
- c. To establish a framework which may be used to prepare policy, law and administrative procedures for implementing Article 12 of the Convention.

Stages in developing the briefing paper

1. Analysis of data on Article 12 of the CRPD from select sources;
2. Analysis of the provisions of various laws and policies in Kenya on legal capacity;
3. Develop interview guides for the various categories of respondents (DPOs, persons with disabilities and a psychologist);

4. Interviews with the target group of respondents;
5. Processing of data and information obtained as a result of the interviews; and
6. Preparation of the report.

Time period: April – June 2013

Selecting the target groups of respondents

The briefing paper is based on qualitative research, since it seeks to *inter alia* understand the subjective meanings held by the various actors including persons with disabilities and their organizations. The groups and individuals were identified via non-probability sampling, specifically purposive sampling (expert sampling and snow-balling). Thus, the following organizations and persons were interviewed:

Organizations⁶

- Schizophrenia Foundation of Kenya⁷
- Users and Survivors of Psychiatry- Kenya⁸
- Kenya Association of the Intellectually Handicapped⁹
- Inclusion International¹⁰
- Women Challenged to Challenge¹¹
- Sense International¹²
- United Disabled Persons of Kenya¹³

⁶ A total of 9 people from the various organizations were interviewed.

⁷ A voluntary organization helping families, friends and people with schizophrenia and related disorders <<http://www.world-schizophrenia.org/activities/fpc/kenya.html>> accessed 4 June 2013

⁸ A membership organization whose major objective is to promote and advocate for the rights of Persons with Psychosocial Disabilities in Kenya) <<http://www.uspkenya.com/>> accessed 4 June 2013

⁹ A members-based organization of people with intellectual disabilities and their families <<http://kaihid.org/>> accessed 4 June 2013

¹⁰ A global federation of family-based organizations advocating for the human rights of people with intellectual disabilities worldwide <<http://www.inclusion-international.org/>> accessed 4 June 2013

¹¹ A national organization which brings together women with different disabilities in Kenya <<http://www.kenyadisability.or.ke/index.php/resources/disabled-persons-organizations/134-women-challenged-to-challenge>> accessed 4 June 2013

¹² An organization that provides specialist training, information and support to ensure that every person living with deafblindness can achieve their full potential <<http://www.senseinternational.org.uk/pages/kenya.html>> accessed 4 June 2013

Individuals

- Lawrence Mute¹⁴
- Yotam Tolub¹⁵
- Gatune¹⁶
- Focus Group Discussion with a group of 16 persons with psychosocial disabilities in Kiambu County

1.3 Limits of the study

- There are no centralized statistics at the national level on the number of people under guardianship;
- The research was conducted in Nairobi and its environs while it is a fact that there are marked differences between life in rural areas and in urban areas in Kenya;
- This is an exploratory, rather than a representative study of decision making for persons with disabilities. As such, the data was mainly gathered from persons with disabilities and not so much from affected third parties such as legal practitioners, judges, banks and other financial institutions and professionals in mental healthcare.

¹³ A cross disability organization that seeks to unite groups, associations and organizations of people with disabilities, for the purpose of empowering and enhancing their advocacy role
<<http://www.kenyadisability.or.ke/index.php/resources/disabled-persons-organizations/65-united-disabled-persons-of-kenya>> accessed 4 June 2013

¹⁴ A Member of the African Commission on Human and Peoples' Rights (ACHPR) and a former commissioner at the Kenya National Commission on Human Rights

¹⁵ Attorney working at Bizchut – The Israel Human Rights Centre for People with Disabilities
<<http://bizchut.org.il/en/>> accessed 4 June 2013

¹⁶ A street entertainer who plays the mouth organ in Nairobi City

2. The import of Article 12 of the Convention on the Rights of Persons with Disabilities

This section will introduce Article 12 of the CRPD. It will look into the import of Article 12 particularly as laid down by the Committee on the Rights of Persons with Disabilities. The section will also examine support, reasonable accommodation and safeguards.

2.1 Legal Capacity – Article 12 of the CRPD

Article 12¹⁷ (equal recognition before the law) of the UN Convention on the Rights of People with Disabilities lies at the heart of the Convention. It addresses recognition before the law, legal capacity and decision-making. Article 12, paragraphs 1 and 2, of the Convention requires States Parties to recognize persons with disabilities as individuals before the law, possessing legal capacity, including capacity to act, on an

¹⁷ 1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognize 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.

equal basis with others. Paragraphs 3 and 4, requires states to provide access by persons with disabilities to the support they might require in exercising their legal capacity and establish appropriate and effective safeguards against the abuse of such support.¹⁸ Paragraph 5 requires the state to ensure that persons with disabilities enjoy the right to own property, and to access credit facilities at an equal basis with others. Article 12 is central to the structure of the Convention and has been termed ‘the very lynchpin of the Convention’.¹⁹

Legal capacity is important because it goes beyond decision-making to the core of what it means to be human.²⁰ Without legal capacity, our freedom to make choices is greatly diminished, yet life choices are part of who we are. Having all or most decisions made for a person teaches them dependence and helplessness which devalues their humanity. Without legal capacity, many, if not all rights become meaningless (for instance, the right to own property, the right to private life, the right to work, the right to political participation and the guarantee of free and informed consent with regard to the right to health).

Legal capacity is also important because it has a huge impact on how other people (for example, service providers, public officials and members of the community) view persons with disabilities. If persons with disabilities are seen to be incapable of making any decisions about their own lives, negative stereotypes about disability are reinforced, yet these stereotypes are a significant barrier to the inclusion and participation of persons with disabilities in society.

¹⁸ United Nations, *Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary General: Thematic Study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities* (A/HRC/10/48)

¹⁹ Gerard Quinn, ‘Legal Capacity Law Reform – the Revolution of the UN Convention on the Rights of Persons with Disabilities’ (Galway, Summer 2011)

²⁰ Gerard Quinn, ‘Personhood & Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD’, HPOD Conference, Harvard Law School, 20 February 2010

2.2 Defining legal capacity in the Kenyan context

Legal capacity means the capacity to have rights and the power to exercise those rights. Both of these elements are integral to the concept of legal capacity because they establish the rights and responsibilities of persons with disabilities to make their own decisions.²¹ Practically, legal capacity is the law's recognition of the validity of a person's choices.²² It is what allows a person to act within the framework of the legal system. It makes a human being a subject of law. Legal capacity is something that most people take for granted; that upon reaching the age of majority (in Kenya, 18 years of age) one will be able to make one's own decisions which will be respected. For most people, adulthood automatically means the right to become a self-determining individual. This has not been so for persons with disabilities, who have tended to be treated in the past as 'objects' to be managed as opposed to rights holders with their own interests and desires.²³

Legal capacity comprises of two parts: the capacity to have rights and the capacity to act or exercise these rights. The first part includes the right to be a subject before the law; for instance, to be somebody who can own property, have a job or start a family. The second part (to exercise rights) goes further and includes the power to dispose of one's property and claim one's rights before a court.²⁴ The main difficulty with disability generally - and intellectual disability and psychosocial disability specifically - is the all-too-easy assumption that disability simply equates with a lack

²¹ The European Group of National Human Rights Institutions, Amicus Brief in the European Court of Human Rights - *D.D v Lithuania* Application No. 13469/06 11 April 2008 <<http://www.interights.org/userfiles/Documents/DDAmicusHumanrightsinstitutions.pdf>> accessed 4 June 2013

²² Essential Principles: Irish Legal Capacity Law <<http://www.amnesty.ie/reports/essential-principles-irish-legal-capacity-law>> accessed 5 June 2013

²³ Gerard Quinn and Theresia Degener, (eds), 'Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability' (Geneva: Office of the United Nations Commissioner for Human Rights, 2002)

²⁴ 'Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities' (Strasbourg, 20 February 2012, CommDH/Issuepaper(2012)2). Available at: <<https://wcd.coe.int/ViewDoc.jsp?id=1908555>> accessed 6 September 2012

of capacity. In large part this assumption rests on stereotypes and exaggerates the effects of disability. That is, it fails to see the person behind the disability.²⁵

While the right to legal capacity is particularly important to people with intellectual disabilities and people with psychosocial disabilities, it is an important right to all persons with disabilities. Hence, this paper seeks to address legal capacity in a cross disability manner/as it applies to persons with the various types of disabilities. As will be clear going forward, discussions on legal capacity in Kenya reveal two elements. The first element has to do with the law, and largely addresses the aspect of legal capacity that entails the capacity to have rights, encompassing laws that forbid people with disabilities from having certain rights on account of their disability. Examples of the foregoing are laws that deny the vote to ‘persons of unsound mind’ and laws that allow for guardianship for persons with disabilities. The second element of the way legal capacity plays out in Kenya has to do with the practice on the ground, and largely addresses the aspect of legal capacity that entails the capacity to exercise rights. This latter element (capacity to exercise rights) was greatly emphasized in interviews conducted for this paper.

In Kenya, the law is not the greatest barrier to the exercise of the right to legal capacity by persons with disabilities. Factors such as poverty and high rates of unemployment among persons with disabilities and the dependency that ensues as a result, a largely inaccessible environment, limited state support and services and unaddressed mental health care needs *inter alia* negate the exercise of the right to legal capacity by persons with all types of disabilities. Hence, the problem of exercising legal capacity in Kenya is largely an informal rather than a formal one.

Admittedly, this is a broad conceptualization of legal capacity. However, the interviews revealed that the law is not the key factor as to why persons with disabilities are not the controlling authority in their lives in Kenya – and this was

²⁵ The European Group of National Human Rights Institutions, Amicus Brief in the European Court of Human Rights - *D.D v Lithuania* Application No. 13469/06 11 April 2008 <<http://www.interights.org/userfiles/Documents/DDAmicusHumanrightsinstitutions.pdf>> accessed 4 June 2013

said to be the case across disability type. Hence, to leave out the practical element/the capacity to exercise rights element in the definition of legal capacity in the Kenyan setting is to leave out the most significant element of the lives of people with disabilities in Kenya. A further example at this juncture suffices. Article 12(5) provides that States Parties shall ensure the equal rights of persons with disabilities to own and inherit property. Interviews revealed that because of deeply embedded cultural stereotypes persons with all categories of disabilities are often disinherited. This, despite the fact that the Constitution of Kenya at Article 40 provides for the right to own property for all people. But, practice on the ground is that persons with disabilities often are not able to exercise this right for extra-legal reasons.

The focus on the two elements of legal capacity is important in the Kenyan setting for additional reasons – it goes to the recommendations that one can make on effecting Article 12 in Kenya. Law reform is a critical element to the realization of Article 12 in Kenya, but even more critical if Article 12 is to be realized in the country is a focus on the practical element, the informal places in which the right to legal capacity is routinely denied. And this requires even wider reaching reforms – broad based awareness raising, accessifying the environment and addressing the widespread poverty among people with all types of disabilities in Kenya.

Having discussed at length what Article 12 should encompass in the Kenyan setting, the following section examines the CRPD Committee’s recommendations to States Parties on Article 12.

2.3 The Committee on the Rights of Persons with Disabilities on Article 12

The CRPD Committee has issued several concluding observations to States Parties on Article 12 as required under Article 36 of the Convention. This part summarizes what Article 12 requires as gleaned from issues that the Committee has expressed concern to States Parties about and from the Committee’s recommendations to States Parties so far:

1. That States Parties replace substitute decision-making by supported decision-making in the exercise of legal capacity,²⁶ since laws which are based, or continue to be based, on a substitute decision-making model that overrides the wishes of the persons concerned clearly run counter to article 12 of the Convention.²⁷
2. That States Parties guarantee the effective participation in the review process of organizations representing persons with disabilities in the amendment and standardization of laws with the CRPD.
3. That States Parties abolish the practice of judicial interdiction and²⁸ review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making²⁹ which respects the person's autonomy, will and preferences³⁰ and is in full conformity with article 12 of the Convention, including with respect to the individual's right, in his/her own capacity, to give and withdraw informed consent for medical treatment, to access justice, to vote, to marry, to work, and to choose a place of residence.³¹
4. That States Parties amend laws that deny the ability to exercise the right to marry to any category of persons with disabilities in order to adequately

²⁶ Tunisia - Committee on the Rights of Persons with Disabilities, 5th Session (11-15 April 2011) <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session5.aspx>>, Peru - Committee on the Rights of Persons with Disabilities, 7th Session (16-20 April 2012) <<http://www.ohchr.org/Documents/HRBodies/CRPD/7thsession/CRPD.C.PER.CO.1-ENG.doc>>, Spain - Committee on the Rights of Persons with Disabilities, 6th Session (19-23 September 2011) <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session6.aspx>>, Argentina - Committee on the Rights of Persons with Disabilities, 8th Session (17-28 September 2012) <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session8.aspx>> all accessed 4 June 2013

²⁷ Argentina - Ibid

²⁸ Peru (n 26)

²⁹ Tunisia (n 26)

³⁰ Spain (n 26), (Peru (n 26), Argentina (n 26) China - Committee on the Rights of Persons with Disabilities, 8th Session (17-28 September 2012) <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session8.aspx>> all accessed 4 June 2013

³¹ Hungary - Committee on the Rights of Persons with Disabilities, 8th Session (17-28 September 2012) <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session8.aspx>> accessed 4 June 2013

- guarantee the exercise of civil rights, in particular the right to marry, to *all* persons with disabilities.³²
5. That justice officials readily apply the rules that set limits on a court's discretion in restricting the legal capacity of persons with disabilities;³³ the concept of judicial prohibition should be done away with and judges should not have *complete* discretion to appoint a trustee or decide on what decision-making support tools are needed by persons with disabilities.³⁴
 6. That States Parties provide training on legal capacity to all relevant public officials and other stakeholders,³⁵ and that such training be carried out in consultation and cooperation with persons with disabilities and their representative organizations, at the national, regional and local levels for all actors, including civil servants, judges, and social workers, on the recognition of the legal capacity of persons with disabilities and on mechanisms of supported decision-making.³⁶
 7. That States Parties organise training workshops on the human rights model of disability for judges to encourage them to adopt the supported decision-making system instead of granting guardianships or trusteeships.³⁷
 8. That State Parties promptly initiate programmes in order to provide identity documents to persons with disabilities, including in rural areas and in long-term institutional settings, and to collect complete and accurate data on people with disabilities in institutions who are currently undocumented and/or do not enjoy their right to a name.³⁸

³² Peru (n 26)

³³ Argentina (n 26)

³⁴ Argentina (n 26)

³⁵ Tunisia (n 26)

³⁶ Hungary (n 31)

³⁷ Argentina (n 26)

³⁸ Peru (n 26) - the committee expressed concern that persons with disabilities did not have identity cards, and sometimes, also, did not have names.

9. That States Parties, in consultation with organizations of persons with disabilities, prepare, legislate and implement a blueprint for a system of supported decision-making, which includes:
 - a) Recognition of all persons' legal capacity and right to exercise it;
 - b) Accommodations and access to support where necessary to exercise legal capacity;
 - c) Regulations to ensure that support respects the person's autonomy, will and preferences and establishment of feedback mechanisms to ensure that support is meeting the person's needs;
 - d) Arrangements for the promotion and establishment of supported decision-making.

The Committee expressed concern at the lack of information concerning the number of persons who have been subjected to guardianship and trusteeship and the lack of legal remedies and safeguards, such as independent review and right to appeal, that are in place in order to revoke those decisions.³⁹ The Committee also expressed concern about the possibility of maintaining a modified regime of substitute decision-making in the drafting of new laws.⁴⁰

Having examined what the import of Article 12 of the CRPD is from the perspective of the CRPD Committee, it suffices now to distinguish supported decision making from substituted decision-making.

2.4 Substituted Decision making

Prior to the CRPD, the traditional legal response to decision making deficits was to allow other people to make decisions in place of the person with disabilities. This resulted from attribution of incapacity to an individual, which happened through

³⁹ Peru (n 26)

⁴⁰ Hungary (n 31)

status attribution, or the application of the outcome test or the functional test.⁴¹ Under status attribution, once it is established that any individual is a person with disabilities, the law presumes a lack of capacity. Hence, the very existence of a particular impairment is sufficient to strip the individual of legal capacity, regardless of the individual's actual capacities.⁴²

Under the outcome test, the attribution of incompetence is made on the basis of the decision arrived at by the person with disabilities. Hence, if a person makes a decision that is viewed as not conforming to 'normal' or 'societal values' then the person is regarded as lacking capacity.⁴³ This approach to capacity is now out-dated, as there is recognition that 'we all have the right to make our own mistakes' and that it is unjust to set the decision making bar higher for persons with disabilities.⁴⁴

Under the functional test, disability is treated as a threshold condition in that only persons with such conditions run the risk of having their capacity questioned. This approach assesses capacity on an 'issue-specific' basis.⁴⁵ The approach enables capacity to be determined on a particular matter. Hence, the person with disabilities is considered incapable if, by reason of the disability, he or she is unable to perform a specified function.⁴⁶ The focus is on the individuals' cognitive capacities, i.e his/her ability to understand the nature and consequences of a certain decision.

Increasingly, there has been a move away from the status approach, with the functional approach being the most widely accepted approach, although it is also

⁴¹ Amita Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the future?' (2006-2007) 34 Syracuse J. Int'l L. & Com. 429

⁴² Ibid

⁴³ John Bellhouse, Anthony Holland, Isobel Clare, Michael Guinn, 'Decision-making Capacity in Adults: Its Assessment in Clinical Practice', *Advances in Psychiatric Treatment*, vol. 7, pp. 294 -301, 2001

⁴⁴ Gerard Quinn, 'Personhood & Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD', HPOD Conference, Harvard Law School, 20 February 2010

⁴⁵ Ibid

⁴⁶ Amita Dhanda (n 41)

undergoing modification in various jurisdictions.⁴⁷ In this regard, the European Court of Human Rights in *Shtukaturv v Russia* (“*Shtukaturv*”), stated that:

“...the existence of a mental disorder, even a serious one cannot be the sole reason to justify full incapacitation.”⁴⁸

Once a person is deemed to lack capacity, another person is appointed to make decisions for the person with disabilities; in Kenya, the person so appointed is termed a ‘guardian’ or ‘manager’ where the person is appointed for the management of the estate of the person with disabilities. The guardian or manager then makes decisions for the person with disabilities based on the ‘best interest’ principle.

Article 12 does not deny that there are still decision-making deficits that must be addressed.⁴⁹ In this regard, it creates a shift from substituted decision making to supported decision making, as has been emphasized by the Committee on the Rights of Persons with Disabilities (CRPD Committee).

2.5 Supported decision making

Article 12 emphasizes respect for the persons’ will and preferences⁵⁰ as the determining factor in decisions about their life and this requires a shift from the

⁴⁷ Essential Principles: Irish Legal Capacity Law <<http://www.amnesty.ie/reports/essential-principles-irish-legal-capacity-law>> accessed 5 June 2013

⁴⁸ *Shtukaturv v. Russia*, EHR, 44009/05, 27 March 2008, at pp. 18-19, para. 94

⁴⁹ ‘Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities’ (Strasbourg, 20 February 2012, CommDH/Issuepaper(2012)2). Available at: <<https://wcd.coe.int/ViewDoc.jsp?id=1908555>> accessed 17 June 2013

⁵⁰ Where the ‘will and preferences’ of the person are not known, the facilitated decision-maker has to determine what the person would want based on all the information they have about the person (spending time with the person and trying all forms of communication, speaking to those who know the person well, thinking about the person’s life, their likes and dislikes, etc) Gerard Quinn, ‘Essential Principles: Irish Legal Capacity Law’ (Looking Globally, Legislating Locally, Dublin, March 2012) Available at <<http://www.amnesty.ie/reports/essential-principles-irish-legal-capacity-law>> accessed 5 June 2013.

'best interests' approach which brings with it the significant risk of paternalism and substitute decision-making.⁵¹

Supported decision-making has been defined in a variety of ways. According to Michael Bach and Lana Kerzner:

A 'supported decision making status'...involves a trusted individual or network of individuals assisting the individual in decision making. Support can be provided in a variety of ways including interpretation and plain language support, as well as assistance in representing the person to others who may not understand his or her ways of communicating. Effectively, supported decision making distributes decision-making abilities required for competent decision-making processes across an individual and his/her supporters, as directed by the individual's will and/or intention...⁵²

According to Inclusion International:

Supported decision-making recognizes we all make decisions with support from others – we talk with family and trusted friends; we get additional information to understand the implications of decisions etc. Supported decision-making is an individual-specific, life-long process that grows and changes as the person does. It gives legal status to the process of using support to make decisions. The support provided through supported decision-making models can take many forms. It could include: the provision of information in plain language; support to understand the options and consequences of decisions; or, extra time to make decisions. For people with more significant support needs and/or difficulties in communicating, support could be a network of people who express and articulate a decisions based on the will and intent of the individual and the knowledge they have of the individual as a result of a trusting relationship.⁵³

A recent Australian definition of supported decision-making is that:

Supported decision-making is a framework within which a person with a disability can be assisted to make valid decisions. The key concepts are

⁵¹ Sinead O'Donnell and Charles O'Mahony, 'The UN Convention on the Rights of Persons with Disabilities: Exploring the synergy Between Article 12 (legal capacity) & Article 19 (independent living)' (Contemporary Housing Issues in a Changing Europe Conference, Galway, April 2012)

⁵² Michael Bach and Lana Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' 2010 <<http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>> accessed 30 May 2013

⁵³ Inclusion International, 'The Right to Decide: Background Information on Decision-making' <<http://therighttodecide.org/background-information-on-decision-making/>> accessed 2 June 2013

empowerment, choice and control. Responsibility, including legal responsibility, is another essential aspect that needs to be considered.⁵⁴

India's draft National Trust Act Amendments⁵⁵ defines a Supported Decision-Maker as 'an Associate who assists the person with disability in deliberating choices, providing needed information for making choices, and may also help in communicating decisions to others'.

From the foregoing, supported decision-making can include a range of processes that enable the decisions to be driven by the persons own 'will and preferences'. In instances in which there is difficulty discerning the person's will and preferences, states should make available skilled supporters trained in establishing proper communication while respecting the obligation to respect autonomy.⁵⁶ This reflects the revolution in the Convention in moving away from treating persons with disabilities as 'objects' to be managed or cared for by others to 'subjects' capable of determining their own destinies and deserving of equal respect. ⁵⁷ This is the distinction that is drawn between the 'medical model' of disability and the 'social' or 'human rights model' of disability.

Supported Decision-Making is a particularly relevant support measure for persons with cognitive disabilities. In supported decision making, everyone is presumed to have the capability to make decisions (acknowledging a level or residuum of

⁵⁴ Barbara Carter, 'Supported Decision Making: Background and Discussion Paper' Victorian Office of the Public Advocate (November, 2009)

<http://www.publicadvocate.vic.gov.au/file/file/Research/Discussion/2009/0909_Supported_Decision_Making.pdf> accessed 4 June 2013

⁵⁵ Capacityrights.org, 'Draft National Trust Act Amendments'

<http://capacityrights.org/uploads/3/1/8/0/3180011/national_trust_amendment-2.pdf> accessed 7 July 2013

⁵⁶ Office of the High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities Day of General Discussion on Article 12 of the CRPD – The Right to Equal Recognition Before the Law (21 October 2009) IDA CRPD Forum, 'Principles for Implementation of CRPD Article 12' <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 30 May 2013

⁵⁷ Gerard Quinn and Theresia Degener, (eds), 'Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability' (Geneva: Office of the United Nations Commissioner for Human Rights, 2002)

capacity), and the focus is on how people can be supported to make their own decisions.

2.6 Support and reasonable accommodation

Support and reasonable accommodation are closely interlinked. Michael Bach theorizes that abilities in addition to supports and in addition to accommodations equal decision-making capability.⁵⁸ The close connection between the two concepts was emphasized severally in papers submitted to the Committee on the Rights of Persons with Disabilities (hereinafter CRPD Committee) on its day of general discussion on Article 12 held on October 21, 2009. The International Disability Alliance submitted a paper to the CRPD Committee on this occasion in which it stated that, ‘support and/or reasonable accommodation may be necessary to equalize the effective enjoyment of these rights (Article 12) and fulfillment of duties.’⁵⁹ The close relationship between support and reasonable accommodation has been especially emphasized in the interviews conducted for this paper. It was emphasized that in a context of limited accessibility of the physical environment, support must be broadly defined.⁶⁰ Hence, this paper defines support broadly to include reasonable accommodation but this is not to say that support and reasonable accommodation are synonymous.

Article 2 of the CRPD defines reasonable accommodation to mean ‘necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms’. The article also defines discrimination on the basis of disability to include denial of reasonable accommodation. Reasonable

⁵⁸ Michael Bach, ‘Overview of the Right to Legal Capacity & Supported Decision Making’ October 2012

⁵⁹ Office of the High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities Day of General Discussion on Article 12 of the CRPD – The Right to Equal Recognition Before the Law (21 October 2009) World Network of Users and Survivors of Psychiatry <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 30 May 2013

⁶⁰ KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

accommodation is also emphasized at Article 5 of the CRPD on equality and non-discrimination which states that 'in order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided'. Article 4 of the CRPD places the obligation to ensure human rights for all people with disabilities on States Parties, and hence the obligation to provide reasonable accommodation undoubtedly rests on States Parties. By implication, public bodies are under duty to accommodate. In addition, Article 5(3) can be said to implicate third parties in providing reasonable accommodation.⁶¹ The implications of this are far-reaching because the duty to accommodate is a critical part of equality and non-discrimination with regard to persons with disabilities, and equality and non-discrimination are in their nature civil and political rights, giving rise to immediate realization obligations. To a large extent, the CRPD's requirement on others to make reasonable accommodations will be fundamental to its success.⁶²

This paper takes the view that accommodations are always supports but supports are not always accommodations. But because accommodations are specific to 'a particular case', in instances where accommodations are required to facilitate decision-making but are denied, it is possible to argue discrimination. The advantage of a support measure amounting to an accommodation is that it places an obligation on third parties to provide the support measure at the risk of being guilty of discrimination. Hence, the determination of whether a support measure that is required amounts to an accommodation would be made on a case by case basis. Hence, while support is broad and general, when it comes to specific cases in which a person with disabilities needs support of a particular kind in decision

⁶¹ Michael Bach and Lana Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' 2010 <<http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>> accessed 30 May 2013

⁶² Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship) <http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

making, the kind of support required may give rise to a duty to accommodate. An example:

A Deaf woman is pregnant and goes to the hospital to deliver. A decision needs to be made as to whether she will deliver normally or by caesarian section. The woman would need information to make this decision. Suppose the doctor in charge does not sign? The kind of support the woman needs in this scenario is a sign language interpreter. The hospital has a duty to provide all patients with enough information to make an informed decision. In her case, spoken language will not do. Hence, for her not to be discriminated against and not to have her right to information infringed, the hospital is under duty to provide the information in accessible format. In this case, the provision of a sign language interpreter is a reasonable accommodation measure that supports her in decision-making. Sign Language interpretation is the form that support takes in the instance of a Deaf woman needing to make a healthcare decision.

Excerpts from the interviews further demonstrate the inter-linkages between support and accommodation in the Kenyan context. A question was posed as to whether persons who are deafblind make their own financial decisions:

‘most deaf-blind people are shut away ... they don’t have access to information even to exactly determine what they want and for this reasons they end up basically having to contend with decisions made on their behalf even worse still, the people who make those decisions don’t tell them this decision is being made on your behalf...communication is key to decision-making. For deafblind people, if communication is not facilitated Article 12 remains empty words on paper.’⁶³

A discussion ensued on how general accessibility issues relate to legal capacity in Kenya:

‘The line is very thin in situations of poverty, and situations of general inaccessibility of the environment... some of the barriers that people face in

⁶³ Interview with Sense International (Nairobi, Kenya, 16 May 2013)

exercising legal capacity are communicative barriers so at that level then, sign language interpretation becomes a support measure, there isn't a limited list of supports. It is very case specific... for instance, someone with an intellectual disability may require extra time to complete a task at work, which is a reasonable accommodation measure and at the same time, it is a measure of support.⁶⁴

Another way to conceptualize the issue of supports and accommodations is to see accommodations broadly as being 'attached' to the service provider (for example a sign language interpreter at the hospital) while support is usually based on trust and as such is 'attached' to the person.⁶⁵

Some measures that have been identified as being support measures include independent advocacy, communicational and interpretive supports, support networks, personal ombudsperson, community services, peer support, advance planning and personal assistants. Some of these measures will be discussed in more detail in Chapter 5 on good practice from other jurisdictions. Some support measures currently in place in Kenya will also be discussed in Chapter 4 on the Kenyan situation with regard to legal capacity.

It is important to keep in mind the fact that the line between giving advice, information or support and actually making or being seen to be making decisions for another person without their guidance is a faint one and one must always be wary of crossing it.⁶⁶

⁶⁴ KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

⁶⁵ Email from Yotam Tolub, Attorney, Bizchut - the Israel Human Rights Centre for People with Disabilities to author (5 June 2013)

⁶⁶ Michael Bach and Lana Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' 2010 <<http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>> accessed 30 May 2013

2.7 Support in decision-making – the nuts and bolts

Article 12 imposes a positive duty on the state to establish support measures to ensure that the barriers to exercising legal capacity are removed and that the supports are in place for people with disabilities to fully enjoy and exercise their legal capacity.⁶⁷ Support should comply to the standard set by the CRPD: respect for the rights, will and preferences of the person, freedom from conflict of interest and undue influence, and being tailored to individual circumstances.

The International Disability Alliance (IDA) in its paper to the CRPD committee on the Committee's day of general discussions on Article 12, defined support:

Support means the development of a relation and ways of working together, to make it possible for a person to express him or herself and communicate his or her wishes, under an agreement of trust and respect reflecting the person's wishes... Types of support may include, for example, support networks, personal ombudsperson, community services, peer support, personal assistant, and advance planning.⁶⁸

IDA's paper also emphasized that all people who have difficulty exercising their legal capacity can be accommodated within the support paradigm. Hence, one way to envisage support is to imagine a continuum in which all people can fit, with some requiring more support, and some less support, but with all being accommodated in

⁶⁷Office of the High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities Day of General Discussion on Article 12 of the CRPD – The Right to Equal Recognition Before the Law (21 October 2009) IDA CRPD Forum, 'Principles for Implementation of CRPD Article 12' <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 30 May 2013

⁶⁸ Office of the High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities Day of General Discussion on Article 12 of the CRPD – The Right to Equal Recognition Before the Law (21 October 2009) IDA CRPD Forum, 'Principles for Implementation of CRPD Article 12' <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 30 May 2013

the continuum. In light of this, 'different types of support should be promoted and encouraged to meet the wide range of needs among people with disabilities and allow for personal choice among different options'.⁶⁹

The following are some measures that have been identified as being support measures, discussed in brief. The aim of this section is to lay the foundation for the more in depth discussion on support measures that will follow.

Independent Advocacy

Michael Bach and Lana Kerzner define independent advocacy as being paramount to challenging the limiting assumptions of third parties who may assume that people with more significant disabilities cannot guide their own decision-making. They emphasize that access to independent advocacy may be a needed support to assist the individual in expressing their wishes and informing other parties of the individual's rights, and of the other parties' duties to respect those rights and accommodate accordingly.⁷⁰ Independent advocacy is often put forward as a viable alternative in instances where one has no family or social network to offer assistance or in instances where one would prefer support that is separate from that offered by families and/or health and other kinds of professionals. Advocates should be well resourced, independent and accountable.⁷¹

Communicational and Interpretive supports

One of the main challenges that persons with more significant intellectual, cognitive and psychosocial disabilities face in decision-making processes with other parties

⁶⁹ Office of the High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities Day of General Discussion on Article 12 of the CRPD – The Right to Equal Recognition Before the Law (21 October 2009) IDA CRPD Forum, 'Principles for Implementation of CRPD Article 12' <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 30 May 2013

⁷⁰ Michael Bach and Lana Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' 2010 <<http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>> accessed 30 May 2013

⁷¹ Amnesty International Ireland, 'A Citizen's Jury on Legal Capacity Law' <www.amnesty.ie> accessed 30 May 2013

relates to their oftentimes unique forms of communication which may not be understood by third parties.⁷² The World Network of Users and Survivors of Psychiatry in its contribution to the CRPD Committee day of discussion on Article 12 stated that, 'support to exercise legal capacity, or supported decision-making, begins with accessible communication, which is also required by CRPD Articles 9 and 21, and communication as defined in Article 2'.⁷³

The CRPD at article 2 defines communication to include language (including sign language), display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology. Other communicational supports include assistive devices for hard of hearing people and an active and patient listening style to converse with people with psychosocial disabilities,⁷⁴ gestural and vocalization systems, computer-assisted and electronic devices as well as non-electronic communication output aids. All of these supports assist a person in managing the communication and processing of information essential to making decisions and communicating them to others.⁷⁵

Communicational and interpretive supports constitute one of the key areas in which supports tend to amount to accommodations, giving rise to immediate realization obligations. In the Kenyan context, communicational supports such as sign language and the provision of information to persons who are blind in accessible format is limited.

⁷² Michael Bach and Lana Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' 2010 <<http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>> accessed 30 May 2013

⁷³ Office of the High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities Day of General Discussion on Article 12 of the CRPD – The Right to Equal Recognition Before the Law (21 October 2009) World Network of Users and Survivors of Psychiatry <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 30 May 2013

⁷⁴ WNUSP Ibid

⁷⁵ Michael Bach and Lana Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' 2010 <<http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>> accessed 30 May 2013

Supporting Decision-Maker⁷⁶

A Supporting Decision-Maker assists the person with disabilities in deliberating choices, provides needed information for making choices, and may also help in communicating decisions to others. The agreement between the person with disabilities and the supporter may be either written or oral. The formality of the agreement is contingent upon the task for which the person with disabilities requires a supporter. A written agreement may be preferred for a financial decision, whilst for more personal matters an oral understanding may suffice.

The degree to which an arrangement is formal may also depend upon the relationship between the person with disabilities and the Supporting Decision-Maker. In this regard, an oral arrangement between a person with disability and his/her parents, relative or trusted friend without witnesses may be considered sufficient by both parties. However if there are disputes in the family then a written agreement with independent witnesses may be preferred.

The Supporting Decision-Maker provides a spectrum of support including support of a technical nature. Examples of possible roles for the supporting decision-maker includes keeping accounts and a monthly budget, banking, assisting in decision-making on where to live and how to travel, whether to take a job and so on.

Support networks

A support network (more than one individual providing support) can be helpful especially when support needs are high, when there is a risk of misinterpreting communication, or simply to have backup in case a primary support person is unavailable or conflicts emerge in the relationship.⁷⁷ The support network would

⁷⁶ Derived from India's draft National Trust Act Amendments Capacityrights.org, 'Draft National Trust Act Amendments'
<http://capacityrights.org/uploads/3/1/8/0/3180011/national_trust_amendment-2.pdf> accessed 7 July 2013

⁷⁷ Office of the High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities Day of General Discussion on Article 12 of the CRPD – The Right to Equal Recognition Before the Law (21 October 2009) World Network of Users and Survivors of Psychiatry

express and articulate a decision based on the will and intent of the individual and the knowledge they have of the individual as a result of a trusting relationship.⁷⁸

Personal ombudsperson

In the year 2000, the Swedish Government established a nationwide system of Personal Ombudsmen (Pos) that provides support in decision-making for persons with severe mental or psychosocial disabilities.⁷⁹ POs are highly skilled persons who do outreach work and establish, foremost, trusting relationships with individuals in need of support. They assist individuals in taking control of their own situation, identify care needs and ensure that they receive the necessary help. Ultimately, the POs should help clients build a network that can take over when they (Pos) leave.⁸⁰ This method of support shall be discussed in more detail in Chapter 6 on good practice from other jurisdictions.

Community services

Creativity is required when thinking about support, and it is important for the State to involve persons with disabilities in designing support measures. For instance, persons with psychosocial disabilities from South Africa presented a paper to the CRPD Committee on its general day of discussion on Article 12, in which they made the following suggestion:

‘We suggest the creation of Trauma Centers in the communities where persons can be taken to in times of crisis. This Centre can be seen as place where peer-support and non medical intervention takes place and take decisions as to whether medical intervention is desirable. It is envisaged as a place free of coercion and one of support and safety. People in crisis can be informed and referred to the centers for 72 hours with consideration for a longer stay if the crisis continues. Community and personal crisis interventions can assist to alleviate the distress of the person. Supported

<<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>>
accessed 30 May 2013

⁷⁸ Inclusion International, ‘The Right to Decide: Background Information on Decision-making’
<<http://therighttodecide.org/background-information-on-decision-making/>> accessed 2 June 2013

⁷⁹ Swedish Government Decision 2000-05 18 No 16

⁸⁰ Case Study – Sweden <<http://www.zeroproject.org/about/publications/>> accessed 2 June 2013

decision making can continue with different options explored in an environment conducive to well being. Most importantly, decisions around hospitalization are free of undue medical influence and bias.⁸¹

Peer support

Peer support occurs when people provide knowledge, experience, emotional, social or practical help to each other. Peer support is also used to refer to initiatives where colleagues, members of self-help organizations and others meet as equals to give each other support on a reciprocal basis. Peer in this case is taken to imply that each person has no more expertise as a supporter than the other and the relationship is one of equality.⁸² Peer support provides an opportunity for people to be able to respectfully challenge each other when they find themselves in conflict. This allows members of the peer community to try out new behaviors with one another and move beyond previously held self-concepts built on disability and diagnosis.⁸³ Peer support is an especially relevant support measure in decision making for persons with intellectual disabilities and persons with psychosocial disabilities. Peer support is a practical way through which a person is enabled to arrive at a decision that reflects the person's will and preferences. An example:

A person with a psychosocial disability who is in a peer support group wants to get off medication. The person may share with his peers what he/she is proposing to do. The peers may then discuss this issue, and the person has the benefit of hearing from people who have gotten off their medication, and from people who are still on their medication, being enabled to weigh the pros and cons, and to explore alternatives without being *told* what to do.

⁸¹ Office of the High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities Day of General Discussion on Article 12 of the CRPD – The Right to Equal Recognition Before the Law (21 October 2009) Ubuntu Centre of South Africa, 'Supported Decision-Making' <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 30 May 2013

⁸² Wikipedia, 'Peer Support' <http://en.wikipedia.org/wiki/Peer_support> accessed 2 June 2013

⁸³ Shery Mead, David Hilton and Laurie Curtis, 'Peer support: A Theoretical Perspective' <<http://mentalhealthpeers.com/pdfs/peersupport.pdf>> accessed 2 June 2013

Examples of peer support in Kenya will be given in Chapter 3 on the situation of persons with disabilities in Kenya, particularly in the section that showcases the initiatives of two DPOs (Kenya Association of the Intellectually Handicapped and Users and Survivors of Psychiatry-Kenya) on Article 12.

Advance directives

An advance directive is an example of a tool used in advance planning. Different jurisdictions define advance directives differently. In Canada, an advance directive constitutes written instructions about what health care a person does or does not want in the future if the person becomes incapable and a health care decision needs to be made.⁸⁴ Hence, in this jurisdiction, advance directives are restricted to healthcare matters only. India's draft National Trust Act Amendments⁸⁵ defines advance directives in a much broader way and identifies that these tools can be used by persons with disabilities in order to make known their life choices of health, financial, and property matters.

The important fact about advance directives is that they allow a person to specify certain circumstances under which a supporter can make certain types of decisions for the person. This does not mean that the person loses his or her right to make those decisions; indeed, an advance directive can be changed, modified or replaced by the maker. The supporter is bound to keep making the effort to communicate and to follow the person's wishes as far as they may be known.⁸⁶

⁸⁴ NIDUS Personal Planning Resource Centre and Registry, 'Advance Directive' <http://www.nidus.ca/?page_id=261> accessed 2 June 2013

⁸⁵ Capacityrights.org, 'Draft National Trust Act Amendments' <http://capacityrights.org/uploads/3/1/8/0/3180011/national_trust_amendment-2.pdf> accessed 7 July 2013

⁸⁶ Office of the High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities Day of General Discussion on Article 12 of the CRPD – The Right to Equal Recognition Before the Law (21 October 2009) IDA CRPD Forum, 'Principles for Implementation of CRPD Article 12' <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 30 May 2013

Personal Assistant⁸⁷

A personal assistant provides practical services to persons with disabilities in personal and legal tasks so they can live independently in the community. A personal assistant can perform a variety of functions ranging from daily activities such as cooking and assistance in mobility to banking and paying bills. There may be more than one personal assistant at any given time performing the same or different tasks.

The needs and wishes of the person with disability exclusively determine the scope of the support service. This is especially important since a person may not want the individual who assists them with technical things to also be the individual who supports them in making decisions.

Support measures should be subject to safeguards.

2.8 Safeguards

Article 12(4) of the CRPD recognizes the need for safeguards to ‘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’. Safeguards are meant to prevent abuse and to ensure that persons with disabilities exercise their rights on an equal basis with others. Retaining rights should not mean that either people themselves or the community will be at greater risk.⁸⁸ It is therefore necessary to strike the correct balance between autonomy and protection.

⁸⁷ Derived from India’s draft National Trust Act Amendments Capacityrights.org, ‘Draft National Trust Act Amendments’
<http://capacityrights.org/uploads/3/1/8/0/3180011/national_trust_amendment-2.pdf> accessed 7 July 2013

⁸⁸ Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship)

Different countries have taken different approaches to the question of safeguards. In British Columbia, Canada, the Representative Agreement Act allows (and in some cases requires) that a person choose their own monitor to ensure that the Representative complies with their duties.⁸⁹ Clause 14A of India's draft National Trust Act Amendments envisages setting up Local Level Committees which are required to regularly consult persons with disabilities about the quality of the support they are receiving and take appropriate measures for improvement where required.⁹⁰

One of the questions posed to the respondents was what would constitute appropriate safeguards in the Kenyan Context.

In the first place, it was emphasized that safeguards must be context specific; that the briefing paper covers the different ways in which persons with different types of disabilities exercise legal capacity and hence, the safeguards are necessarily different for the different categories of people. It was also emphasized that ideally, communities should be inclusive and self monitoring, which would have the effect of reducing the incidence of abuse. Ultimately the community is responsible for the well being of all its members.⁹¹ Indeed, inclusion and social capital are the foremost protective factors for people with disabilities. This does not mean that they might

<http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

⁸⁹ Representation Agreement Act (RSBC 1996) Chapter 405

<http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_96405_01> accessed 4 June 2013

⁹⁰ Capacityrights.org, 'Draft National Trust Act Amendments'

<http://capacityrights.org/uploads/3/1/8/0/3180011/national_trust_amendment-2.pdf> accessed 7 July 2013

⁹¹ Office of the High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities Day of General Discussion on Article 12 of the CRPD – The Right to Equal Recognition Before the Law (21 October 2009) Ubuntu Centre of South Africa, 'Supported Decision-Making' <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 30 May 2013

not need protection while ‘included’ but if so, this can be provided by universal measures.⁹²

Concrete responses on what appropriate safeguards would be in the Kenyan context ranged from the establishment of a separate judicial body, perhaps a tribunal which would deal specifically with capacity issues, to capacitating existing courts to deal with capacity issues, to capacitating specific bodies which deal with complaints of a specific nature such as the Central Bank of Kenya which could enforce accessibility of financial services to all persons with disabilities thus ensuring that persons with disabilities can control their own financial affairs. It was also proposed that if well capacitated, social workers under the department of social services would also act as safeguards since they work closely with people in the community.⁹³

Further, Kenya is in the process of developing a Legal Aid Bill. This bill establishes Justice Advisory Centres that are to be located at the local level. The Justice Advisory Centres are to resolve conflicts at the local level, and only when conflicts cannot be resolved at this level will court processes commence. Justice Advisory Centres were put forward as a possible safeguard to ensure that support measures work effectively.⁹⁴

The option of a separate tribunal was not popular as it was largely felt that it is better to work with the existing justice structures. Hence, the judiciary was put forward as the more preferred body to deal with complaints arising under Article 12 and to ensure that supported decision-making arrangements worked well. One proposal was to have specific courts designated as ‘capacity courts’ in the same way that there are ‘children’s courts’ that are well capacitated to deal with matters involving children. While this may be desirable given the need for judicial officers to be well trained on legal capacity, there is always the fear of these ‘capacity courts’

⁹² Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship)
<http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

⁹³ KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

⁹⁴ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

turning into one more ‘special’ thing for persons with disabilities. Separate ‘things’ for persons with disabilities run the risk of reinforcing stereotypes and prejudices of persons with disabilities as ‘other’ and of lower standards prevailing in services for persons with disabilities. ‘Capacity courts’ may also run contrary to the goal of mainstreaming.

It is important to note that the availability of a range of alternative supports outlined above will significantly limit the need for court involvement. The role of the court should be to safeguard against the deprivation of legal capacity and abuse of persons where they receive supports that assist them in exercising their legal capacity.⁹⁵ Court officials must be well trained to ensure that they do not defer to a medical model approach in deciding on capacity and be overly reliant on medical opinion when a person’s capacity is called into question.⁹⁶ Further, if courts are to deal with not only issues of denial of legal capacity but also issues of augmenting legal capacity, specific training on this will be required. A question may be raised as to whether courts can realistically have the time and ability to handle the various issues that may arise in supported decision-making arrangements. Hence, this issue will require further consultations to ensure that the range of safeguards chosen work well.

For safeguards to work appropriately, the state should raise awareness about supported decision-making among all involved parties including persons with disabilities, their families, doctors, lawyers, judges social workers and service providers.⁹⁷

⁹⁵ Centre for Disability Law and Policy, ‘Submission on Legal Capacity to the Oireachtas Committee on Justice, Defence and Equality’

<http://www.nuigalway.ie/cdlp/documents/cdlp_submission_on_legal_capacity_the_oireachtas_committee_on_justice_defence_and_equality.pdf> accessed 4 June 2013

⁹⁶ Centre for Disability Law and Policy, ‘Submission on Legal Capacity to the Oireachtas Committee on Justice, Defence and Equality’

<http://www.nuigalway.ie/cdlp/documents/cdlp_submission_on_legal_capacity_the_oireachtas_committee_on_justice_defence_and_equality.pdf> accessed 4 June 2013

⁹⁷ Essential Principles: Irish Legal Capacity Law’ (Looking Globally, Legislating Locally, Dublin, March 2012) Available at <<http://www.amnesty.ie/reports/essential-principles-irish-legal-capacity-law>> accessed 8 May 2013

3. Policy and legislative framework on legal capacity in Kenya⁹⁸

3.1 Introduction

This section provides an analysis of the legislative and policy framework in Kenya to ascertain the extent of compliance and/or non-compliance with Article 12 of the CRPD. Kenya has a complex web of laws that address situations where individuals, because of a disability, are adjudged to have lost the capacity to make certain types of important decisions.⁹⁹ This legal framework is based on a system of substitute decision-making, to occur in the best interests of the person who is deemed to lack legal capacity. Kenya has narrow guardianship laws that tend to target particular areas of decision making, for instance making it possible for one to lose legal capacity with regard to the management of property and financial affairs but retain legal capacity with regard to the decision to marry.¹⁰⁰ None of the legal provisions touching on legal capacity in Kenya mention the central role of the persons' will and preferences in making decisions affecting their lives. Generally, the laws do not recognize the state obligation to provide access by persons with disabilities to the support they may require in exercising legal capacity as required under Article 12.¹⁰¹

The spectrum of laws that touch on legal capacity in Kenya raise difficult issues. On the one hand, it may be asserted that these laws are a careful balance between the

⁹⁸ All laws quoted are available at Kenya Law Reports, 'Laws of Kenya' <http://www.kenyalaw.org/kenyalaw/klr_home/> accessed 4 June 2013

⁹⁹ These laws include the Constitution of Kenya 2010, 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.

¹⁰⁰ Section 107 of the Children's Act points to a situation in which a guardian is appointed in cases where a person is incapable of maintaining himself, or of managing his own affairs and his property on account of a disability. Section 107(5) of the same act allows for the guardianship to be varied, modified or revoked upon the marriage of the person with disabilities – hence presumes the person's capacity to enter into marriage.

¹⁰¹ The Sexual Offences Act allows the use of intermediaries in criminal proceedings where a witness is deemed vulnerable but does not place an obligation on the state to pay for intermediaries in circumstances in which the intermediaries are not family members.

*security*¹⁰² and *autonomy*¹⁰³ of persons with disabilities which, if properly implemented can promote their well-being. On the other hand, many persons with disabilities have long raised concerns about the assumptions that underlie both the substance and the implementation of laws ostensibly meant for their security and protection. Concern has been raised that laws of this nature continue to view persons with disabilities as objects to be cared for, protected and managed by others as opposed to as full persons with equal rights, dignity and worth.¹⁰⁴ In this regard, this section will examine three cases in which applications to put persons with psychosocial disabilities under guardianship were heard in order to establish the manner in which courts decide on matters related to Article 12 of the CRPD.

It is important to note that in Kenya, few people are under guardianship,¹⁰⁵ so while the law provides for it, guardianship is not a widely used mechanism. In this regard, it may be much easier to eliminate guardianship in Kenya than in countries in which the mechanism is more widely utilized. The argument is that jurisdictions that have strong guardianship laws reveal that guardianship is very damaging to people. Kenya is managing without it; which is a strong argument for repealing laws that provide for it.

For the majority of persons with disabilities in Kenya, decision-making happens informally. In this regard, data on how this impacts upon the lives of persons with disabilities is harder to come by. Are their rights abused? Are they disinherited of property? Do they remain chained in their homes? It seems that the answer to these

¹⁰² Laws that may be argued as being meant to promote the security of persons with disabilities include the Mental Health Act, the Children's Act, the Civil Procedure Act, the Sale of Goods Act, the Penal Code and the Traffic Act.

¹⁰³ Laws that may be argued as being meant to promote the autonomy of persons with disabilities include the Constitution of Kenya, 2010 and the Sexual Offences Act.

¹⁰⁴ Law Commission of Ontario, 'A Framework for the Law as it Affects Persons with Disabilities: Advancing Substantive Equality for Persons with Disabilities Through Law, Policy and Practice' (Final Report 2012) <<http://www.lco-cdo.org/en/content/persons-disabilities>> accessed 12 April 2013

¹⁰⁵ While research has not been carried out on a large enough scale to demonstrate empirically how ingrained (or not) guardianship is, preliminary data from the respondents indicates that the court process is rarely used to deprive or restrict legal capacity in Kenya. Interview with Schizophrenia Foundation of Kenya (Nairobi, Kenya, 29 April 2013); Interview with Users and Survivors of Psychiatry - Kenya (Nairobi, Kenya, 1 May 2013); Interview with member of the Law Society of Kenya (Nairobi, Kenya, 11 May 2013).

questions is that it varies from family to family, and the danger is that it is more difficult to document abuse in informal setups. This then is the dilemma – on the one hand, it is a good thing that Kenya does not utilize its guardianship laws extensively, but on the other hand, one is not in a position to know to what extent the rights of persons with disabilities are respected within the informal setting.

This section will examine the law-related aspect of these issues in more detail (the next chapter will examine the informal aspect in more detail). This section will draw data from the state report to the CRPD Committee on Article 12¹⁰⁶ in order to show how the State evaluates its laws and policies *vis a vis* Article 12. The section has various subsections:

- 1) Laws that establish guardianship
- 2) Laws that touch on legal capacity but do not directly establish guardianship
- 3) Other measures identified by the state in its report as being key to implementing Article 12

¹⁰⁶ Committee on the Rights of Persons with Disabilities – Future Sessions
<<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/futuresessions.aspx>> (accessed 12 April 2013)

3.2 Laws that establish guardianship

In Kenya, guardianship is expressly provided for under the Mental Health Act, the Children's Act and the Civil Procedure Act and Rules. In its report to the CRPD Committee on Article 12, the State does not mention the Mental Health Act as being one of the laws that relates to Article 12 at all, a significant omission.

3. 2.1 The Mental Health Act (Cap. 248)

According to its preamble, the intent of the Act is to amend and consolidate the law relating to; (a) the care of persons who are suffering from mental disorder or mental subnormality with mental disorder; (b) the custody of their persons and the management of their estates; and (c) the management and control of mental hospitals and other connected purposes. The Act defines a persons with mental disorder as 'a person who has been found to be suffering under the Mental Health Act and includes a person diagnosed as a psychopathic person with mental illness and person with mental impairment due to alcohol or substance abuse'.¹⁰⁷

Appointment of manager and/or guardian and their remuneration

Section 26 of the Act provides that the court may make orders for the management of the estate of any person suffering from mental disorder; and for the guardianship of any person suffering from mental disorder by any near relative or by any other suitable person. The Act does not define who 'any other suitable person' may be. In the event that a person has no known relative or other suitable person, the court may order that the Public Trustee be appointed manager of the estate and guardian of the person suffering from mental disorder. Section 34 gives the court the power to remove any guardian or manager appointed by it, and appoint any other fit person in his place. According to Section 27(2), where the person appointed as manager and/or guardian is unwilling to act gratuitously, the court may fix such

¹⁰⁷ Section 2 of the Mental Health Act

allowance to be paid out of the estate of the person in respect of whom the manager or guardian has been appointed.

The Act recognizes that the roles may be split or joint: the court may either appoint one entity as both manager of the estate and guardian of the person or appoint two entities, one as manager and the other as guardian. The Act then proceeds to have detailed provisions on how property is to be managed by the person appointed as 'manager' but to be largely silent on the role of the guardian.¹⁰⁸ This gives credence to the assertion that laws that allow substituted decision-making tend to value property above persons.

The purpose of establishing guardianship

¹⁰⁸ A distinction is made in the Israeli context between a personal guardian and a property guardian that may inform our context <<http://bizchut.org.il/en/rights/the-right-to-personal-autonomy>> accessed 14 May 2013:

Personal guardian – a guardian who is responsible for all the individual's personal affairs. A personal guardian is responsible for:

- Living arrangement
- Physical needs – clothing and proper nutrition
- Medical needs – monitoring medical condition, medication, consent or refusal for medical treatment
- Employment – finding an appropriate vocational framework; salary conditions
- Realizing rights – contacting the appropriate authorities to ensure the receipt of all rights, such as National Insurance or the “rehabilitation basket”
- Leisure – developing fields of interest and encouraging enrichment and leisure activities
- Psychological, social and spiritual needs – such as community integration, coping with psychological distress, and maintaining contacts with the family

Property guardian – a property guardian (or estate guardian) is responsible for all the individual's property and financial affairs, including:

- Managing the ward's bank account and assets
- Maximizing the ward's financial rights (including submitting financial claims)
- Protection against financial exploitation
- Developing the ward's ability to act independently in the financial sphere
- Approving expenses to improve the ward's quality of life

The purpose of establishing guardianship under the act is hinged on inability to manage one's affairs. According to Section 26(3), if the court finds that a person is incapable of managing his affairs, the court may make such orders as it may think fit for the management of the estate of such person, including proper provision for his maintenance and for the maintenance of such members of his family as are dependent upon him for maintenance.

On the other hand, if the court finds that a person suffering from a mental disorder is not only incapable of managing his affairs but also dangerous to himself or to others or likely to act in a manner offensive to public decency, the court may make such orders as it may think fit for the management of the estate of such person, in addition to orders as to the custody of the person. This section then, is closely linked with Section 16 of the Act which authorizes a police or administrative officer to take into custody and hand to a mental hospital a person with mental disorder on the justification that the person; (a) is dangerous to himself or others; (b) on account of the mental disorder is likely to offend public decency;(c) is not under proper care and control; and (d) is being cruelly treated and neglected by a relative or guardian.

Once guardianship is established, the court requires that the manager make an annual inventory of the property belonging to the person of whose estate he has been appointed manager together with a statement of all debts owed by or due to such person.¹⁰⁹

The Act does not expressly specify that a guardian may make health care decisions, including decisions touching on confinement for the person under guardianship. In Kenya, one does not need a guardian in order to be confined in a mental healthcare facility against ones will – anecdotal evidence points to the fact that families routinely commit their family members with psychosocial disabilities to mental

¹⁰⁹ Section 33(1), Mental Health Act

healthcare institutions.¹¹⁰ This makes a strong case for doing away with guardianship laws (since in any event one does not have to have a guardian in order to be confined in a mental healthcare facility against one's will) and increasing scrutiny on what is happening to persons with disabilities in the informal setting.

It is important to note that the Convention makes a shift from the approach under Section 16 of the Mental Health Act (taking into custody a person suffering from 'mental disorder' against their will) by forbidding deprivation of liberty based on disability, including mental or intellectual, as discriminatory. Hence, unlawful detention includes cases where the deprivation of liberty is grounded in the combination between a mental or intellectual disability as well as other elements such as dangerousness, or care and treatment. In light of the fact that such measures are partly justified by the person's disability, they are to be considered discriminatory and in violation of the prohibition of deprivation of liberty on the grounds of disability, and the right to liberty on an equal basis with others prescribed by article 14.¹¹¹

Powers of the manager and their limitation

Under Section 27 the court may order that the manager shall have such general or special powers for the management of the estate as the court considers necessary. The manager requires the permission of the court in order to mortgage, charge or transfer immovable property of which the estate may consist. Special permission is also required in instances where the manager wants to lease any such property for a term exceeding five years or to invest in certain kinds of securities.

¹¹⁰ Interview with Schizophrenia Foundation of Kenya (Nairobi, Kenya, 29 April 2013) and Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

¹¹¹ United Nations, *Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary General: Thematic Study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities* (A/HRC/10/48) <<http://www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.48.pdf>> accessed 4 June 2013

The manager (as well as the Minister and the Public Trustee) is authorised to make an application to court for the determination of any question arising out of the management of any estate in respect of which an order has been made. A similar power is not given to the person in respect of whom an order has been made.

Section 27(1)ii limits the powers of the manager in instances that may give rise to conflict of interest. It requires that a manager shall not invest any funds belonging to the estate of which he is manager in any company or undertaking in which he himself has an interest.

Termination of appointment of manager

Section 36 provides for the power of the court to make just and expedient orders in instances where it is shown that the person has recovered from the mental disorder. One can only surmise from this that the court may possibly make orders cancelling out the judicial declaration of incapacity. The Act provides that evidence in such a case may be provided 'by affidavit or otherwise'. The Act is silent on who may take out the affidavit.

Other Orders related to appointment of manager and/or guardian

Power to apply property for maintenance of person suffering from mental disorder without appointing manager

Section 29(2) envisages a situation in which temporary orders may be made where it appears to the court that a person is suffering from mental disorder of a temporary nature and that it is expedient to make temporary provision for his maintenance or for the maintenance of such dependent members of his family. The court in such instances may direct that the person's property or sufficient part of it be applied for such purpose.

Order for delivery of patient into care of relative or friend

Under Sections 16 (4) and 22, the person in charge of the hospital may after examining the person with a mental disorder, if he thinks fit, make the person admitted into the mental hospital over to the care of any relative or friend or detain the person in the mental hospital as an involuntary patient. The person in charge of the hospital is required to consult with the medical practitioner in charge of the person's treatment in the mental hospital and the Board before making such an order.

A look at cases decided under the Mental Health Act on the question of legal capacity in Kenya is important at this juncture.

Re Simon Peter Karanja Kiarie

Re Simon Peter Karanja Kiarie [2006] ECLR¹¹² is a case that was filed in the High Court of Kenya at Nairobi under the Mental Health Act, being an application for custody, management and appointment of a guardian. The petitioner in the case was Lydia Wangui, mother of the 'subject' Simon Peter Karanja Kiarie. She sought an order of the court to be appointed a guardian of the said Simon Peter Karanja Kiarie on a permanent basis, and further, she prayed that she be accorded 'custody and management of affairs of the said Simon Peter Karanja Kiarie...' Lydia also sought an order to be appointed 'guardian ad litem of Simon Peter Karanja Kiarie', for purposes of the court proceedings.

Before the application could be heard, the subject's father James Raphael Gakiri sought to be 'added as a party in the current suit as an applicant'. Lydia objected to this application on the grounds that James Raphael Gakiri himself was 'not fit to act as guardian for Simon Peter Kiarie', and that he needed to first submit to a psychiatric evaluation to determine his suitability to act as Simon Peter Karanja Kiarie's guardian. Both Parties separately wanted to take charge of the affairs of

¹¹² Kenya Law Reports

<http://www.kenyalaw.org/CaseSearch/view_preview1.php?link=81818192222339102136643>

High Court at Nairobi (Nairobi Law Courts) Misc Civ Cause 49 Of 2005

their son, the subject who, in the words of the court 'is said to have some mental problem'.

The court directed that both Lydia Wangui Kiarie the mother of the subject and James Raphael Gakiri Kiarie the father of the subject to file further affidavits and attach medical reports to show their "mental status", as they both seemed to accuse one another of mental instability.

Only Lydia Wangui Kiarie provided a medical report, which stated that she was 'Mentally normal and can be able to continue with her responsibilities in life.....' James Raphael Gakiri produced a report on the subjects' mental status and not on his own mental status as directed by the court.

Hence, the court ruled:

Going by the medical evidence on record so far, I can say with authority that the subject's mother Lydia Wangui Kiarie is 'mentally normal, to be able to continue with her responsibilities in life'. I have had no medical assessment of the subject's father, despite asking for it. I cannot therefore declare him medically fit or otherwise for lack of evidence. However, given the fact that he is the subject's biological father and further, given the 'sensitivity' of this matter, I have decided that I will allow him to take part in the hearing...

A few preliminary observations can be drawn from this case. First, the case is indicative of the courts complete reliance on medical evidence to make an assessment of capacity and that in the view of the court, mental capacity informs legal capacity exclusively. Second, it is instructive to note that the court did not seek the presence of the subject 'Simon Peter Karanja Kiarie' in court, considering that the court deemed the case to be 'sensitive' enough to allow the father to take part in in spite of his having defied the courts order to produce his own medical report. The lack of involvement and participation by Simon Peter Karanja Kiarie is also worrying in light of the evident conflict between the two potential guardians. On a positive note, the court recognizes that the case is of a sensitive nature, and that it would be useful to allow the father to take part in the hearing. The judge referred

the matter back to the Family Division for hearing as the matter had only been directed to the High Court for hearing on points of objection. As at the time of completing the briefing paper, I have not been able to find the court's final decision on the substantive matter.

K v K

K v K 2009 eKLR¹¹³ is a case that was filed in the High Court at Nairobi in 2009 for the guardianship of GKK and management of his estate under section 26(1) and section 29 of the Mental Health Act. The petition was filed by SKK, a son of GKK averring that GKK was a person suffering from mental disorder within the meaning of the Mental Health Act and hence subject to be dealt with as provided under the Act. The grounds of knowledge and belief of the mental disorder/incapacity of GKK were interalia founded on a medical and psychiatrist report. It was alleged that GKK is not capable of managing and administering his property, business matters, legal transactions and other dealings and affairs of similar kind as set out under the Act. The petitioner (GKK's son) therefore sought to have Mohammed Muigai Advocates appointed as the managers of GKK's estate.

At the time of the case, GKK was 78 years of age, on treatment for diabetes and blind in his right eye. The medical report was to the effect that he 'is able to carry out the activities of daily living, has good judgment and average intelligence. He exhibits adequate mental capacity to continue playing an active role in his company.' The report also indicated that 'he shows signs of early senile dementia as evidenced by slight impairment of his recall memory and abstract reasoning' a fact that was heavily emphasized by the petitioner, SKK. SKK also emphasized the fact that he was a son of GKK and therefore had a right to see that GKK's health and estate are protected. SKK claimed that he sought the court orders in the best interest of GKK.

SKK named the wife of GKK with whom he was living as well as an adult daughter to be appointed as managers jointly with him. The Petitioner emphasized that the

¹¹³ *K v K* (2009) eKLR High Court at Nairobi (Nairobi Law Courts) Petition 36 of 2009

petition 'is not a suit for properties but proper management thereof and for personal welfare of GKK. It is made in good faith' and thus it was urged that the same be granted.

On the other hand, GKK contended that he was able to keep managing his affairs. It was submitted by his advocates that the medical report neither states that GKK is suffering from mental disorder under the Act nor does it state that he is incapable of managing his own estate. On its part, the court held that:

'the court shall be very wary of making an order which can go to the extent of deprivation of a person's liberty and property. I do agree with the observations made in the case of BS that 'Any interference must be necessary in a democratic society which introduces the principles of proportionality.' The applicant has not shown any cause where I would interfere with the fundamental rights of GKK enshrined in our Constitution.'

Hence, the court dismissed the petitioner's application.

Several preliminary observations can be made of this case. The first, is that as with *Re Simon Peter Karanja Kiarie*, the petitioner was not in court. It may, however, be argued that often, when people hire counsel in civil cases, they do not then themselves get to court. Still, it seems that given that we have ratified the CRPD which stresses very much the need for people with disabilities to be involved in matters relating to them, it would have been necessary to have input from GKK. In addition, one would hope that given that a person's capacity is being determined, the court would deem it important to see the person whose capacity the court is determining. The second observation is that neither counsel nor the court relied on Article 12 nor indeed any other article of the CRPD despite the fact that the case was decided in 2009 and Kenya ratified the CRPD in 2008. Thirdly, before giving its ruling, the court stated that:

No one can carry any doubt that the matter is involved and also, if I may venture to say, unprecedented. I do not say unprecedented in the sense of

applications under The Act having been made. There were many which have been filed and determined in the past, but no other judicial officer has been presented with the issues and submissions which have been so made before this court.

It is interesting then, that the judge in effect states that many applications for guardianship are made. This is particularly so in light of the fact that most people interviewed for this paper indicated that guardianship is *not* common, and they did not know of anyone who was under formal guardianship. A recommendation then is to have a database that documents the extent to which guardianship is employed in Kenya.

Republic v Chairperson Kilibwoni Disputes Tribunal & 2 others

*Republic v Chairperson Kilibwoni Disputes Tribunal & 2 others*¹¹⁴ is a case for judicial review orders that was instituted by J.K.M, the biological son of J.K.R. He instituted the application as Guardian and Next Friend of J.K.R. who is an adult, averring that J.K.R. suffers from mental illness and psychosis and therefore lacks the requisite legal and mental capacity to take proper care of himself. To support this allegation, J.K.M. annexed copies of medical reports to prove this fact. A preliminary objection was raised to the effect that J.K.M lacks the mandatory legal capacity to institute the instant proceedings because J.K.R. had not been legally pronounced as a person of unsound mind and therefore J.K.M. was a stranger to the suit. The court held that from a reading of Section 26 of the Mental Health Act and Order 31, Rule 15 of the Civil Procedure Rules:

It is only a Court of law which can adjudge a person to be of unsound mind for purposes of suing or being sued. 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 the present case no Court adjudged J.K.R. to be of unsound mind as required under Order 31, Rule 15. Also, the Applicant did not obtain leave of the Court to have legal powers of custody, management and guardianship of his father and father's Estate. The doctor's letter dated 10.09.08 is not premised on any law and cannot invalidate J.K.R's voluntary acts and transactions. Such a declaration

¹¹⁴ High Court at Eldoret 2009 eKLR Misc. Civ. Appli. 74 of 2009

that any transactions by Kimeli be considered void can only be given by a Court of law.

The court struck out the application.

A few preliminary observations can be made based on this case as well. The first, is that a doctor's report in and of itself is not enough to base the label 'unsound mind' on. This is particularly relevant in the context of Kenya where many laws use the words 'unsound mind' without defining what is meant by unsoundness of mind. Further, from the interviews conducted, it emerged that the practice of attempting to use a doctor's letter to stop a person from making 'bad decisions' is rather common place:

We had a carer who came to the support group last time and she was talking about taking a letter from the doctor to the bank because her sister who has a psychosocial disability was withdrawing huge sums of money from her account, withdrawing hundreds of thousands and giving it out. The bank did not honour the letter and the carer was saying, "banks are very unfair, how could they allow her to misuse her money?"¹¹⁵

The respondent recounted yet another situation:

I only know of a lady who took her matter to court, because her family had taken her child on the authority of her psychiatrist, they got a letter from the psychiatrist and FIDA (an organization that lobbies for women's rights) represented the lady in this matter, and she went to court and the court gave her custody of her baby.¹¹⁶

Secondly, the decision is a 2009 decision, and yet the CRPD is not one of the laws relied upon in making the judgment. Indeed, neither side to the dispute raises the Convention.

3.2.2 Civil Procedure Act (Cap. 21) and the Civil Procedure Rules, 2010

The Civil Procedure Act makes provision for procedure in civil suits in Kenya. The State in its report to the CRPD Committee asserts that 'Every Kenyan citizen has legal capacity in civil proceedings. However, where exceptions have to be made then

¹¹⁵ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

¹¹⁶ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

the same is done in accordance with the law.’ This then demonstrates that the position of the state is that there are circumstances in which some people may not enjoy legal capacity on an equal basis with others. An in depth look into the Civil Procedure Act demonstrates the truth of this fact.

Order 4 of the Civil Procedure Act indicates that where the plaintiff or defendant is a minor or person of unsound mind, a statement to that effect shall be made. The Act also introduces partial guardianship in cases where a person of unsound mind is a litigant. To be exact, Rule 15 states that the provisions relating to minors apply to persons who have been adjudged to be unsound mind and to persons who though they have not been so adjudged are found by the court after inquiry to be of unsound mind and are incapable of protecting their interests when suing or being sued. This provision considers minors and persons of unsound mind as lacking capacity on the same basis and standard despite the different circumstances.

Section 93 of the Civil Procedure Act strips a person with disability their right to legal capacity by recognising that a *guardian ad litem* or next-of-friend may oust the capacity of a person with disability to litigate a suit.¹¹⁷ This provision is general to all disabilities as it does not use the terminology ‘unsound mind’. The provision is flawed and discriminatory as it fails to treat persons with disabilities as equals before the law in terms of legal action. It presumes that all persons with disabilities do not have the legal capacity to institute a suit. The section stipulates that:

“In all suits to which any *person under disability* is a party, any consent or agreement as to any proceeding shall, if given or made with the express leave of the court by the next friend or guardian for the suit, have the same force and effect as if such person were under no disability and had given such consent or made such agreement”

3.2.3 The Children’s Act No. 8 of 2001

Ordinarily and in accordance with the Act, the appointment of a guardian shall be determined upon the child attaining the age of eighteen years, unless exceptional

¹¹⁷ See also Order 1 Rule 10(2) and Order 32 Rule 1(2) of Civil Procedure Rules, 2010

circumstances exist that would require a court to make an order that the appointment be extended. Such exceptional circumstances according to Section 107(2) are when a child suffers from a mental or physical disability or illness rendering him or her incapable of maintaining himself or herself or managing his own affairs and property without a guardian's assistance. In such cases, the court may order extension of guardianship for such a child.

Orders extending guardianship under the Children's Act are made prior to the child's 18th birthday, and are made on application by the child or the parent or guardian of the child, or a relative of the child. Such order though should be made with the consent of the child if he is capable of giving such consent. The Act does not clarify how the consent is obtained and what happens if consent is refused. Such an order may be accompanied by conditions on duration and how the order should be carried out. This provision proceeds in type when it provides that an application to vary or revoke its order may be lodged by such person's guardian or, if he or she marries, their spouse.¹¹⁸ This provision makes it clear that one may lose the legal right to make decisions on some aspects of their life (management of property) and still retain the right to make decisions on other aspects of their life (the decision to marry).

The provision provides no opportunity for the person with disabilities to be heard in the event that they may want the guardianship order revoked. As worded, it is possible for guardianship orders to carry on for life without the opportunity for review by a competent, independent and impartial authority or judicial body as envisaged under Article 12(4).

The Children's Act is one of the laws that the state identifies in its report as relating directly to Article 12. The State makes no mention of efforts to review this Act to bring it more in line with Article 12.

¹¹⁸ Children's Act (No. 8 of 2001)

3.3 Laws that touch on legal capacity but do not directly establish guardianship

There are several laws that touch on legal capacity without directly establishing guardianship.

3.3.1 The Constitution of Kenya, 2010

In August 2010, Kenya adopted a Constitution that has been seen as progressive, and which specifically protects the rights of persons with disabilities.¹¹⁹ Article 2 of the Constitution of Kenya 2010 affirms the supremacy of the Constitution and further states that any treaty or convention ratified by Kenya forms part of the law of Kenya. As has been stated before, the CRPD is part of the law of Kenya by dint of Article 2(6); Kenya having signed and ratified the Convention on the Rights of Persons with Disabilities in 2008, is constitutionally bound by its provisions. In this regard, it is important to note that Kenya has also ratified the African Charter of Human and Peoples' Rights which provides to every individual the right to equality before the law and equal protection of the law.¹²⁰

¹¹⁹ Article 54: (1) A person with any disability is entitled–

(a) to be treated with dignity and respect and to be addressed and referred to in a manner that is not demeaning;

(b) to access educational institutions and facilities for persons with disabilities that are integrated into society to the extent compatible with the interests of the person;

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

(d) to use Sign language, Braille or other appropriate means of communication; and

(e) to access materials and devices to overcome constraints arising from the person's disability.

(2) The State shall ensure the progressive implementation of the principle that at least five percent of the members of the public in elective and appointive bodies are persons with disabilities.

¹²⁰ Article 3 of the African Charter of Human and Peoples' Rights

Legal capacity under the Constitution

An imperative Article in ensuring that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life is Article 27. It states that ‘every person is equal before the law and has the right to equal protection and benefit of the law.’ It further prohibits discrimination against a person on any ground including health status, age or disability. The state report identifies that Article 27 ‘guarantees equal treatment, including the right to equal opportunities in political, economic, cultural and social spheres’.¹²¹

With regard to the Constitution of Kenya and Article 12(5), the state report identifies that the Government of Kenya has put in place constitutional guarantees that ensure the equal right of persons with disabilities to own or inherit property. This, the State reports, is contained in Article 40 of the Constitution of Kenya, 2010, which guarantees the rights of every person, including persons with disabilities, to acquire and own property. The State however acknowledges that the issue of inheritance, especially for land, for persons with disabilities is still a major challenge as they are often disinherited of their property by their kin and guardians.

According to Article 38 every adult citizen has the freedom to make political choices which include the right to be registered as a voter and be a candidate for public office without unreasonable restrictions. The Constitution however fails to interpret what “unreasonable restriction” means. Indeed sections 83(1)b, 99(2)e and 193(2)d of the Constitution are potentially in conflict with Kenya’s obligations under the CRPD¹²² to ensure that persons with disabilities are able to enjoy legal capacity on an equal basis with others.¹²³

¹²¹ Committee on the Rights of Persons with Disabilities, ‘Future Sessions; Consideration of Reports’ (National Report: Kenya’s Initial Report Submitted Under Article 35(1) of the United Nations Convention on the Rights of Persons with Disabilities - 31st August 2011) <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/futuresessions.aspx>> accessed 22 May 2013

¹²² Article 29 of the CRPD

¹²³ Equal Rights Trust and Kenya Human Rights Commission, ‘*In the Spirit of Harambee: Addressing Discrimination and Inequality in Kenya*’ 2012 p.141

Article 83(1)b qualifies Article 38 by providing that a person qualifies for registration as a voter at elections or referenda if the person is not declared to be of unsound mind. Article 99(2)e disqualifies persons of 'unsound mind' from being elected a member of Parliament. Article 193(2)d disqualifies persons of 'unsound mind' from being elected a member of a county assembly. However, the Constitution is silent on the definition of 'unsound mind', and the term 'unsound mind' is not defined anywhere in the Laws of Kenya.¹²⁴

The foregoing provisions on political participation (Articles 83(1) b, 99(2)e and 193(2)d) have a huge potential of disenfranchising a huge number of Kenyans, and denying them legal capacity on an equal basis with others. It has been argued that:

the bulk of persons with intellectual disabilities (...) are technically not unsound of mind; and indeed (...) even if they were adjudged to be of unsound mind, fundamental rights still accrue to them.¹²⁵

Of note is the fact that the State does not identify the foregoing Articles of the Constitution on political participation as touching on Article 12 of the CRPD at all. The UN High Commission has stated that norms of laws disqualifying a person from office or performing a function on the basis of their disability, including norms disqualifying persons with disabilities from running for political positions also need to be abolished.¹²⁶

In practice, the government of Kenya has given mixed signals with regard to people with disabilities exercising their legal capacity with regard to political rights, specifically, voting for people with intellectual disabilities and/or mental

¹²⁴ Equal Rights Trust and Kenya Human Rights Commission (Ibid). The court in *Republic v Chairperson Kilibwoni Disputes Tribunal & 2 others* (High Court at Eldoret 2009 eKLR Misc. Civ. Appli. 74 of 2009) stated that only a court of law can declare a person to be of 'unsound mind'.

¹²⁵ Lawrence Mute, 'Shattering the Glass Ceiling: Ensuring the Right to Vote for Persons with Intellectual Disabilities In Kenya' (2010) 2 *Thought and Practice: A Journal of the Philosophical Association of Kenya (PAK)*, p. 6.

¹²⁶ United Nations, *Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary General: Thematic Study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities (A/HRC/10/48)*

disability.¹²⁷ Advocacy by some non-governmental organisations including the Disability Caucus on the Implementation of the Constitution and the Kenya Association of the Intellectually Handicapped prior to the August 2010 constitutional referendum resulted in the government registering and assisting some adults with intellectual disabilities in exercising their right to vote.¹²⁸ The government for the first time allowed persons with intellectual disabilities to have their supporters assist them in casting the ballot.

The Independent Electoral and Boundaries (IEBC) had reservations based on the practice of voter bribery – the fear was that once a voter accepted a bribe to vote a certain way, the voter could then ‘pretend’ to have an intellectual disability and the person offering the bribe could be the ‘supporter’ who would then have the opportunity of ensuring that the person voted the ‘right’ way. The IEBC also expressed reservations with regard to whose decision it is anyway (the choice of candidate decision) – and how to make sure that it is the decision of the person with an intellectual disability and not the decision of the supporter.¹²⁹ The reservations expressed by the IEBC raise an interesting question, broadly, with regard to supported-decision making. How can we be sure that the will of the person with disabilities is being expressed? How do we know that supported decision-making is not substituted decision making by another name? And should the fact that we

¹²⁷ During the constitutional referendum campaign in 2010, the Interim Independent Electoral Commission (IIEC) Chief Executive Officer reportedly said that, ‘Voter registration and the act of voting means exercising discretion. Exercising discretion after considering all the relevant factors is a very intellectual exercise and perhaps if you are mentally impaired, you may not be able to exercise that capacity to use the vote’. About a month later, he is quoted as having said ‘There are about 3.6 million people with mental disabilities but what do you do with that number? How do you make the world realise that you are there? The only way to do that is to be a contributor in the major decision making process in your country ... let us make sure that at least a half of those with disabilities are registered’. Lawrence Mute, ‘Shattering the Glass Ceiling: Ensuring the Right to Vote for Persons with Intellectual Disabilities In Kenya’ (2010) 2 *Thought and Practice: A Journal of the Philosophical Association of Kenya (PAK)*, p. 6

¹²⁸ Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013) and Interview with United Disabled Persons of Kenya (Nairobi, 29 May 2013)

¹²⁹ Interview with United Disabled Persons of Kenya (Nairobi, 29 May 2013)

might not always be 100% sure whose decision it is mean that we should do away with the idea of supported decision – making altogether?

3.3.2 Age of Majority Act (Cap 33)

The Age of Majority Act deems a person to have full legal capacity on the attainment of 18 years.¹³⁰ Full legal capacity to enter into transactions presumes that a person is of sound mind. The parents' or guardians' rights to act on behalf of their children cease when the child reaches the legal adult age. This must be the same for all persons to avoid classifying people with disabilities as children at an older age than others.¹³¹

3.3.3 Matrimonial Causes Act (Cap 152)

One of the grounds of divorce according to section 8 of the Matrimonial causes Act is where a spouse is incurably of unsound mind and has been continuously under care and treatment for a period of at least five years immediately preceding the presentation of the petition. Apart from this ground, all the other grounds of divorce are either as a result of an action or inaction on the part of the spouse. The fact that this ground of divorce is premised on disability makes it a discriminatory ground and hence objectionable. In addition, being disabled mentally is not by choice and as such this provision is demeaning. Section 8(2) further elaborates on the circumstances and uses discriminatory and derogatory language that presents a person with disability as one that should be denied capacity to make an informed decision on life choices as follows:

“.....a person of unsound mind shall be deemed to be under care and treatment while he is detained, whether in Kenya or else-where, in an

¹³⁰ Section 2 Age of Majority Act Cap 33 'A person shall be of full age and cease to be under any disability by reason of age on attaining the age of eighteen years.'

¹³¹Office of the High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities Day of General Discussion on Article 12 of the CRPD – The Right to Equal Recognition Before the Law (21 October 2009) IDA CRPD Forum, 'Principles for Implementation of CRPD Article 12' <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 30 May 2013

institution duly recognized by the Government as an institution for the care and treatment of *insane persons, lunatics* or *mental defectives*, or is detained as a *criminal lunatic* under any law for the time being in force in Kenya.

In the same way, one of the grounds for nullifying a marriage under section 14(f) is where either party was at the time of marriage of unsound mind or subject to recurrent fits of insanity or epilepsy. This will be allowed where the petitioner was at the time of the marriage ignorant of the mental status, the proceedings for nullity are instituted within a year from the date of the marriage and marital intercourse with the consent of the petitioner has not taken place since the discovery that the partner is subject to recurrent fits of insanity or epilepsy. The Act further makes the assumption that persons with disabilities do not have legal capacity and states that “every petition in a matrimonial cause shall be signed by the petitioner and in the case of an infant or a person of unsound mind it shall be signed by his next friend.” The Act like many other likens a person with disabilities to an infant or a child in terms of legal capacity and out rightly embraces the model of substituted decision making.

3.3.4 Sale of Goods Act

According to contract law, a person is said to be of sound mind for the purpose of contract if at the time when he makes it, he is capable of understanding it and of forming a rational judgment as to its effect upon his interests. Contracts entered into by a person of unsound mind are voidable at his option if it is proved that he did not understand what he was doing and that the other party was aware of his mental condition. Conversely persons ‘who by reason of mental incapacity are incompetent to contract’ are held liable to pay reasonable prices for all necessaries (these include food) supplied to them at their point of need as stipulated in section 4 of Sale of Good Act.

3.3.5 Law of Succession Act (Cap 160)

Under section 5 of the Act, a person who is not of sound mind has no legal capacity to dispose of his or her free property by will. A person who alleges that another was

not of sound mind when he or she made a will has the burden of proof to confirm the allegation.¹³²

With regard to Article 12(5) of the CRPD, the state acknowledges that the issue of inheritance, especially of land, for persons with disabilities is still a major challenge as they are often disinherited of their property by their kin or guardians. The State undertakes to address this under the ongoing review of the Law of Succession Act to among other things protect the rights of persons with disabilities to inherit property. This would be a commendable move as being disinherited has been cited as greatly affecting persons with disabilities.¹³³

3.3.6 Traffic Act (Cap 403)

Section 31 of the Act restricts the legal capacity of persons with disabilities to be licensed to drive: Deaf persons in Kenya have in particular found it extremely hard to be granted drivers' licenses. One condition for the grant of a driving license is a declaration by an applicant that he or she is not 'suffering from (...) physical disability which would be likely to cause the driving by him of a motor vehicle (...) to be a source of danger to the public'.¹³⁴

This was raised as a legal capacity issue¹³⁵ although it may be argued to be more of a discrimination issue.

3.3.7 Penal Code, Cap 63

The code provides for the presumption of sanity under section 11 and places the onus of proving (in)sanity on the person that alleges under section 12.¹³⁶ By dint of Section 12, a person is not criminally responsible for an act or omission if at the time of doing the act or making the omission he is through any disease affecting his mind

¹³² Section 5 (4), Law of Succession Act

¹³³ Interview with Schizophrenia Foundation of Kenya (Nairobi, Kenya, 29 April 2013); Interview with Lawrence Mute, Member of the African Commission on Human and Peoples' Rights (ACHPR) and former commissioner at the Kenya National Commission on Human Rights (Nairobi, Kenya, 7 May 2013) and Interview with United Disabled Persons of Kenya (Nairobi, 29 May 2013)

¹³⁴ The Traffic Act (Cap. 403)

¹³⁵ KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

¹³⁶ See also the Evidence Act, section 11 (2) (c)

incapable of understanding what he is doing, or of knowing that he ought not to do the act or make the omission. The defence of mental incapacity or incompetence (commonly known as the insanity defence) gives life to the perception that the defence is an easy solution to evading jail time. However, the reality is that in Kenya, once a person is found not guilty by reason of insanity or guilty but insane, the person is detained in a mental hospital, usually Mathare hospital. Concerns have been raised that once this finding is made, detention is indefinite – one may be released *only* ‘at the pleasure of the president.’¹³⁷

The defence of mental incapacity also runs the risk of criminalizing persons with disabilities in the public’s eye. Section 12 has been interpreted severally by the courts. In a *criminal appeal no. 88 of 1982*, the Court of Appeal at Nairobi held that in order to establish the defence of insanity, the onus was upon the appellant to prove to the court that at the time of committing the crime he was; (i) suffering from disease affecting the mind and; (ii) through such disease he was incapable of understanding what he was doing or knowing he ought not to commit the crime.

The 2006 case of *Republic versus Winny Sigei*,¹³⁸ illustrates the above. In this case, the court made a special finding that while the Accused was ‘guilty’ of the act charged she was insane when she committed it. The court was satisfied that the Accused has proved on a balance of probability that at the material time, she was mentally sick and did not know what she was doing. In this case the court considered the evidence of a Provincial Psychiatrist, who, testified that he treated Accused at a Provincial General Hospital for acute psychosis with paranoia on a referral from a District Hospital.

It has been argued that the defence of mental incapacity or incompetence is one of the areas that will need reviewing in light of Article 12 of the CRPD.¹³⁹ On the one

¹³⁷ Section 162 of the Criminal Procedure Code <http://kenyalaw.org/kenyalaw/klr_app/frames.php> accessed 10 June 2013

¹³⁸ Criminal Case 8A of 2006

¹³⁹ Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship)

hand is the view that the defence is incompatible with legal capacity, 'which entails responsibility for one's own actions'.¹⁴⁰ This view proposes that this defence be abolished.¹⁴¹ Sentencing under this defence includes detention for the purpose of treatment,¹⁴² which has been said to amount to disability-based detention in violation of CRPD Article 14.¹⁴³ Instead, it is proposed to apply disability-neutral doctrines on the subjective element of the crime, which take into consideration the situation of the individual defendant.¹⁴⁴

On the other hand is the view that this defence may still continue to apply with appropriate safeguards to protect against the rights abuses that often occur once a person is detained for the purpose of treatment. It has been stated that 'modern approaches to this (retaining the defence of incompetence) are based on solid and well accepted principles of justice, human rights and civil society; arguably a more just and humane response to crimes committed by people with a mental impairment – with recovery, treatment and rehabilitation being the primary and social justice outcomes'.¹⁴⁵

<http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

¹⁴⁰ Tina Minkowitz, 'Summary of Points Related to Expert Meeting December 13-14, 2012'

<https://dk-media.s3.amazonaws.com/AA/AG/chrusp-biz/downloads/281598/Summary_of_points.pdf> accessed 10 June 2013

¹⁴¹ United Nations Human Rights Council, 'Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary General' (OHCHR A/HRC/10/48 para 47)

<<http://www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.48.pdf>> accessed 10 June 2013

¹⁴² Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship)

<http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

¹⁴³ Tina Minkowitz, 'Summary of Points Related to Expert Meeting December 13-14, 2012'

<https://dk-media.s3.amazonaws.com/AA/AG/chrusp-biz/downloads/281598/Summary_of_points.pdf> accessed 10 June 2013

¹⁴⁴ United Nations Human Rights Council, 'Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary General' (OHCHR A/HRC/10/48 para 47)

<<http://www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.48.pdf>> accessed 10 June 2013

¹⁴⁵ Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship)

Section 38 of the Prisons Act allows a medical officer to direct that a prisoner be moved to a mental hospital in instances where such prisoner is, in the opinion of the medical officer, 'of unsound mind'.

To conclude this issue, the move should be towards decreasing the use of incarceration as much as possible and limiting it to genuine cases of crime and dangerousness. This should be the case for everyone – including persons with disabilities. In addition, it is important to ensure that persons with disabilities are supported in the justice process, including maximizing accommodations in the regular criminal justice system. Further, the fact of mental impairment could be a mitigating factor during sentencing. This would minimize the instances of people resorting to this defence. Kenya needs to deliberate on this issue further in order to come up with a response that is suited to its context.

3.3.8 Criminal Procedure Act (Cap. 75)

The Criminal Law (Amendment) Act, 2003, amended the Penal Code, the Evidence Act and the Criminal Procedure Code by deleting such derogatory terms as imbecile which was insensitive and derogatory to persons with disabilities. The Code recognizes cases where persons with disabilities are not able to give their defence because of their disabilities. The Code authorizes a proceeding judge to order that such persons be released unconditionally or be put in a mental hospital. Several questions follow. Does the authorized detention of those who are adjudged mentally disabled amount to a violation of the person's right of equal protection before the law, presumption of innocence, as well as right to liberty? If a person is declared incapable of formulating a criminal intent germane to commit a crime, should it necessarily follow that they should be released unconditionally in accordance with sections 162, 163 and 164 of the Criminal Procedure code? The one fact that remains clear is the need to maximize accommodations within the criminal justice system to ensure a fair trial of persons with disabilities accused of crimes.

<http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

Sections 162, 163, 164 and 280 of the Criminal Procedure Code establish the procedure through which a court may determine that a person is of unsound mind and the subsequent consequences, including that once so declared a person may be consigned to a mental hospital or, in the wording of section 280, a “lunatic asylum” until such time as the medical officer or the court or the Attorney General deem such person to be of sound mind.

3.3.9 Sexual Offences Act (Act No. 3 of 2006)

The Sexual Offences Act makes provision about sexual offences, their definition, prevention and the protection of all persons from harm from unlawful sexual acts. It is one of the Acts that is identified in the state report as being one of the States’ core areas of compliance with Article 12 of the CRPD.

According to Section 2 the Sexual Offences Act, complainant ‘means the Republic or the alleged victim of a sexual offence and in the case of a child or a person with mental disabilities, includes a person who lodges a complaint on behalf of the alleged victim where the victim is unable or inhibited from lodging and following up a complaint of sexual abuse’. The Act additionally introduces progressive provisions that comply with Article 12 of the CRPD by recognizing the right of person with disabilities when they are acting as witnesses in court. The Act introduces an accommodation measure to ensure that persons with disabilities exercise their legal capacity on an equal basis with others. The Act recognizes persons with disabilities as ‘vulnerable witness’ under Section 31 and provides support measures to enable them engage with the judicial system. The Act recognizes support measures to ensure that a person with disabilities who is a victim of sexual abuse may communicate effectively with the court as required, if necessary through the use of intermediaries.

According to the Act:

- a. A court may declare as a vulnerable witness a witness who has a mental disability.¹⁴⁶
- b. A witness with psychological, intellectual or physical impairment may apply for the court to declare him or her as a vulnerable witness.
- c. The court may seek advice from an intermediary on the vulnerability of a witness. An intermediary is 'a person authorized by a court, on account of his or her expertise or experience, to give evidence on behalf of a vulnerable witness and may include a parent, relative, psychologist, counselor, guardian, children's officer or social worker.'¹⁴⁷
- d. The court may, having regard to all the circumstances of the case including the witness's views, direct that a vulnerable witness give evidence via an intermediary; but such direction may be varied or revoked.
- e. An intermediary may communicate the essence of a question to the vulnerable witness and may also communicate to the court on the well-being of the witness.

Section 31 of the Sexual Offences Act subsection (10) is however problematic as it provides that an accused shall not be convicted solely on the uncorroborated evidence of an intermediary. Subsection 10 of the section 31 makes reservations on the credibility of a person with disabilities as a witness and portrays them as persons without legal capacity. Moreover, the use of intermediaries is a new concept

¹⁴⁶ Section 2 of the Sexual Offences Act 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."

¹⁴⁷ Sexual Offences Act

and as such may need further legal tools to guide its implementation to guarantee the rights of persons with disabilities to equal protection before the law.

3.3.10 Evidence Act (Cap 80)

Section 126(1) of the Evidence Act states that:

A witness who is unable to speak may give his evidence in any other manner in which he can make it intelligible, as, for example, writing, or by signs, but such writing must be written, and the signs made, in open court.

Section 135 of the Act confers as privileged communications, communications between interpreters and their clients.

Section 125 further states that:

All persons shall be competent to testify unless the court considers that they are prevented from understanding the questions put to them, or from giving rational answers to those questions, by tender years, extreme old age, disease (whether of body or mind) or any similar cause.

Section 125 clearly assumes that some people have no capacity to give evidence in court, without going into how they may be supported to do so (except in the case of Deaf witnesses). In its report, the State acknowledges that this is the situation:

Persons with disabilities also often find themselves victims and/or witnesses in criminal cases that then require them to provide evidence. This usually presents different challenges depending on the nature of disability and severity of the effect of the offence. Courts in most cases find it difficult to convict suspects in these cases where the victim or witness either could not see or hear thus making their evidence to lack credibility thereby leading to dismissal of cases.

The State undertakes that this ‘challenge is being addressed in the ongoing review of the Evidence Act’. It is hoped that the review will take into account Article 12 of the CRPD and repeal Section 125 of the Evidence Act or word it in such a way as to provide for support for persons with disabilities engaging with the justice system.

3.3.11 Elections Act (Act No. 24 of 2011)

Section 3 of the Act states that every adult citizen has the right to vote in accordance with *Article 38 (3)*¹⁴⁸ of the Constitution. *Article 38 (3)* provides that:

Every adult citizen has the right, without unreasonable restrictions-

- (a) To be registered as a voter;
- (b) To vote by secret ballot in any election or referendum; and
- (c) To be a candidate for public office, or office within a political party of which the citizen is a member and if elected, to hold office.

The Constitution grants every adult citizen the right to vote and participate in the electoral process. This right is subject to “***reasonable restrictions***”, a phenomenon that is abstract and if unchecked, can be abused and stretched beyond its intended limits.

Section 9 of the Act states that where a person has been adjudged or found to be of unsound mind, where the person is entitled to appeal the decision, the person shall not be disqualified from being registered until the expiration of thirty days after being so declared or until the appeal has been determined. Where a person, having duly applied to be registered as a voter, has not been so registered the person may lodge a claim to the registration officer and may appeal to the Principal Magistrates Court or further to the High Court.

The Act disqualifies a person of unsound mind from being nominated as a Member of Parliament, county assembly, governor, speaker and other public offices.

¹⁴⁸ 38 (1) Every citizen is free to make political choices, which includes the right-

- (a) To form, or participate in forming a political party;
- (b) To participate in the activities of, or recruit members for a political party; or
- (c) To campaign for a political party or cause

(2) every citizen has the right to free, fair and regular elections based on universal suffrage and the free expression of the will of the electors for-

- (a) any elective public body or office established under the Constitution; or
- (b) any office of any political party of which the citizen is a member

Section 36 outlines the criteria for allocation of special seats by political parties which include a requirement that the list shall include eight candidates four of whom shall be persons with disabilities.

3.3.12 HIV and AIDS Prevention and Control Act - Cap 14

The HIV and AIDS Prevention and Control Act¹⁴⁹ has provisions that touch on legal capacity. Section 22 of the Act addresses disclosure of information concerning the result of an HIV test. In part, this section provides that if, in the opinion of the medical practitioner who undertook the HIV test, the person tested has a disability by reason of which the person appears incapable of giving consent, disclosure of information concerning the result of an HIV test may be given with the written consent, in order, of-

- (i) a guardian of that person;
- (ii) a partner of that person;
- (iii) a parent of that person; or
- (iv) an adult offspring of that person;

This provision does not envisage the exploration of communication methods by which the person with disability who has undergone the test may be supported in order to understand, and make the decision as to whether to disclose information concerning his or her HIV status. The provision is also steeped in the pre-CRPD model – that of guardianship and that of presuming incapacity and resulting to substitute decision-making as opposed to augmenting the person’s decision-making capacity.

¹⁴⁹ Kenya Law Reports <http://www.kenyalaw.org/kenyalaw/klr_app/frames.php> accessed 4 June 2013

3.3.13 Persons with Disabilities Act, No. 14 of 2003

The object of the Act is to provide for the rights and rehabilitation of persons with disabilities and to achieve equalization of opportunities for them, and recommend measures to alleviate discrimination. Despite the various gains secured by the Act, it remains silent on the issue of legal capacity for persons with disabilities.

3.4 Other Legislation

Below is a sample of various legislative provisions that relate to the capacity to vote and to be voted for, and to hold state office. *Section 21* of the National Land Commission Act (No. 5) of 2012 provides that the Secretary of the National Land Commission may be removed from office, among other things, for: “inability to perform the functions of the office of the secretary arising out of physical or mental incapacity”.¹⁵⁰ Correspondingly, *Section 11 (1) (c)* of Commission for Implementation of the Constitution Act (No. 9) of 2010 stipulates that the office of the chairperson or a member shall become vacant if the holder is unable to discharge the functions of his office by reason of physical or mental infirmity. As a ground to vacate state office, mental infirmity or declaration of being of unsound mind is commonplace in legislation that establish various institutions.

3.5 Policy and Administrative Framework

3.5.1 The Draft National Disability Policy, 2006

The National Disability Policy, 2006 was developed by the Department of Social Services under the Ministry of Gender, Sports, Culture and Social Services. The policy aims to guide the Ministry’s plans on how to address the needs and concerns of persons with disabilities. It recognises that persons with disabilities are a distinct group whose needs, capabilities and aspirations require special attention. The policy however does not recognise the right to legal capacity as being key to persons with

¹⁵⁰National Land Commission Act (No. 5 of 2012)

disabilities attaining equality and inclusion. On the topic of protection and legal services, the policy correctly notes that persons with disabilities are usually assumed not to have legal rights and in some cases, their capacity to make decisions is hijacked often eventuating in their exploitation, abuse or at the least misrepresentation of their interests. In view of this, the policy makes a statement to ensure that the Persons with Disabilities Act is harmonized with international instruments to which Kenya is signatory. It further provides that persons with disabilities should be sensitized on their rights. Ultimately, the policy therefore fails to give the issue of legal capacity the weight it ought to have in the promotion and protection of the rights of persons with disabilities.

The National Guidelines for HIV Testing and Counseling

The National Guidelines for HIV Testing and Counseling in Kenya recognize that provisions should be made for persons with disabilities to access HIV Testing and Counselling (HTC) services in a manner that meets their specific needs. According to the Guidelines, this means ‘incorporating approaches such as local sign language, wheelchair accessible spaces, providers who specialize in issues of mental handicaps, and flexibility on the part of HTC service providers in reaching clients where they are most accessible’. The Guidelines recognize that in some cases, providers may attend to the client or patient in the home or another appropriate setting.

The Guidelines further state that HTC service providers should have the skills to determine if a person is mentally fit to receive their HIV test results, and should know where to refer a client to for further care and support when needed. If the provider is uncertain, the client or patient may be referred to the nearest health facility.¹⁵¹ It would be interesting to find out how well trained the service providers

¹⁵¹ Ministry of Public Health and Sanitation, ‘National Guidelines for HIV Testing and Counseling in Kenya’ 2nd Edition, October 2010

are with regard to making the determination as to whether a person is mentally fit to receive their HIV results. While this is a measure of protection, it may result in persons with intellectual disabilities and persons with psychosocial disabilities not being able to access HTC services on an equal basis with others.¹⁵²

The Draft Mental Health Policy

The draft Mental Health Policy is silent on the right to equal protection before the law, specifically the right to legal capacity of persons with mental illnesses. It fails to envisage situations where persons with mental illness would be denied this right as a result of their vulnerability. The policy is however not come to force since it is still in draft form. Meanwhile there has never been any policy directive in regard to mental health.

The Draft National Human Rights Policy

The development of this Policy was through a transparent, consultative, and participatory process that was spearheaded by the Ministry of Justice, National Cohesion and Constitutional Affairs (MOJNCCA) and the Kenya National Commission on Human Rights, (KNCHR). The policy is silent on the right to equal protection before the law as a priority area, especially with respect to how it impacts of persons with disabilities and even, older persons.

<<http://nascop.or.ke/library/HTC/National%20Guidelines%20for%20HTC%20in%20Kenya%202010.pdf>>accessed 7 June 2013

¹⁵² KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

3.6 Other measures identified by the state in its report as being key to implementing Article 12

The State identifies Section 37 of the Persons with Disabilities Act, 2003, as being key to implementing Article 12(5) of the CRPD. Section 37 of the Persons with Disabilities Act sets up a system that is meant to encourage credit unions, co-operatives and other lending institutions to extend credit to persons with disabilities. The State also reports that it has also provided a budget of KES 200 million in the 2010/2011 financial year, part of which monies was used towards the provision of grants to persons with disabilities to start up their own business and grants to empower persons with disabilities, among others. The State reports that in order to make the loan accessible to persons with disabilities, minimum collateral is required and there is no interest charged. Further, funds provided for other marginalised groups (such as the Youth Enterprise Fund and the Women's Enterprise Fund) provide that at least 10% of the resources should be set aside for persons with disabilities.

The State recognises that 'the issue of legal capacity still remains a challenge to some persons with disabilities, particularly to those with mental and cognitive disabilities, where decisions are made on their behalf without consulting them'.¹⁵³ The State goes on to further state that 'in an effort to overcome this, the Government is pushing for a shift from substituted decision making to supported decision making for persons with disabilities and that there be a distinction between legal capacity which all persons with disabilities enjoy and capacity to act where they may require support'. The latter sentence calls for careful interpretation. In the first place, legal capacity entails the capacity to hold rights and to act upon rights. Does the distinction drawn by the State mean that guardianship may be one of the

¹⁵³ Committee on the Rights of Persons with Disabilities – Future Sessions
<<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/futuresessions.aspx>> (accessed 12 April 2013)

'support measures' envisaged by the State? Indeed the State does not at any point commit to replacing guardianship with supported decision making.

4. The Kenyan situation with regard to Article 12 of the Convention on the Rights of Persons with Disabilities and local dilemmas

This section aims at situating the research in the Kenyan setting. Hence, it relies heavily on interviews with Disabled Peoples' Organisations (DPOs) and with persons with disabilities. The section first inquires into whether formal guardianship is common in Kenya. It then examines the situation on the ground with regard to three main areas of decision making:

- 1) Health care decisions
- 2) Financial decisions
- 3) Personal life decisions

The section aims at showing the situation on the ground with regard to Article 12 for *all* persons with disabilities. However, emphasis is placed on persons with intellectual disabilities and persons with psychosocial disabilities, taking into account that the state in its report to the CRPD Committee identified these groups as being particularly vulnerable:

However, due to lack of awareness on the rights of persons with disabilities, the issue of legal capacity still remains a challenge to some persons with disabilities, particularly to those with mental and cognitive disabilities, where decisions are made on their behalf without consulting them.¹⁵⁴

In the course of discussing decision-making in the Kenyan context, several dilemmas are identified that would require further deliberations in order to resolve. Local good practice models are also incorporated into the discussions.

¹⁵⁴ Committee on the Rights of Persons with Disabilities, 'Future Sessions; Consideration of Reports' (National Report: Kenya's Initial Report Submitted Under Article 35(1) of the United Nations Convention on the Rights of Persons with Disabilities - 31st August 2011) <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/futuresessions.aspx>> accessed 12 April 2013

4.1 Guardianship in Kenya

The first question posed to all the respondents is whether guardianship is common in Kenya. Unanimously, the answer is “No”:

In this country we deal with matters outside the court, as much as possible. I don't know anyone – we have the extended family dealing with things. The guardianship law is not active.¹⁵⁵

We run support groups for persons with psychosocial disabilities in four counties and there is no one I know who is under formal guardianship...Last year I went to the Family Division of the High Court to research this and I can tell you that formal guardianship is extremely rare in Kenya.¹⁵⁶

Most of the people with intellectual disabilities in the organizations are under what I would call informal guardianship. In our context, when you get a child with an intellectual disability, you're automatically the guardian. You don't go to court, it's natural, naturally you become the guardian. With regard to the court process, amongst our members, no one is under formal guardianship.¹⁵⁷

In my time at the Kenya National Commission on Human Rights, I never encountered anyone under formal guardianship.¹⁵⁸

I have practiced law for 19 years and have only done one case on guardianship. That tells you that guardianship is not a common thing in this country.¹⁵⁹

Various explanations were given for the fact that the formal guardianship process is so rarely used in Kenya. First, is that people find the formal justice system in Kenya inaccessible, particularly because it is deemed to be expensive. Secondly, people in Kenya tend to deal with things informally, as much as possible – across the board, not just with regard to issues regarding persons with disabilities.¹⁶⁰ Thirdly, formal guardianship would probably be resorted to in instances where a person with a

¹⁵⁵ Interview with Schizophrenia Foundation of Kenya (Nairobi, Kenya, 29 April 2013)

¹⁵⁶ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

¹⁵⁷ Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013)

¹⁵⁸ Interview with Lawrence Mute, Member of the African Commission on Human and Peoples' Rights (ACHPR) and former commissioner at the Kenya National Commission on Human Rights (Nairobi, Kenya, 7 May 2013)

¹⁵⁹ Interview with a member of the Law Society of Kenya (Nairobi, Kenya, 11 May 2013)

¹⁶⁰ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

disability came to property, and that is not too common given the widespread poverty in the country.¹⁶¹ A fourth reason could be because there is generally lack of awareness about guardianship.¹⁶²

It is interesting to note that the court in *K v K* 2009 eKLR¹⁶³ states that many applications for guardianship are made under the Mental Health Act:

No one can carry any doubt that the matter is involved and also, if I may venture to say, unprecedented. I do not say unprecedented in the sense of applications under the Act having been made. *There were many which have been filed and determined in the past* (emphasis mine) but no other judicial officer has been presented with the issues and submissions which have been so made before this court.

This apparent contradiction may need to be probed further. A recommendation in this regard may therefore be that official statistics be gathered on persons formally under guardianship. It is necessary to keep a 'strict record of the cases of persons which need support in exercising their legal capacity and of the appointed guardians, as well as to perform continuous monitoring of such cases'.¹⁶⁴ This will make it possible to plan support services at the local level.

The foregoing makes it clear that the main barrier to persons with disabilities exercising their legal capacity on an equal basis with others in the Kenyan context is not guardianship. Hence, the study sought to find out whether, in the absence of an ingrained guardianship regime, people with disabilities in Kenya were making

¹⁶¹ Interview with Lawrence Mute, Member of the African Commission on Human and Peoples' Rights (ACHPR) and former commissioner at the Kenya National Commission on Human Rights (Nairobi, Kenya, 7 May 2013)

¹⁶² Interview with Sense International (Nairobi, 16 May 2013). Further, in the course of conducting the interviews, I often had to explain to people what guardianship is since it was a new concept to quite a number of the respondents.

¹⁶³ *K v K* (2009) eKLR High Court at Nairobi (Nairobi Law Courts) Petition 36 of 2009

¹⁶⁴ United Nations Office of the High Commissioner for Human Rights, 'The System of Guardianship in Practice in the Republic of Moldova: Human Rights and Vulnerability of Persons Declared Incapacitated' (2013) <http://www.un.md/key_doc_pub/STUDY_The_System_of_Guardianship_in_Practice_in%20Republic_of_Moldova.pdf> accessed 4 June 2013

decisions in the various aspects of their lives, and whether those decisions were being respected.

4.2 Making decisions in the Kenyan Context

Legal capacity includes the ‘capacity to act’, intended as the capacity and power to engage in a particular undertaking or transaction, to maintain a particular status or relationship with another individual, and more in general to create, modify or extinguish legal relationships.¹⁶⁵

It is important to consider diversity in decision-making; by which is meant that decision-making for persons with disabilities in Kenya varies depending on geographical area (rural/urban divide),¹⁶⁶ gender,¹⁶⁷ and age.¹⁶⁸ These factors are important considerations in deciding how to better facilitate the right to legal capacity for persons with disabilities. The following subsection will establish the Kenyan context.

Setting the Context

One of the more significant benefits of supported decision-making is that it gives clarity to informal arrangements.¹⁶⁹ In Kenya, informal arrangements (outside formal guardianship) are the default and accepted position. Is supported decision-making still relevant in our context? This is one of the more taxing questions that faces the country as it looks to implement Article 12. Already, support in exercising legal capacity is for the most part given outside formal guardianship. Of what benefit is Article 12 in our context? This briefing paper considers that Article 12 is very relevant in the Kenyan setting. At first sight, it may appear as if, without formal

¹⁶⁵ Office of the United Nations High Commissioner for Human Rights, ‘Legal Capacity: Background conference document’ (2005) <<http://www.un.org/esa/socdev/enable/rights/ahc6documents.htm>>

¹⁶⁶ Rural communities are closer knit, with the concept of the extended family still being more entrenched and it is more likely to have a broader informal support base for persons with disabilities in rural areas than in urban areas. - Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013); Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013)

¹⁶⁷ Women with disabilities face heightened difficulties in exercising their legal capacity in Kenya. Interview with Women Challenged to Challenge (Nairobi, Kenya, 10 May 2013)

¹⁶⁸ KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

¹⁶⁹ Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship) <http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

guardianship, people are living lives of their own choosing. However, interviews reveal that this is not so, that in fact, the lives of persons with disabilities are heavily dominated by others.¹⁷⁰ An example here suffices:

In Israel, if a complex medical procedure needs to be performed on a person with an intellectual disability, and hence a consent form needs to be signed, the doctor would most likely consider that the person does not understand the implications of the operation and as such would require that the parents of the person take the decision. However, to be able to sign on behalf of their adult with an intellectual disability, the parents would need to prove that they are the adults' legal guardians. This is an example of formalized substitute decision-making.¹⁷¹ If the same decision needed to be made in Kenya, very likely the parents or spouse (or adults accompanying the person) would sign for the person and it would not occur to the doctor to ask the parents whether they are the legal guardian; it would be automatic.

In many developed countries, the core barrier to persons with disabilities exercising legal capacity on an equal basis with others is guardianship. The above example shows how, even in the absence of formal guardianship, persons with disabilities are not supported to make their own decisions; and instead, decisions are made *for* them, often without being involved in any way. Interviews carried out reveal that in Kenya, even in the absence of an ingrained guardianship system, persons with disabilities do not make decisions about their lives; including 'small' decisions such as what to eat, what to wear or what to do for recreation. Various reasons were put forward to explain why persons with disabilities in Kenya do not enjoy legal capacity on an equal basis with others.

¹⁷⁰ KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

¹⁷¹ Skype conversation with Yotam Tolub, Attorney, Bizchut - the Israel Human Rights Centre for People with Disabilities (9 May 2013)

In the first place, while attitudes towards persons with disabilities are changing for the better throughout the country,¹⁷² the social model of disability is yet to take root in the country. Persons with disabilities are still largely seen as recipients of care. So with regard to making decisions about their lives, the predominant view would be that their family would ‘know what is best for them’; societal attitudes are such that persons with disabilities are still not seen as equal persons with equal rights, and with the determining voice about their lives. This is so for all persons with disabilities (regardless of specific impairment):

I remember the first time I left home on my own as a grown man, they almost made a ‘lost person’ advert on the radio. That I am lost. But when I went back home, I told them that I am not a child, I must live life the way I want to live it. So I went on telling them this, until they got used to me living my own life. They understood that yes, this person may be blind but he can survive on his own...¹⁷³

The societal attitude of persons with disabilities as ‘unequal’ is particularly dominant for persons with intellectual disabilities, with psychosocial disabilities and with multiple disabilities.¹⁷⁴ An example was given that with regard to inheriting property, the parents of a person who is deafblind would most likely leave property to the non-disabled siblings to hold on behalf of their family member who is deafblind.¹⁷⁵

Societal attitudes affect the choices that are presented to persons with disabilities, and the experiences they are able to have. Choices are influenced by whether or not one has had the opportunity to experience different situations. The opportunity to experience life is often denied to people with disabilities.¹⁷⁶ This is compounded by diminished expectations based on false assumptions about the abilities of persons

¹⁷² Interview with Women Challenged to Challenge (Nairobi, Kenya, 10 May 2013)

¹⁷³ Interview with Gatune, Street Entertainer (Nairobi, 16 May 2013)

¹⁷⁴ Interview with Schizophrenia Foundation of Kenya (Nairobi, Kenya, 29 April 2013); Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013) and Interview with Sense International (Nairobi, 16 May 2013)

¹⁷⁵ Interview with Sense International (Nairobi, 16 May 2013)

¹⁷⁶ Interview with Sense International (Nairobi, 16 May 2013)

with disabilities – for instance, interviews revealed that in education settings, the career options that are presented to persons with disabilities tend to lean towards manual labour as opposed to professional courses.¹⁷⁷

Second, the majority of persons with disabilities live with their families in a context of limited state provided services, and in a context of high unemployment rates, particularly among persons with disabilities. Hence, many persons with disabilities are financially dependent on their families, which impacts on the power dynamics towards limiting their autonomy. Often times, the result is that the lives of persons with disabilities are unnecessarily dominated by others. This is not disability specific – it is so for persons with all types of disabilities who find themselves living with their families in a state of dependence. Hence, even persons with disabilities who can easily express their will and preferences still have their right to legal capacity curtailed. It is important to point out here, that the more dominant view on the overprotection of persons with disabilities by their families is that it is driven by love.¹⁷⁸ However, a contrary view was expressed:

Love is about giving people space and letting people fail then you take it up but I don't think when we... it can't be love when there is no room for me to even stretch my hand - that's imprisonment.¹⁷⁹

Of note is the fact that in the absence of a centralized system of guardianship, there are most likely great variances on the exercise of legal capacity by persons with disabilities since it all boils down to the family for the majority of people with disabilities in Kenya. Many families may very well already be supporting their members to live their own lives, while in some families; abuse of the rights of their family members with disabilities prevails. The problem in the Kenyan setting is insidious, because the exercise of legal capacity is for the most part carried conducted informally; people lives are lived *for* them informally. This raises

¹⁷⁷ Interview with Lawrence Mute, Member of the African Commission on Human and Peoples' Rights (ACHPR) and former commissioner at the Kenya National Commission on Human Rights(Nairobi, Kenya, 7 May 2013)

¹⁷⁸ Interview with Gatune, Street Entertainer (Nairobi, 16 May 2013); Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013)

¹⁷⁹ Interview with Sense International (Nairobi, 16 May 2013)

significant questions about how best to ensure the right to legal capacity for persons with disabilities while safeguarding against abuse.

The foregoing demonstrates the centrality of families to the lives of persons with disabilities in Kenya. What happens in the Kenyan context in circumstances in which one has no family to fall back on, or in which one would prefer not to be supported by their family members with regard to making some decisions? Interviews reveal that in the Kenyan setting, there are hardly any alternatives for a person who has no family to fall back on. In rural areas, the community in which a person lives may offer support,¹⁸⁰ not so much in urban areas.¹⁸¹ In urban areas, often, when a person with disabilities has no job and has no family to fall back on, they end up having to live on the streets.¹⁸² The issue of how persons with disabilities may be supported in the absence of family remains unresolved.

Ideally, for people who do not have families, 'effort must be made to help the person establish or re-establish supportive relationships that may over time develop into decision making support arrangements. In this case, the arrangements are a hybrid form of support: either facilitated network building for supported decision-making or where a person may have agreed to having a volunteer, unknown to them to initially take on this role.'¹⁸³ How viable is this in the Kenyan context? Which body would take the lead in creating these options?

A further *dilemma* arises with regard to families being so central to the lives of persons with disabilities in Kenya. What are the consequences of this with regard to the centrality of will and preferences in Article 12? How can we ensure that support offered by families to their family member with disabilities is free of conflict of interest and undue influence?

¹⁸⁰ Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013)

¹⁸¹ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

¹⁸² KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

¹⁸³ Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship)
<http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

The third reason put forward to explain why persons with disabilities in Kenya do not enjoy legal capacity on an equal basis with others is the high rates of poverty currently being experienced in the country, which have an impact on decision-making for all people. To compound this, many persons with disabilities did not access an education that would allow them to get employment in a highly competitive labour market,¹⁸⁴ a finding that was emphasized strongly in most interviews:

When you don't have a job, when you have no means of income mainly because of your disability ... you are not different from a severely handicapped person in terms of you need to eat, you need to dress...when you're dependent, this issue of your life being dictated and guided by others is very strong irrespective of your disability.¹⁸⁵

With regard to persons with disabilities, particularly those with high support needs, poverty makes it more difficult for them to access the support that they need in order to exercise their legal capacity. For instance, people who communicate in non-verbal ways may not have access to skilled communicators whom they would need to express their will and preferences. Hence, for the most part, persons with disabilities with high support needs are subjected to informal substitute decision making.

In this country, persons who are deafblind do not have access to information. How then can they make decisions for themselves – any kind of decisions?¹⁸⁶

The issue of poverty raises a *dilemma* in the context of a low income country such as Kenya context because poverty is widespread across the citizenry and peoples' choices are limited generally for reasons that have nothing to do with disability:

Many young people in Kenya live with their parents way into their 30s, simply because they cannot afford to move out of their parents' home.¹⁸⁷

¹⁸⁴ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013); KNCHR Technical Committee Meeting on Legal Capacity (Nairobi, 15 May 2013)

¹⁸⁵ KNCHR Technical Committee Meeting on Legal Capacity (Nairobi, 15 May 2013)

¹⁸⁶ Interview with Sense International (Nairobi, 16 May 2013)

The dilemma then is how to most strategically engage with the state in order to ensure action the issue of legal capacity for persons with disabilities amidst competing priorities.

Fourth, in Kenya, the accessibility of the environment in the broadest sense remains a significant barrier to persons with disabilities exercising their right to legal capacity on an equal basis with others. Interviews revealed that for the most part, third parties do not accommodate persons with disabilities. The issue of persons who are blind accessing financial services on an equal basis with others was raised repeatedly.¹⁸⁸ This inaccessibility makes it difficult for persons who are blind to control their financial affairs. Sign language interpretation is not widely available to persons who are Deaf when they seek services, for instance in hospitals and courts.¹⁸⁹ The public transport system is for the most part inaccessible to persons who have physical disabilities.¹⁹⁰ Information in plain language is not widely available.¹⁹¹ Alternative communication methods are for the most part lacking.¹⁹² This means that in the Kenyan context, there is a thread that starts out with Article 12 and continues to discrimination and exclusion in general, and it is not an easy thread to disentangle.

Fifth, there is limited state provision and access to a range of services that are available in many developed countries. For instance, Kenya has limited respite care

¹⁸⁷ Interview with Lawrence Mute, Member of the African Commission on Human and Peoples' Rights (ACHPR) and former commissioner at the Kenya National Commission on Human Rights(Nairobi, Kenya, 7 May 2013)

¹⁸⁸ Interview with Lawrence Mute, Member of the African Commission on Human and Peoples' Rights (ACHPR) and former commissioner at the Kenya National Commission on Human Rights(Nairobi, Kenya, 7 May 2013); KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013); Interview with Sense International (Nairobi, 16 May 2013)

¹⁸⁹ Interview with United Disabled Persons of Kenya (Nairobi, 29 May 2013)

¹⁹⁰ Interview with Women Challenged to Challenge (Nairobi, Kenya, 10 May 2013)

¹⁹¹ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013); Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013)

¹⁹² Inability to communicate is the greatest barrier to decision-making for persons who are deaf-blind. Interview with Sense International (Nairobi, 16 May 2013)

services, which is closely related to cases of families locking up and tying up their family members with disabilities:¹⁹³

...Most of those (persons who are deafblind) that we work with we identified them when they were shut out, locked somewhere in a room. There is this argument that don't lock a child and its of course denying them their freedom ... but the parent can give you a counter argument and say this is a person who needs permanent care giving. If a mother has to go out every morning to fetch water and sell it so that at the end of the day they get a hundred shillings which they'll use to buy food, pay rent and they have a deaf-blind child and are poor so they cannot hire any other care giver ...so they end up locking them in the house ...essentially to protect them.¹⁹⁴

Commendably, the state has introduced a Cash Transfer Programme for Persons with Severe Disabilities. However, this financial support to persons with disabilities from the state is still limited. Families, for the most part do their best under difficult circumstances and interviews revealed that great strides would be made on Article 12 were the Cash Transfer Programme scaled up:

...the other thing we need is for the government to support the families, most of the families live in deplorable situations. Most mothers they don't go to work because they care for this child twenty four seven. I mean they cannot do anything else, you can imagine a child with very high support needs, the mother cannot fail to be there, you cannot even employ a house girl ...so support to the families, full support to the families to be able to care, the burden of caring is just too much for the parents and most of them even go into depression and psychosocial disabilities because of the intellectual disability.¹⁹⁵

Sixth, decisions are made as a result of certain factors, including there being alternatives in the first place. Lack of alternatives was put forward as a barrier to decision-making, particularly with regard to making healthcare decisions for people with psychosocial disabilities.¹⁹⁶ In Kenya, there are very limited alternatives to medication in the context of psychosocial disability. Yet, medication is not a panacea:

¹⁹³ Interview with United Disabled Persons of Kenya (Nairobi, 29 May 2013)

¹⁹⁴ Interview with Sense International (Nairobi, 16 May 2013)

¹⁹⁵ Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013)

¹⁹⁶ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

I wanted to ask, in taking medication, do they bring side effects? My wife, was 100% normal. But after taking medication for many years now, her hand is almost paralyzed. What can I do so that she does not keep getting worse?¹⁹⁷

A *dilemma* arises with regard to respecting healthcare decisions of a person with psychosocial disabilities (particularly if the decision is to refuse treatment) in a context in which quality mental healthcare is very expensive (It may cost about USD 3,200 for a three weeks' stay in a private mental health care facility), and would for the most part be met by families. The worse off a person is when being taken to hospital, the longer the person is likely to be hospitalized for, and the more expensive the treatment is likely to be. Families tend to take their member with a psychosocial disability to hospital by force at the first sign of a crisis; they are largely unwilling to risk waiting until the person meets the 'danger to self' or 'danger to others' threshold for forced treatment as this may lead to their paying more for the person's treatment:

It is better to treat the person by force. Because you know the person is on the verge of a total relapse. And when a total relapse happens, the complete burden of care is on you as the carer, it is your sole responsibility.¹⁹⁸

Traditional healers and faith based healers tend to be the alternative to medication in some areas of Kenya. Largely, they operate outside a legal framework, and there is need to find ways of ensuring that people are not abused or exploited by these healers.

Seventh, cultural considerations and expectations influence decision-making for persons with disabilities in Kenya. While Kenya is moving towards becoming more individualized particularly in urban areas, there is still a predominant communal

¹⁹⁷ Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013)

¹⁹⁸ Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013)

way of life in the country.¹⁹⁹ The communal outlook ‘emphasises the social aspect of man’s nature, holding that the individual’s life can only find fulfilment when that individual co-operates with other members of the community, and puts the interests of the community before his own interests’.²⁰⁰ In a communal setting, inter-dependence is valued more than independence; an example is that the need to live physically apart from one’s parents is not as emphasized, particularly in rural Kenya as it is in more developed countries.²⁰¹ This outlook significantly influences decision-making and this is true across the board – not just for persons with disabilities.

A **dilemma** arises with regard to balancing communal interests²⁰² with an individual’s will and preferences. This is particularly so with regard to respecting health care decisions of people with psychosocial disabilities, particularly when their choice is to refuse treatment. This is further complicated in instances where the person, once the crisis is over, expresses gratitude to the family for having enabled them get treatment:

Yes, me I have been injected by force. And I had declined completely, but afterwards, when I was well again, I was able to recognise that they were only helping me.²⁰³

¹⁹⁹ Elizabeth Kamundia, ‘Choice, Support and Inclusion: Implementing Article 19 of the CRPD in Kenya’ (L.L.M Thesis, National University of Ireland, Galway 2012)

²⁰⁰ Reginald M.J. Oduor, ‘Ethnic Minorities in Kenya’s Emerging Democracy: Philosophical Foundations of their Liberties and Limits’ (DPhil Thesis, University of Nairobi 2011)

²⁰¹ KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

²⁰² Oduor in discussing communalism in the context of traditional African ethical outlook states ‘Communalism. . . denotes that outlook which emphasises the social aspect of man’s nature, holding that the individual’s life can only find fulfilment when that individual co-operates with other members of the community, and puts the interests of the community before his own interests. . . Consequently, these communities (traditional African communities) emphasised the need for every member to do his best to contribute towards the good of the community’ - RMJ Oduor ‘Ethnic minorities in Kenya’s emerging democracy: Philosophical foundations of their liberties and limits’ unpublished PhD thesis, University of Nairobi 2011.

In this way of life, the common good trumps over individual good, social consensus over personal will, inter-dependence over self-dependence. See P Erny *The child and his environment in black Africa* trans G.J. (1981).

²⁰³ Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013)

The foregoing quote is **not** by any means meant as a blanket statement that ‘all persons with psychosocial disabilities appreciate forced interventions once the crisis is over’. Indeed there are many people with psychosocial disabilities who experience forced interventions as traumatic. The statement is useful only for highlighting the dilemmas that face families, which dilemmas should be taken into account by any efforts geared towards raising human rights awareness among families.

4.3 Making healthcare, financial and personal life decisions in Kenya

This subsection will probe decision making in relation to three broad areas: healthcare, financial and personal life decisions. The section will also speak to the issues in a disability specific manner as was requested in terms of reference for the briefing paper, taking into account that one of the goals of the paper is to guide policy makers in issues relating to Article 12. While this approach may be criticised as being medical-model based, ‘failure to differentiate disabilities can lead to poor access, inappropriate responses by third parties, loss of rights, poor access to justice or other mechanisms for protection, redress and recovery’.²⁰⁴ Increasingly, there is acknowledgement that there is interplay between a particular impairment and the scale of the barrier experienced by the person with disabilities.²⁰⁵

4.4 Health care decisions

Article 25 of the CRPD is to the effect that ‘States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.’ The study sought to find out whether persons with disabilities were making their own decisions with regard to

²⁰⁴ Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship)
<http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

²⁰⁵ India’s ‘The Rights of Persons with Disabilities Bill, 2011’ at Section 92 provides for the development of a Socio-medical scale to examine the interplay between a particular impairment and the barriers. See Capacityrights.org, ‘Current Reform Efforts Resources India’
<<http://capacityrights.org/uploads/3/1/8/0/3180011/draftbill-pwd.pdf>> accessed 26 May 2013

healthcare. The results indicate that it depends largely on the type of disability one has. To a large extent, persons with intellectual disabilities, and persons with multiple disabilities and high support needs have their healthcare decisions made for them.²⁰⁶ Persons with psychosocial disabilities often attempt to make their own healthcare decisions, but where the decision they make is in conflict with the decision of their family or of the healthcare providers, the decision of the two latter groups prevail.²⁰⁷ Women with disabilities (all types) tend to have their reproductive healthcare decisions made for them, but tend to make their own decisions with regard to other aspects of life (excluding women with intellectual disabilities, with multiple disabilities and high support needs or with psychosocial disabilities who experience heightened barriers to decision making in all areas of life).²⁰⁸ Excluding the disability types and the gender aspect already accounted for, persons with other disabilities (persons with long-term physical and/or sensory impairments) tend to make their own healthcare decisions.

Persons with intellectual disabilities and decision-making on healthcare

Although there are no universally accepted standards for establishing the ability of individuals to consent to medical treatment, researchers and clinicians have developed a number of measures to assess decision-making capacity.²⁰⁹ Such assessment typically involves determining an individual's ability to understand and retain relevant information, appreciate the nature and consequences of the decision at hand, and express or communicate a decision.²¹⁰ The decision must also be

²⁰⁶ Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013)

²⁰⁷ Interview with Schizophrenia Foundation of Kenya (Nairobi, Kenya, 29 April 2013); Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013); Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013)

²⁰⁸ Interview with Women Challenged to Challenge (Nairobi, Kenya, 10 May 2013)

²⁰⁹ Moyer J, Marson DC. Assessment of decision-making capacity in older adults: An emerging area of practice and research. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 2007;61:P1–P11. [[PubMed](#)]

²¹⁰ Foster J, Turner FJ. Implications of the Mental Capacity Act 2005 on advance care planning at the end of life. *Nursing Standard*. 2007;22:35–39. [[PubMed](#)]

voluntary and free from coercion or other forms of undue influence.²¹¹ Individuals with intellectual disabilities face several challenges that threaten to undermine their capacity to make decisions, including difficulties with memory and communication. Such challenges often lead to the misconception that they lack the capacity to participate in any medical decision-making.²¹² This is confirmed by the interview with the Kenya Association of the Intellectually Handicapped:

Persons with intellectual disabilities are not making their own decisions on any of those areas – deciding where or with whom to live, managing finances, decisions to do with healthcare, any of those areas.²¹³

Hence, for the large part, persons with intellectual disabilities have their healthcare decisions made for them. This situation persists despite the fact that research has shown that many of these individuals have sufficient cognitive capacity to engage in at least some of the decision-making process and that only a small percentage of individuals with intellectual disability are severely or profoundly affected.²¹⁴

Persons with psychosocial disabilities and decision-making on healthcare

The law of Kenya allows for treatment without the consent of the person in the context of mental health. Section 16 of the Mental Health Act authorizes a police or administrative officer to take into custody and hand to a mental hospital a person with mental disorder on the justification that the person; (a) is dangerous to himself

²¹¹ Kathleen M. Fisher, Fredrick K. Orkin and Anand Bhattacharya, 'Proxy Healthcare Decision-Making for Persons with Intellectual Disability: Perspectives of Residential-Agency Directors' American Journal on Intellectual and Developmental Disabilities
<<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2945884/#R19>> accessed 26 May 2013

²¹² Kathleen M. Fisher, Fredrick K. Orkin, [...], and Anand Bhattacharya 'Proxy Healthcare Decision-Making for Persons With Intellectual Disability: Perspectives of Residential-Agency Directors' American Journal on Intellectual and Developmental Disabilities
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2945884/#R19> accessed 26 May 2013

²¹³ Interview with Inclusion International (9th May 2013)

²¹⁴ Kathleen M. Fisher, Fredrick K. Orkin, and Anand Bhattacharya 'Proxy Healthcare Decision-Making for Persons With Intellectual Disability: Perspectives of Residential-Agency Directors' American Journal on Intellectual and Developmental Disabilities
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2945884/#R19> accessed 26 May 2013

or others; (b) on account of the mental disorder is likely to offend public decency;(c) is not under proper care and control; and (d) is being cruelly treated and neglected by a relative or guardian. Under Section 10(3) of the Mental Health Act, a person received as a voluntary patient intending to leave the hospital must give the person in charge of the hospital seventy-two hours' notice in writing of his intention to leave and the release shall be at the discretion of the person in charge of the mental hospital. There are no safeguards around the discretion of the person in charge of the mental hospital, and his/her decision in this regard is final.

Interviews conducted for this study indicate that forced treatment is common place, and that the majority of persons with psychosocial disabilities are not allowed to take their own healthcare decisions.²¹⁵ The fact that persons with psychosocial disabilities are not allowed to make their own decisions with regard to healthcare was confirmed not only by persons with psychosocial disabilities, but also by a professional in the mental healthcare field:

Families never respect the will and preferences of people with mental health conditions. The people who come here for counseling, I have hardly seen a person who has come for counseling here, whose will has been respected. They are pushed to come for counseling. It is very hard for me to initiate counseling, because the people are brought to me involuntarily. Rarely have I seen voluntary cases, and where there are voluntary cases, the healing is almost automatic. With regard to treatment, with regard to admission in hospital -it is all involuntary; they are forced to do what they don't want. We even exaggerate their condition because we want them away from home, where we see them as a bother!²¹⁶

The issue of making decisions with regard to healthcare is compounded by the fact that in general, there are few alternatives to medication in the Kenyan context. To make a choice, one needs alternatives, a fact that was highlighted in the course of a Focused Group Discussion with persons with psychosocial disabilities and their carers:

²¹⁵ Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013)

²¹⁶ Interview with Schizophrenia Foundation of Kenya (Nairobi, Kenya, 29 April 2013)

No, there are no other services except medication in the hospital nearest to us.²¹⁷

In the course of this Focused Group Discussion, the issue of forced treatment was discussed in detail.²¹⁸ The views were mixed, ranging from those who felt that forced treatment can be avoided and those who expressed the opinion that forced treatment is almost inevitable. Ultimately, the consensus was that the issue manifests differently from family to family. One carer opposed forced treatment:

It's all up to the person you live with...the carer knows the best approach to use to persuade the person to get treatment. So if the approach is good and suitable to the ill person, they will agree to treatment. Usually if you approach the person peacefully and well, they calm down and then treatment is possible.

Another carer expressed a different view:

It is better to treat the person by force. Because you know the person is on the verge of a total relapse. And when a total relapse happens, the complete burden of care is on you as the carer, it is your sole responsibility.²¹⁹

The issue of decision-making on healthcare for persons with psychosocial disabilities is contentious all over the world. On the one hand is the interpretation of the CRPD to the effect that 'forced psychiatric interventions violate the universal prohibition of torture'²²⁰ and must not be allowed under any circumstances. On the other hand is the interpretation that involuntary detention and treatment is

²¹⁷ Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013)

²¹⁸ It is important to note that forced treatment is an issue of decision-making in a very specific manner. It may not be about decision-making strictly speaking, rather, it is often about the fact that society says, "whatever decision you have reached as a person with a psychosocial disability with regard to treatment, we will overlook it, and make a decision on your behalf that seems to us as society to be in your best interests".

²¹⁹ Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013)

²²⁰ Tina Minkowitz, 'The United Nations Convention on the Rights of Persons with Disabilities and the Right to Be Free From Nonconsensual Psychiatric Interventions' (2007) *Syracuse Journal of International Law and Commerce*, Vol. 34, No. 2, <http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1481512> accessed 26 May 2013

consistent with the CRPD;²²¹ the assertion here being that that circumstances sometimes exist that may warrant such interventions as a last resort and subject to safeguards. The circumstances under which forced interventions are sanctioned by law differ from country to country, with the most common ones being when a person with a psychosocial disability is a danger to himself or to others.

Be that as it may, the standards issued by the Special Rapporteur on Torture²²² in relation to medical treatments on people with disabilities help to strengthen the requirement of free and informed consent as an exercise of legal capacity and individual autonomy. In particular, the Rapporteur maintains that intrusive and irreversible medical treatments, without a therapeutic purpose or aimed at correcting or alleviating a disability, that are performed without the consent of the person concerned, may constitute torture or ill-treatment. Abortion and sterilization, and administration of mind-altering drugs including neuroleptics, electroshock and psychosurgery were given as examples of such treatments.²²³

The fact that there are unaddressed mental health needs in Kenya is not in doubt. On 12th May 2013, 40 mentally ill patients escaped Mathare Hospital after overpowering the guard, claiming that the medicine they received from the hospital is ineffective.²²⁴ The patients were also protesting against overcrowding, poor quality food, poor sanitation amongst other ills that are rife in the institution. Hence, in Kenya, the exercise of legal capacity for persons with psychosocial disabilities

²²¹ See Australia's Declaration United Nations Treaty Collection, 'Convention on the Rights of Persons with Disabilities' <http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en#EndDec> accessed 26 May 2013

²²² United Nations, 'Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E. Méndez' A/HRC/22/53

²²³ Office of the High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities Day of General Discussion on Article 12 of the CRPD – The Right to Equal Recognition Before the Law (21 October 2009) IDA CRPD Forum, 'Principles for Implementation of CRPD Article 12' <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 30 May 2013

²²⁴ Kenya Television Network, 'Mathare Hospital Escape' <<http://www.standardmedia.co.ke/ktn/video/watch/2000065666/-mathare-hospital-escape>>. See also <http://www.the-star.co.ke/news/article-120258/police-hunt-40-patients-who-escaped-mathare> both accessed 27 may 2013

would be greatly aided by major improvements in the mental healthcare system. Such improvements would include crisis and recovery supports, multidisciplinary home-based and assertive outreach care and a comprehensive range of relevant medical, psychological and social therapies for service users and their families.²²⁵

Restrictions on making healthcare decisions for persons with psychosocial disabilities extend beyond making mental health care decisions. Persons with psychosocial disabilities run the risk of not being able to access HIV testing on an equal basis with others. The National Guidelines for HIV Testing and Counseling in Kenya state that HIV Testing and Counseling service providers if uncertain about a person's mental fitness may refer the client to the nearest health facility.²²⁶ It would be interesting to find out how well trained the service providers are with regard to making the determination as to whether a person is mentally fit to receive their HIV results. While this is a measure of protection, it may result in persons with intellectual disabilities and persons with psychosocial disabilities not being able to access HTC services on an equal basis with others.²²⁷

Persons with other types of disabilities and decision-making on healthcare

Study results indicate that persons with other types of disabilities have greater leeway in making decisions with regard to healthcare generally:

So my answer is it depends on the disability. So if you're blind you probably make your own healthcare decisions.²²⁸

²²⁵ Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship)
<http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

²²⁶ Ministry of Public Health and Sanitation, 'National Guidelines for HIV Testing and Counseling in Kenya' 2nd Edition, October 2010
<<http://nascop.or.ke/library/HTC/National%20Guidelines%20for%20HTC%20in%20Kenya%202010.pdf>> accessed 7 June 2013

²²⁷ KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

²²⁸ Interview with Lawrence Mute, Member of the African Commission on Human and Peoples' Rights (ACHPR) and former commissioner at the Kenya National Commission on Human Rights (Nairobi, Kenya, 7 May 2013)

However, women with disabilities across all disability types are denied the right to make their own reproductive healthcare decisions. A report carried out by the Kenya National Commission on Human Rights on reproductive health states that ‘people with disabilities complained that healthcare providers performed medical procedures on them without obtaining their consent’.²²⁹ In the course of an interview carried out for this briefing paper, one respondent shared the challenges that women with physical disabilities face with regard to reproductive healthcare:

I would say that women with disabilities do not make their own healthcare decisions. Especially in the area of reproductive health. In the first place, you find people discouraging you a lot from getting pregnant. There are all these assumptions – that you’re not able to feed yourself, and to do anything, according to the society. So these assumptions get into your mind, you begin to doubt yourself. Again, if you have a physical disability, it is a caesarean section from the word go. It is written in your file, and you are not able to access the information in the doctor’s file. You only hear when you go to deliver, that for you, it is going to be a caesarean section. They even tell you which hospital to go – usually Kenyatta Hospital (Kenya’s main referral hospital) where they have more facilities. On one hand it’s good, they want to protect you. But the real idea is that you don’t have a choice, they want you to go to that hospital, because there caesarean section can be done, and they don’t wait for you to go into labour, the decision is already made. You cannot carry your pregnancy to the end. And when they do these caesarean, quite a number of us have been sterilised without our consent, without even being informed. Much later, the women I’ve talked to, later on they are told by the doctor, “We closed you. You will not give birth again. You don’t have the strength to keep getting pregnant.” So really, we don’t have much decision there. People are deciding for you.²³⁰

With other disability types, the inaccessibility of the environment in the broadest sense of the word is the core barrier to decision-making in the realm of healthcare. The Kenya National Commission on Human Rights report on reproductive health identifies that ‘the modes of communication in most health facilities are not in

²²⁹ Kenya National Commission on Human Rights, *Realizing Sexual and Reproductive Health Rights in Kenya: A Myth or Reality?* (A Report of the Public Inquiry into Violations of Sexual and Reproductive Health Rights in Kenya April 2012)

<http://www.knchr.org/Portals/0/Reports/Reproductive_health_report.pdf> accessed 4 June 2013

²³⁰ Interview with Women Challenged to Challenge (Nairobi, Kenya, 10 May 2013)

friendly formats that can be accessed by those who are blind, deaf or have intellectual or cognitive impairments'²³¹ a fact that was echoed in the interviews conducted for this paper:

Decision-making with regard to healthcare varies with disability type. Whereas you could put it down to issues of capacity, sometimes it could be more about communication. That is a factor. So for example, if you're trying to communicate, if you're not patient when communicating with a Deaf person, it's conceivable that you just simply move on, decide for them quickly. So that's a failure of communication which makes a health professional make the determination one way or another without having consulted the person enough.²³²

In this regard, providing healthcare information in accessible formats and facilitating communication for all persons at health care facilities would go a long way towards enabling persons with disabilities to make their own healthcare decisions.

Another area in which decision-making on healthcare is restricted across the board is with regard to HIV testing. In this regard, healthcare professionals assume that persons with disabilities 'could not possibly have HIV'²³³ and persons with disabilities are often forced to beg or threaten in order to have healthcare providers respect their decision to be tested for HIV.

4.5 Financial Decisions

This study probed whether persons with disabilities are able to make their own decisions with regard to managing finances. Examples of such decisions include

²³¹ Kenya National Commission on Human Rights, *Realizing Sexual and Reproductive Health Rights in Kenya: A Myth or Reality?* (A Report of the Public Inquiry into Violations of Sexual and Reproductive Health Rights in Kenya April 2012)

<http://www.knchr.org/Portals/0/Reports/Reproductive_health_report.pdf> accessed 4 June 2013

²³² Interview with Lawrence Mute, Member of the African Commission on Human and Peoples' Rights (ACHPR) and former commissioner at the Kenya National Commission on Human Rights(Nairobi, Kenya, 7 May 2013)

²³³ Interview with Women Challenged to Challenge (Nairobi, Kenya, 10 May 2013)

opening and operating bank accounts, accessing bank loans, buying and selling goods and services, making investments and inheriting property.

The right to own property is one of the issues that the state responded to in its report to the CRPD Committee:

The Government of Kenya has put in place Constitutional guarantees that ensure the equal right of persons with disabilities to own or inherit property. This is contained in Article 40 of the Constitution of Kenya, 2010, which guarantees the rights of every person, including persons with disabilities, to acquire and own property. The Government of Kenya acknowledges that the issue of inheritance, especially of land, for persons with disabilities is still a major challenge as they are often disinherited of their property by their kin or guardians. However, this is being addressed under the ongoing review of the Law of Succession Act to among other things protect the rights of persons with disabilities to inherit property.²³⁴

Indeed the issue of being disinherited on account of disability was raised by the respondents in this study:

The CRPD article 12 is lovely, but it's just words for now. The rights here are very good, but they are not recognized here. It's grounds that you can be dispossessed for having a mental health condition. We have two members complaining that they have been dispossessed of their property by their families on account of having a mental health condition.²³⁵

I think I have heard lots of anecdotes about disabled people who are disinherited. At that point it's a function of culture and a function of power, even more than it's a function of law. There is an expression that if you're disabled you're weak, you're vulnerable, so we can gang up against you and

²³⁴ Committee on the Rights of Persons with Disabilities, 'Future Sessions; Consideration of Reports' (National Report: Kenya's Initial Report Submitted Under Article 35(1) of the United Nations Convention on the Rights of Persons with Disabilities - 31st August 2011)

<<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/futuresessions.aspx>> accessed 12 April 2013

²³⁵ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013). I advised that they refer their members to the Kenya National Commission on Human Rights when they raise issues that reveal human rights violations.

take your property, so that's one level that cannot be discounted even as we speak about law. That would be across disability...²³⁶

As with making healthcare decisions, legal capacity with regard to financial decisions varies depending on the type of disability.

Persons with intellectual disabilities and decision-making on financial matters

To start with, persons with intellectual disabilities in Kenya tend not to have identity documents as 'many families do not register their child with an intellectual disability at birth'.²³⁷ This is where the invisibility of persons with intellectual disabilities in Kenya begins. This non-registration hampers the ability of persons with intellectual disabilities to take part in transactions involving third parties.

The majority of persons with intellectual disabilities in Kenya are not in employment, and therefore find it difficult to have financial resources of their own. There are no state benefits for unemployment, and the benefits that are given by the state for persons with severe disabilities are allocated to the household, not to the individual person with disabilities.²³⁸ Even where persons with intellectual disabilities work, their families tend to want to take control of their financial affairs:

Most parents say that the persons with intellectual disabilities don't understand the value of money... As KAIH, there is a time our self advocates were doing a lot of performing arts and making money, and also we are going to a lot of trainings, and they get money and you'd find that the parents would take the money from them and decide what to spend the money on, on behalf of the self advocates. So as KAIH, we have opened bank accounts for the self advocates...in the self advocates own names. But often, parents take the money earned by self advocates to support the families, especially taking into account the general poverty in most families. We try to educate the families, saying, "yes, take some money for the family if you must, but leave the self advocate some to make their own choice about...". But we are having

²³⁶ Interview with Lawrence Mute, Member of the African Commission on Human and Peoples' Rights (ACHPR) and former commissioner at the Kenya National Commission on Human Rights(Nairobi, Kenya, 7 May 2013)

²³⁷ Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013)

²³⁸ Elizabeth Kamundia, 'Choice, Support and Inclusion: Implementing Article 19 of the CRPD in Kenya' (L.L.M Thesis, National University of Ireland, Galway 2012)

fighters with families on this, they say, “we’re the caregivers, we know what is best for this person, why are you telling us what we should do?”

Research carried out on the financial decision-making abilities of men and women with mild intellectual disabilities has demonstrated that ‘whilst the financial decision-making abilities of participants with intellectual disabilities were generally weaker than those of other participants, the differences were not discrete, and many individuals were judged to be able to make at least some personal financial decisions’.²³⁹ Therefore, ‘the same way we have accessibility for people who use wheelchairs, we need accessibility for people with intellectual disabilities who need help to understand information and to make decisions’.²⁴⁰

Persons with psychosocial disabilities and decision-making on financial matters

Decision-making on financial matters for persons with psychosocial disabilities must be considered in light of the high unemployment rates among persons with psychosocial disabilities in Kenya:

When it comes to managing finances, the first question is, are there finances to be managed? Because most of these people are not working...²⁴¹

That persons with psychosocial disabilities experience high poverty levels was a main issue of discussion in the Focus Group Discussion:

This group started off with 40 people (there were only 16 members present at the group on the day of the Focus Group Discussion). Because the local clinic was being supported by an organization called Basic Needs. And at that time, anyone who had mental health issues was getting medication for free as a result of the support by an organization called Basic Needs. Basic Needs, after two years finished their project and moved on to another place, they left us. When they left us, a lot of the members could not afford the medication

²³⁹ US National Library of Medicine & National Institutes of Health, ‘Capacity to make Financial Decisions Among People with Mild Intellectual Disabilities’ <<http://www.ncbi.nlm.nih.gov/pubmed/15713195>> accessed 27 May 2013

²⁴⁰ Skype conversation with Yotam Tolub, Attorney, Bizchut - the Israel Human Rights Centre for People with Disabilities (9 May 2013)

²⁴¹ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

that they required, which costs about KES 250 (about 4 dollars) per month, once a month. So the people started leaving the group because in the first place, however hard they tried, they could no longer afford the medication. So they just stayed in their homes, being very oppressed by the illnesses, and when I tried talking to them it's hard because they are in their homes, they are sick and they have no access to medication. So the members present today, these ones are the ones who try – like these ones you're seeing here work on other people's land for small amounts of money so as to be able to afford medication for the month, to prevent getting into a crisis... Most of the members you're seeing here are leaving one by one, because they have great trouble meeting their day to day life expenses as well as affording the essential medication that they need to live a productive life.²⁴²

The point was raised that while poverty is a key barrier to making ones own decisions, other factors come into play as well. Emphasis was laid on the fact that even in wealthy families; persons with psychosocial disabilities still do not make their own decisions:

In our context people (with psychosocial disabilities) don't make their own decisions, yes poverty is one of the problems, but even in rich families, people with psychosocial disabilities still don't make their own decisions. It's a question of rights and stigma. Stigma overrides everything. Ignorance about the rights – both the user, and the carer. They don't know their rights.²⁴³

Hence, even when employed, if living with their families, persons with psychosocial disabilities have difficulty making their own decisions:

The interesting thing i have seen, especially in the rural areas when you live with your family, is that quite a number of people sometimes when paid take the money back to the family...I have seen situations where a guy takes money to his mum then the mum gives him money back to spend! So the stereotypes and erroneous conclusions stand in our way – instead of the family supporting you and helping you to budget for your money, they actually take the money, they buy stuff for the whole house and then give you a small stipend...²⁴⁴

²⁴² Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013)

²⁴³ Interview with Schizophrenia Foundation of Kenya (Nairobi, Kenya, 29 April 2013)

²⁴⁴ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

An illustration from another jurisdiction (Israel) was given on how decision-making on financial matters is being addressed in order to circumvent guardianship while at the same time ensuring sufficient safeguards:

I have an example that we are dealing with here...We are trying to practice Article 12 in real cases, we have this lady, whose parents passed away, and she has been left with large sums of money, together with her brother. She owns three apartments. She wasted a lot of money and got into debt; and she didn't know how to manage her affairs, she had a mild intellectual disability. And she was appointed a legal guardian, her brother. She had a lot of disputes with her brother and then she was appointed an external legal guardian. An external legal guardian can be appointed if there is no family member, or if there is a crisis in the family, you can be appointed an external legal guardian, you pay for the service, and he is the one who manages your affairs, and it's terrible service. And she came to us and she said, I really don't want this legal guardian. And we took this to court and we said that she was in debt in the past and wanted to act responsibly. We went to court with this case, and the court approved of what we asked, we said, listen, we don't want a legal guardian, this is something that infringes on human rights, but we understand that there is a need for some kind of protection. And what we did is that we have a procedure that allows you to write a comment on a property, there is a place where all the estates are registered, it's called a caveat...so we wrote a caveat saying that this person is not allowed to sell her apartment without the approval of the court. It's some kind of restraint so it's not complete independence, but it's not legal guardianship either. So if she ever wants to sell, she needs to go to court and explain to the court that she is doing a reasonable action. That was one thing. The second thing we did, we also asked the court to tell the bank that her bank account cannot go to minus, she cannot take money on credit, like she cannot take money from the bank if she doesn't have that money; so she can't get into debt. Also, for major transactions involving large sums of money, she needed to sign with her own signatures together with the supporter, which is the bank accountant who is going to help her. This is an example that diminishes a person's decision making, but no one can make a decision instead of her...it's a developed protection measure which is not too harsh.²⁴⁵

Persons with other types of disabilities and decision-making on financial matters

Decision making on financial matters for persons with other types of disabilities is influenced by a myriad of factors. These include the fact that most people with

²⁴⁵ Phone conversation with Yotam Tolub (9 May 2013)

disabilities, across disability type are poor and dependent on their families. This is even more compounded for women with disabilities:

The issues of mortgages – and owning that kind of property for women with disabilities is hard. Because most women in Kenya come to property through marriage – yet most women with disabilities are not married in the first place. Remember that the issue of inheritance of property for women in general was a big thing when we were writing a new Constitution in Kenya. So now, am a woman, and a woman with a disability, it's compounded. Most disabled women don't own property, so to access loans is a problem.²⁴⁶

Secondly, the failure to accommodate by banks and other financial institutions impairs the decision-making ability of persons with disabilities:

Banks have a fairly patronising approach to dealings with clients who are blind...where a person opens an account but does not get the full benefits that would apply to everybody else. Banks on occasion will decline to give a blind person an ATM card the argument being that they are protecting the blind person in case someone steals their money from them. That is something, which has happened. I once had to threaten legal action to get an ATM Card.²⁴⁷

Further, interviews revealed that often, ATM machines cannot be accessed by a person using a wheelchair:

to an extent if you are on a wheel chair so there so many points you cannot reach...which leads to the issue of dependency, because you have so many inaccessible facilities ... dependency links up with the decisions you can make and whether you can take control of your own life... that's what hinders our decision making and our control of life ...I mean the dependency now leads to lack of making proper decisions on your own life...²⁴⁸

The CRPD Committee has recently had to make a determination regarding equal access to banking services. The case involved Szilvia Nyusti and Péter Takács, two visually impaired complainants from Hungary. Both claimants were clients of the OTP Bank Zrt. and paid annual fees, equal to those paid by sighted clients, for

²⁴⁶ Interview with Women Challenged to Challenge (Nairobi, Kenya, 10 May 2013)

²⁴⁷ Interview with Lawrence Mute, Member of the African Commission on Human and Peoples' Rights (ACHPR) and former commissioner at the Kenya National Commission on Human Rights(Nairobi, Kenya, 7 May 2013)

²⁴⁸ Interview with Women Challenged to Challenge (Nairobi, Kenya, 10 May 2013)

banking card services and transactions. However, Nyusti and Takács were unable to use the OTP ATM machines without assistance, as the keyboards were not marked with Braille fonts, nor did they provide voice assistance. The complainants sought to substantiate the failure by Hungary, through its institutions, to provide 'equal and effective legal protection against discrimination on the ground of disability; reasonable accommodation; accessibility of information; right to control one's own financial affairs.' The complaint claimed that Nyusti and Takács had been victims of a violation of their rights under articles five, 9 and 12 of the UN Convention on the Rights of Persons with Disabilities, to which Hungary is a party. After having considered the admissibility and the merits of the claim, the Committee concluded that Hungary had failed its treaty obligations under article 9, paragraph 2(b) of the Convention.

The Committee established that 'the State party is under an obligation to remedy the lack of accessibility for the [plaintiffs] to the banking card services provided by the ATMs operated by the OTP.' It also recommended that Hungary take preventive measures against future violations by establishing minimum standards for the accessibility of banking services provided by private financial institutions for persons with visual and other types of impairments; to ensure that all newly procured ATMs and other banking services are fully accessible for persons with disabilities; and provide for appropriate training on the Convention and its Optional Protocol to judges and other judicial officials in order for them to adjudicate cases in a disability-sensitive manner.²⁴⁹

²⁴⁹ Office of the High Commissioner for Human Rights, 'UN Disability Body Confirms that Equal Access to Banking Services Should be Granted to All' <<http://www.ohchr.org/EN/NewsEvents/Pages/accesstobankingservices.aspx>> accessed 3 June 2013

Third, Insurance companies were cited as being inaccessible, in some instances refusing to insure persons with disabilities because they were ‘a high risk’ population.²⁵⁰

4.6 Personal life decisions

Questions were posed to respondents on decision-making with regard to personal life decisions, including deciding where and with whom to live, deciding on social support, working, voting, freedom of movement, being part of community and cultural life and pursuing legal actions.

Results indicate that across the board, there is a tendency to be overprotective of persons with disabilities in the family setting, which denies them the opportunity to make personal life decisions.

Persons with intellectual disabilities and decision-making on personal life matters

Interviews conducted for this paper indicate that there is a culture of exclusion of persons with intellectual disabilities across all spheres of life. Persons with intellectual disabilities are for the most part not considered as full members of the society. The extent of exclusion is far reaching, ranging from not being informed when there is a death in the family, not being allowed to attend burials of close family members, not being involved in rites of passage such as male circumcision, not being allowed the opportunity to make friends, or to work, being hindered in their movement and not being allowed the choice of where and with whom to live:

‘I can say 90% they don’t (make their own decisions on where and with whom to live) it is just naturally, they either live with their parents, or when the parents are not there, they are just tossed from one place to another

²⁵⁰ Interview with Lawrence Mute, Member of the African Commission on Human and Peoples’ Rights (ACHPR) and former commissioner at the Kenya National Commission on Human Rights (Nairobi, Kenya, 7 May 2013) and with Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

apart from a few... Their opinions are not considered basically because people think again they are children, they do not understand...'²⁵¹

Generally, families are overprotective of their family members with intellectual disabilities and this makes it difficult for persons with intellectual disabilities to make personal life decisions across the board.²⁵²

With regard to pursuing legal action, the study results indicate that cases brought to court by persons with intellectual disabilities tend to be mostly on sexual abuse.²⁵³ While the Sexual Offences Act provides for the use of intermediaries in instances where persons with intellectual disabilities are witnesses, it is not clear how well this system is working, and it might be necessary to document this issue in greater detail.²⁵⁴ In one instance, the Kenya Association of the Intellectually Handicapped had to hold demonstrations in Mukurwe-ini to get the court to hear a matter involving the sexual assault of a person with an intellectual disability.²⁵⁵

With regard to voting most persons with intellectual disabilities were able to vote with support during the March 4 2013 elections held in Kenya. This is partly as a result of intense lobbying of the Independent Boundaries and Elections Commission by the Disability Caucus on the Implementation of the Constitution and the Kenya Association of the Intellectually Handicapped.²⁵⁶

Article 12 is about the small decisions as well as the big ones. Decisions on public life issues such as voting and property ownership are easier for the law to proscribe one way or another. But private life decisions such as what to wear, what to eat and what to do for recreation are a bit harder to police yet matter as much as the public life decisions, because they constitute a big percentage of the decisions that we make in our lives. Hence, interventions at family level are required for persons with intellectual disabilities to make decisions about personal life matters. While a lack of

²⁵¹ Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013)

²⁵² Ibid

²⁵³ Ibid

²⁵⁴ Ibid

²⁵⁵ Ibid

²⁵⁶ Ibid

options restricts choice, it does not restrict voice. Limited options may require creativity to respect the wishes of an individual. This could include ensuring the individual has an equal measure of control in the house over household decisions about activities, meals etc.²⁵⁷

Persons with psychosocial disabilities and decision-making on personal life matters

Generally, the incidence of living independently in the community is higher among persons with psychosocial disabilities as compared to persons with intellectual disabilities.²⁵⁸ The extent to which a person with a psychosocial disability makes personal life decisions depends on various factors, the key one being whether the person is employed, and has his or her own independent source of income. To a large extent, persons with psychosocial disabilities who are employed or have a source of income independent of their families make their own personal life decisions:

For people who live independently, they are able to make a lot of their choices, like for me i can decide entirely anything that i want to do, and part of it is connected with the fact that am independent, able to support myself, am working. But then its problematic where people live with their families, because then, first of all, in life when you live with your family there is a limit on which you can make your own decisions, then here comes an additional factor that you're a vulnerable person so it's worse when living with own family.²⁵⁹

With regard to deciding on social support, persons with psychosocial disabilities often face stigma in the community, which makes it difficult for them to form social

²⁵⁷ Inclusion International, 'The Right to Decide: Why does it Matter?' <<http://therighttodecide.org/the-right-to-decide-why-does-it-matter/>> accessed 27 May 2013

²⁵⁸ Elizabeth Kamundia, 'Choice, Support and Inclusion: Implementing Article 19 of the CRPD in Kenya' (L.L.M Thesis, National University of Ireland, Galway 2012)

²⁵⁹ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

connections. However, increasingly, persons with psychosocial disabilities are joining together to form support groups, providing social support for each other.²⁶⁰

With regard to voting, persons with psychosocial disabilities were allowed to vote, with the exception of those who did not have identity cards:

The guys who didn't vote (in the election of 4th March 2013) is because they do not have identity cards. This goes into the fact that some people are 18, but the family is not guiding them, providing information on how to go about being registered and getting an ID. This then affects political participation – where the family is not stepping in to assist the person. I have never heard of anyone denied the right to vote just on account of disability.²⁶¹

With regard to freedom of movement, this largely depends on gender – with most women with psychosocial disabilities experiencing greater restrictions on their freedom of movement. In some circumstances, persons with psychosocial disabilities are 'locked up or tied up' by their family members in a bid to keep them safe.²⁶²

Because many people with psychosocial disabilities are not formally under guardianship, they are able to interact with the legal system, once they surmount the access to justice issues that face persons with disabilities generally,²⁶³ particularly discrimination.²⁶⁴

Persons with other types of disabilities and decision-making on personal life matters

²⁶⁰ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

²⁶¹ Ibid

²⁶² Ibid

²⁶³ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013) and Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013). During the Focus Group Discussion, one of the participants indicated that she is accessing state funded legal aid in pursuing a case.

²⁶⁴ United Disabled Persons of Kenya, 'Baseline Assessment on Access to Criminal Justice System by Persons with Disabilities' 2012

Across the board, persons with disabilities live with their families, and are dependent on them. Also common across the board is the dearth of employment for persons with disabilities. Hence, persons with disabilities do not for the large part decide where and with whom to live. However, persons with other types of disabilities have greater chances at deciding on their own social support, and making friendships outside the family.

Stigma and discrimination greatly affect decision-making on personal life issues for persons with disabilities across the board. The interviews revealed that it is especially difficult for women with disabilities to marry.²⁶⁵

²⁶⁵ Interview with Women Challenged to Challenge (Nairobi, Kenya, 10 May 2013); Interview with United Disabled Persons of Kenya (Nairobi, 29 May 2013)

4.7 Showcasing good local practice:

Initiatives on actualizing Article 12 for Persons with Intellectual Disabilities in Kenya²⁶⁶

The Kenya Association of the Intellectually Handicapped (KAIH) is doing some work on actualizing Article 12 for persons with intellectual disabilities in Kenya. KAIH is based in six regions of the country - Nairobi, Kiambu, Nyeri, Migori, Siaya and Mombasa with a membership of two thousand members, spread into one hundred parents support groups and five self advocate groups. Related to Article 12 is KAIH's work on employment for persons with intellectual disabilities, self-advocacy and peer support and educating families of persons with intellectual disabilities on the rights of their family members with intellectual disabilities. KAIH also has a safeguard mechanism to ensure that support works as intended.

Employment

Persons with intellectual disabilities in Kenya often do not access education on an equal basis with others and as such experience high rates of unemployment.²⁶⁷ With regard to education, state sponsored schools do not offer quality education to persons with intellectual disabilities.²⁶⁸ The skills imparted in most schools for persons with intellectual disabilities are not aligned to the job market. KAIH has model vocational training centers that aim at giving persons with intellectual disabilities skill that are marketable and can enable them get employment on an equal basis with other youth. The vocational schools impart a mix of skills to the self-advocates including performing arts, bakery, catering, hairdressing and information technology (IT). To date, KAIH has trained thirty self advocates and half

²⁶⁶This section is based on interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013)

²⁶⁷ Elizabeth Kamundia, 'Choice, Support and Inclusion: Implementing Article 19 of the CRPD in Kenya' (L.L.M Thesis, National University of Ireland, Galway 2012)

²⁶⁸ Kenya National Commission on Human Rights, *Objects of Pity or Individuals with Rights: The Right to Education for Children with Disabilities* (Occasional Report 2007)
<<http://www.knchr.org/Portals/0/OccasionalReports/Objects%20of%20Pity%20OR%20Individuals%20with%20Rights%20-%20Final%20April%202007.pdf>> accessed 14 July 2013

the number are already in work placements. KAIH's way is to approach owners of businesses such as hairdressing, barbershops, catering shops and place the self advocates to work in these businesses. First, KAIH sensitizes the potential employers about intellectual disabilities and outlines the support and reasonable accommodation measures that the self-advocates may need in order to work.

The effect of employment among persons with intellectual disabilities is threefold- first, it allows persons with intellectual disabilities to be out in the world, demonstrating that given the opportunity and support, persons with intellectual disabilities can work – just like any other person. In this regard, the feedback from KAIH is that:

This has worked really well like the perceptions that most had that persons with intellectual disability cannot do anything ... they (the business owners) are saying this is the best group that we have had because they are performers, they go to work very early, they really value the job and this is a very interesting project for us.²⁶⁹

The second effect of this project is that it is giving persons with intellectual disabilities the opportunity to develop relationships outside their families and as such creating the possibility of their having a support network that is drawn from a from a broader base than just their families. Thirdly, the project allows persons with disabilities to earn their own money, which may shift power relations at home to the favour of persons with intellectual disabilities and which also potentially gives them the opportunity to make more decisions over their lives. This is particularly so once employment is coupled with empowerment through self advocacy training.

Self-advocacy

Self advocacy is based on seeing the potential of persons with intellectual disabilities and believing that just like anyone else, if self advocates are empowered, they can advocate for their own rights. Self-advocacy is about self-representation; encouraging persons with intellectual disabilities to develop their own voice. One of

²⁶⁹ Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013)

the most powerful things about self advocacy is shifting the societal perception that persons with intellectual disabilities are ‘big babies’ who are ‘just there to be seen and not to be heard’.²⁷⁰ The first step towards changing this view is challenging these assumptions with regard to ‘small decisions’ such as what to wear, and what to eat, and encouraging persons with intellectual disabilities to weigh in on these decisions in their homes.

Some of the decisions that the self advocates have been supported in making include healthcare decisions (HIV testing), financial decisions (opening bank accounts) and choosing support persons. To ensure full benefits to the self-advocates, KAIH first sensitized the service providers about intellectual disabilities. KAIH has also trained support persons to give the self advocates a choice of support outside the family.

The five self-advocates groups are registered with the government in the department of social services. The self advocates direct the activities of their groups. KAIH uses natural support as much as possible, working closely with people that the self advocates themselves identify as being the people who can assist them in making decisions.

Peer support

The self-advocacy groups provide the opportunity for self-advocates to work closely together and to share their experiences with each other, which greatly reduces the isolation that is common among people with intellectual disabilities. The self advocates have varying skills among them, and increasingly offer each other practical assistance based on the varying areas of competence within the groups. An example is where a self advocate who is conversant with money assists her peer who is not as conversant with shopping.

Educating families

²⁷⁰ Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013)

Most people with intellectual disabilities in Kenya live with their families who tend to be the sole care-givers. Hence, progress on Article 12 cannot be achieved if families are not made aware of the rights of their family member with an intellectual disability. KAIH trains families about various issues, one of which is the need to be less protective of their family members with intellectual disabilities. Another core area of training is about the right of persons with disabilities to make financial decisions on the money they earn:

We have really been trying to educate the families that even if you take some (money) for the family or whatever at least just give him or her (the family member with an intellectual disability) two or three hundred shillings for them to go and buy what their heart desires.²⁷¹

Safeguards

KAIH has a neutral committee or for resolving conflicts between support persons and persons with intellectual disabilities. In the event of a conflict, the neutral committee is meant to listen to both parties and amicably come to a preferred resolution for both of them. Dialogue is critical to this process.

Challenges

Initially, families are skeptical about allowing their family members with intellectual disabilities to make their own decisions. Families are worried about having to 'pick up the pieces' in case their family member with intellectual disability makes a 'bad' decision. When support persons are not family members, families are concerned, for instance, about their family member with an intellectual disability being exploited financially. It may also be necessary to develop smaller measures of protection to ensure that families buy in to the idea of supported decision-making. An example is that provided above on Israel and the use of caveats to avoid appointment of guardians while ensuring the person with disabilities' financial well-being.

²⁷¹ Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013)

Initiatives on actualizing Article 12 for Persons with psychosocial disabilities in Kenya²⁷²

Users and Survivors of Psychiatry – Kenya (USP-K)

Users and Survivors of Psychiatry – Kenya (USP-K) is doing some work on realizing Article 12 for persons with psychosocial disabilities in Kenya. USP-K is currently working in four counties - Nairobi, Kiambu, Nyeri and Nakuru. Related to Article 12 is USP-K's work on self-advocacy, peer support and educating families of persons with psychosocial disabilities on the rights of their family members with psychosocial disabilities.

Self-Advocacy

USP-K promotes a model of self-advocacy that is based on its members being aware of their rights:

I think for me self advocacy is only relevant to the extent to which people understand their rights. Otherwise, if advocacy is only based on sharing personal experiences, then at the end of the day, it does not actually change much in terms of the society, but the moment people understand, for example issues of forced medication, once people understand the rights perspective, their lives can change. People need to know that it's their right to say "no" to this, and "yes" to that, but before they know that it's a right, decisions will continue being made for them... Even in terms of employment, it is always easy to fire someone who has no idea of their rights, but once such a person starts quoting laws, then the employer sits back and reconsiders.²⁷³

USP-K members have formed groups and began to engage with devolved funds within the country, asserting the need to be considered for award of funds under schemes such as the Constituency Development Fund (CDF). Further USP-K members who are in employment are asserting their right to be exempted from paying income tax under Sections 12(3) and 35 of the Persons with Disabilities Act:

²⁷² Largely drawn from interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013); and Interview with Schizophrenia Foundation of Kenya (Nairobi, Kenya, 29 April 2013)

²⁷³ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

One of our members applied for tax exemption last year, then the Kenya Revenue Authority sent her a reply that what she has is a medical condition and that it does not qualify as a disability. Then we had a training on human rights and after this, we thought, why don't we look at what we have been taught in terms of the law, look at what the Persons with Disabilities Act says, the Constitution, the CRPD and that is what she did as an individual. She wrote a letter of appeal based on the law and took it to the National Council for Persons with Disabilities, took a copy to the Kenya Revenue Authority and another copy to the Kenya National Commission on Human Rights. So what would happen before when persons with psychosocial disabilities were denied tax exemption is that the correspondence would be sent to the Council, but because no one was speaking, the whole issue would die down. But now, with the member following up on the issue, the Council wrote to KRA and told them that their argument is erroneous in law, and they actually recommended that she should get a tax exemption, and now we're waiting for KRA to write back which for me actually is one of the most powerful things that have happened this year in terms of self advocacy.²⁷⁴

Other examples of self-advocacy given include a member of USP-K threatening to sue one of the hospitals in which he was admitted if they injected him by force. Other USP-K members are also advocating to have mental healthcare services availed closer to where they live.

Peer Support

Peer support is a core part of USP-K's work:

I think peer support is the vehicle for empowerment. The members of USP-K are at various levels of empowerment. But we share one platform and we sit as peers, and we speak to each others' aspects of life, whether it is medical, whether its work, whether it's to do with finances. In the peer support group all issues come up, ranging from relationship issues, to medication, to living arrangements, employment, education, everything comes in there. And we sift through those issues and we come up with positions. We don't have a necessarily right or wrong answer. Everyone comes up with their own opinion. Confidentiality is assured.²⁷⁵

The peer support groups are run exclusively by users and survivors of psychiatry as opposed to mental healthcare professionals.

²⁷⁴ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

²⁷⁵ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

Peer support groups are a powerful tool for self-empowerment. An example was given of a member whose doctor recommended ECT. The member identified her spouse as her supporter; and the member's supporter brought the issue for discussion in the peer support group, and the decision was reached after wide consultation, as opposed to circumstances in which a person's family members consent to ECT on a person's behalf solely on the recommendation of the doctor.

Home visits

USP-K carries out home visits during which family members of persons with psychosocial disabilities are educated on various issues, including the rights of the person with a psychosocial disability. Home visits are usually done on invitation except in exceptional circumstances where the need for intervention is evident. Another reason for carrying out home visits is that some people are more comfortable sharing opening up about their lives in their homes that they would be in a 'strange' environment. Home visits are useful for enabling the members to interact with one of their own in their own environment:

...in rural areas we have been doing it (home visits) just to see the environment – its different to meet people at the centre where we have the support group meetings and its different to see them at their environment where they live. And you'll find that when you go to the home visit you get a more accurate picture of what a person goes through, where they come from, you may not know everything but you can see the dynamics.²⁷⁶

Challenges

Currently, the peer support groups are only running in four out of forty seven counties. This is largely out of insufficient funds to replicate the same throughout the country.

Widespread stigma in relation to mental health issues poses a challenge where some people are afraid to identify with peer support groups for fear of social repercussions once identified as having a psychosocial disability.

²⁷⁶ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

Schizophrenia Foundation of Kenya

Schizophrenia Foundation of Kenya runs a clinic that offers mental health services within the community. The clinic has resulted in reduction of institutionalisation among people who seek health care services there. The clinic offers counselling and runs with the support of a psychiatric nurse posted to the clinic by the Government of Kenya. It is hoped to pilot such a clinic in many other parts of the country.²⁷⁷

It is important to document current work on Article 12 in order to possibly replicate the good practices in other regions of the country.

²⁷⁷ Interview with Schizophrenia Foundation of Kenya (Nairobi, Kenya, 29 April 2013)

4.8 Local Dilemmas on Article 12 (specific policy responses may need to be developed for the following situations)

1. Article 12 is about decision-making. But in the context of a low income country such as Kenya, peoples' choices are limited generally for reasons that have nothing to do with disability. How can the right to legal capacity be realized in a context of poverty?
2. Under Article 12(3), States Parties are required to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. Support, as envisaged in Article 12 (3) in the Kenyan context is currently provided by the family, and will continue to be provided by the family for a long time to come:

Support here comes from the family. I am my wife's carer, I live with her. I am able to tell whether she is well or not. When I see that she is not well, I tell her she should go to hospital, have her medication changed, or maybe if she has stopped taking medication, I urge her to get back on course. So I do not wait for support to come from outside. Very few people get support from outside the family, like in this meeting, only this woman (points to the woman who shared about being supported extensively by the community) gets support from outside her family, because there is no one in her family left, but for the majority support is from the family. I can assure you that caretakers tend to be family members.²⁷⁸

Article 12 places the obligation to provide support on States Parties. The reality in Kenya is that support is provided by families. What are the consequences of this with regard to the standard of support (by standard of support I mean the centrality of will and preferences to the Article, the requirement that measures be free of conflict of interest, etc)? How can the standard of support be maintained in the Kenyan context? How can the State best be enabled to increasingly take over the obligation to provide support?

²⁷⁸ Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013)

3. How do we balance the rights of the individual with psychosocial disabilities against the rights of a collective whole (the family)? If a person with a psychosocial disability refuses to take treatment and creates a disturbance in the home that does not meet the 'danger to self and/or danger to others criteria', every person living with him or her is affected. What solutions exist in such cases, in the setting of a family? How does this change if the person with a psychosocial disability is also jobless and dependent on the family for support? How does this affect the balance of whose will and preference will rule? What recommendations can assist in resolving such issues?

4. Some persons with disabilities do not have family to fall back on for support. Other persons with disabilities do have families, but are estranged from them:

There is tension between the person and the family. The family often does not understand. For a number of people at the support group, the biggest enemy is the family. They don't understand, make negative comments... and so the last people the people with psychosocial disabilities want helping them, is the family. But here in Kenya, we don't have alternatives! If not the family, for many, it's the streets! The family needs psycho education.²⁷⁹

Similar sentiments were expressed by carers in the Focused Group Discussion in Kiambu County:

I'd like to share on that issue of refusing treatment. I have one of those cases in my family. My brother, who is very difficult. Because he is very strong willed – when he decides that he will not do something, he will not do it.... he often refuses to take medication, and when this happens, he gets sick, and completely loses touch with the world. He can be in his house for a week alone, without making any contact with the world. And as we talk, he is right now admitted at Kenyatta Hospital. He was very sick before admission, you know our father died recently, and our mother died a long time ago, and so he was living alone. When we asked our big brother to go live with him, our big brother was willing, but he refused/declined, he does not want

²⁷⁹ Interview with Schizophrenia Foundation of Kenya (Nairobi, Kenya, 29 April 2013)

anyone in his house, he says that it is his place, his property, he is the rightful inheritor of that area. So even attempting to go live with him in order to support him becomes a problem. You just can't live with him, he's a very very difficult person. So we let him be, and he continued just being in the house by himself. But you see the result is that he got very very sick on his own, and we his family did not know about it, because we live very far from him. So in fact, it is the neighbours who have since called us, telling us that he is very sick, asking that we go and take him to hospital.... where they found that he was ailing from five different illnesses. Prior to his admission in Kenyatta and after the tests I just told you were conducted, he still wanted to go back to his house, but I declined and insisted that he stay with me...and that's how we ended up taking him to hospital... And hence, sicknesses differ from person to person. Each person's illness is different.²⁸⁰

Who will provide support for these persons who cannot lean on their families? Should a recommendation be that the state funds a system of providing support? Or that it funds DPOs that are providing support to enable them to do so across the country?

5. Recognizing the right to refuse psychiatric services requires that the State provides alternative services outside of the medical paradigm.²⁸¹ What viable alternatives to medication in the context of psychosocial disability can be created to suit the Kenyan context, particularly because medication is not a panacea:

The other day the doctor changed my medication, telling me to take this new pill once a day, in the morning. But when I take it in the morning, I feel like am being choked, my throat...so now I decided I better take the drug at night. Because had I taken that drug this morning, if I was trying

²⁸⁰ Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013)

²⁸¹ Office of the High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities Day of General Discussion on Article 12 of the CRPD – The Right to Equal Recognition Before the Law (21 October 2009) Ubuntu Centre of South Africa, 'Supported Decision-Making' <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DayGeneralDiscussion21102009.aspx>> accessed 30 May 2013

to talk like now, trust me, you wouldn't understand me. It feels as if something is stuck in my throat.²⁸²

6. Article 12(4) requires that measures relating to the exercise of legal capacity apply for the shortest time possible and are subject to regular reviews by a competent, independent and impartial judicial body. Further, safeguards are to be proportional to the degree to which such measures (the measures being referred to here are under Article 12(3) – measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity) affect the person's rights and interests. There is difficulty in this requirement in cases where the measures to provide access to support are being taken by the family. What body would be the most ideal 'competent, independent and impartial judicial body'?

7. Article 12 (5) requires that States take all appropriate and effective measures to ensure the right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to all forms of financial credit. The State should also ensure that persons with disabilities are not arbitrarily deprived of their property.

In the limited cases where persons with a psychosocial disability is a danger to himself or others and hence has to be taken to hospital, and his family has no money to pay the bill, is it acceptable for the family to sell the person's property to foot the bill? Indeed the obligation to provide healthcare is on the State, but the state provision of healthcare in the context of mental health is limited, so families often have to foot the bills. Is this arbitrary deprivation of property?

²⁸² Focus Group Discussion with Kiambu County Support Group for Persons with Psychosocial Disabilities (Kiambu, Kenya, 3 May 2013)

8. How do we address the issue of traditional healers and faith based healers, who tend to be the alternative to medication in some areas of Kenya?
9. How does the right to legal capacity affect the criminal justice system? What does this mean for the insanity defence in the Kenyan context?
10. What is Kenya's transitional strategy as she moves from a system of substituted decision making to one of supported decision making?
11. Access to the right to legal capacity for persons with disabilities seems to depend on 'communication', and technology. This was particularly emphasized in the case of persons who are Deafblind. Persons with psychosocial disabilities emphasized the need for skilled communicators. How do we ensure that these support measures are provided so that Article 12 does not just remain a right on paper for these groups?

5. Good practice on the Right to Legal Capacity - Initiatives to realize Article 12 in other countries

Numerous jurisdictions throughout the world have made significant changes to their capacity laws reflecting the international progression towards the 'social' or 'human rights model' of disability.²⁸³ Some of the examples that follow are more in line with Article 12 of the CRPD (for example, the Personal Ombudsmen, support networks) while some may be said not to be so (for example, enhanced representation agreements under Section 9 of British Columbia's Representation Agreement Act). The guiding factor is that laws that allow a person to retain greater autonomy over their life and /or laws that facilitate the expression of a person's will and preferences and that allow a person's decisions to be based on their own will and preferences are more likely to be compliant with Article 12 than laws that do not.

In the issue paper of 20th February 2012, the Commissioner for Human Rights identified some good practice models with regard to the exercise of legal capacity,²⁸⁴ some of which are reproduced herewith:

5.1 The Example of Personal Ombudsmen²⁸⁵

The personal ombudsmen support model in Sweden was developed based on a recognition that existing legal capacity systems did not meet the needs of many people with psychosocial disabilities who were pushed between authorities and unable to access their rights. It grew out of the Swedish Psychiatric Reform of 1995.

²⁸³ The European Group of National Human Rights Institutions, Amicus Brief in the European Court of Human Rights - *D.D v Lithuania* Application No. 13469/06 11 April 2008
<<http://www.interights.org/userfiles/Documents/DDAmicusHumanrightsinstitutions.pdf>> accessed 4 June 2013

²⁸⁴ 'Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities' (Strasbourg, 20 February 2012, CommDH/Issuepaper(2012)2). Available at:
<<https://wcd.coe.int/ViewDoc.jsp?id=1908555>> accessed 7 May 2012

²⁸⁵ PO-Skåne, 'Swedish User-Run Service with Personal Ombud (PO) for Psychiatric Patients'
<<http://www.po-skane.org/ombudsman-for-psychiatric-patients-30.php>> accessed 22 May 2013

It started as a pilot project, but showed such good results – it was appreciated by the clients, it reduced the number of in-patient hospitalizations and resulted in cost-savings – that today it has become a country-wide permanent arrangement of about 300 ombudsmen supporting 6000-7000 persons with psychosocial disabilities.²⁸⁶ The service is financed by the state (2/3) and by the local community (1/3).

The ombudsman is a professional who works 100% on the commission of the individual, and for the individual only. The ombudsman has no commitments or responsibilities vis-à-vis the medical or social services, the client's relative or any other authority or person. The ombudsman only acts when the client wants him/her to do so. It may take long a time before the ombudsman and the individual have developed a trustful relationship where the individual wants to talk about what kind of support he/she wants, but the ombudsman needs to wait, even if the client's life may appear chaotic.

This type of support has been successful in helping also those who are most hard to reach and who have previously often been left without support. This includes persons diagnosed with schizophrenia, persons experiencing delusions and psychosis, and those who are homeless or live very isolated avoiding all contact with the authorities. To reach this group, the ombudsman has to actively seek contact on the individual's terms; 'the ombudsman cannot sit and wait for them, but has to go out and try to find them in their place of living, and to use all kind of creativity in finding ways to get in touch with them'.²⁸⁷ To make this possible it is necessary that the ombudsman is independent from all authorities. In some places in Sweden ombudsmen are employed by the community; however, when this is the case it's more difficult to reach psychiatric patients who are suspicious or hostile against representatives of the authorities. Hence, an independent NGO is preferred, for example, ombudsmen in Skåne are employed by PO-Skåne, which is an independent

²⁸⁶ The Swedish National Board of Health and Welfare, Egen kraft – egen makt, En antologi om arbetet som personligt ombud (Your own strength – your own power, An anthology about the work of personal ombudsmen), p. 15.21

²⁸⁷ PO-Skåne, 'Swedish User-Run Service with Personal Ombud (PO) for Psychiatric Patients' <<http://www.po-skane.org/ombudsman-for-psychiatric-patients-30.php>> accessed 22 May 2013

NGO run by the user organisation RSMH (The Swedish National Association for Social and Mental Health) and the family organisation IFS (The Schizophrenia Fellowship Association).

A number of characteristics have contributed to the success of the personal ombudsman model. These include:

- No bureaucratic procedure to get a personal ombudsman. Requirements to fill in forms would prevent many who need the ombudsman, to get one. A simple yes to the question from an ombudsman to the client if he/she wants an ombudsman is enough.

- The ombudsman does not work ordinary office hours but holds flexible hours and is prepared to have contact with his/her clients also in the evenings or on weekends.

- The ombudsman does not work from an office, because 'office is power', but works from his/her own home. He/she meets his clients in their home or at neutral places out in town.

- The ombudsman is comfortable to support the client in a number of matters. The priorities of the individual are not always the same as the priorities of the authorities or the relatives. The client's first priorities may not concern housing or occupation but relationships or existential matters. An ombudsman must be able to discuss such matters as well - and not just 'fix' things.²⁸⁸

5.2 The example of support networks

The British Columbia's (Canada) Representation Agreement Act 1996²⁸⁹ is another example of good practice, in particular appreciated by organisations representing

²⁸⁸ Maths Jespersson 'Personal Ombudsman in Skåne – A User-controlled Service with Personal Agents' in P. Stastny and P. Lehmann (Eds.), *Alternatives Beyond Psychiatry*, 2007, p. 299ff

²⁸⁹ British Columbia's (Canada) Representation Agreement Act, R.S.B.C. 1996, chapter 405 <http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/10_199_2001_01/12/11> accessed 4 June 2013

persons with intellectual disabilities.²⁹⁰The purposes of the Act are to: 1) provide a legal alternative to adult guardianship for adults who need help today, and 2) enable planning for the future. The Act establishes a mechanism allowing adults to arrange in advance how decisions should be made if they were to become in a situation where national law does not recognise their capacity to make legally valid decisions without support. The Act provides for the individual to draw up representation agreements where he/she authorises another person, freely selected by the individual, to support the individual or to make decisions on behalf of the individual in selected areas of life. This may include routine financial managements, health care choices or obtaining legal services for the adult, in circumstances where the adult be unable to do so for himself or in the event that the adult cannot communicate these wishes himself/herself. ²⁹¹ One is not required to consult a legal professional to make a Representation Agreement under section 7.

An adult can designate another adult or the Public Trustee to represent the adult in health care matters.²⁹² Credit unions and trust companies are only permitted to represent an adult in financial and legal matters. A representative is in a fiduciary relationship with the adult. Thus, the representative must act in good faith, exercise the care and skill of a reasonably prudent person and cannot act outside the scope of authority given to him under the representation agreement. Having a Representation Agreement does not remove decision making rights from the adult. A Representation Agreement also does not replace the informal support that families and friends provide; it gives legal status to the adult's personal supporters when informal help is not enough.²⁹³ Further, A Representation Agreement cannot authorize one's representative to do anything that is prohibited by law, such as

²⁹⁰ Ibid

²⁹¹ Representation Agreement Act, para 7

²⁹² This section in its entirety is drawn from Heritage Law, 'Representation Agreements' <<https://www.bcheritagelaw.com/legal-services/estate-law-information/estate-planning/representation-agreements-vancouver/>> accessed 22 May 2013

²⁹³ Nidus Personal Planning Resource Centre and Registry 'Representation Agreement with Section 7 Standard Powers' <http://www.nidus.ca/PDFs/Nidus_FactSheet_RA_Section7.pdf> accessed 21 May 2013

euthanasia or assisted suicide. An adult cannot authorize his or her representative to consent to consultation, treatment or care related to the adult's sterilization for non-therapeutic purposes.²⁹⁴

The provision of representative agreements circumvents court involvement. NIDUS is an NGO in British Columbia (formerly representational Agreement Resource Centre) that grew from original efforts for legislative reform and today it provides support and assistance to people with disabilities (including dementia) their families and supporters to make their agreements, which can be registered for a fee with NIDUS. The Act never anticipated, nor legislated for a registration process, so this process is purely voluntary.²⁹⁵

There are two kinds of Representation Agreements:

1. Standard Representation Agreements; and
2. Enhanced Representation Agreements.

5.2.1 Standard Representation Agreements

Standard (Section 7) representation agreements can be entered into by someone who may be incapable of making a contract or managing her affairs provided that:

- It is the adult's desire to have a representative decision maker;
- The adult can make choices and express feelings of approval or disapproval of others;
- The adult can comprehend the effect of a representative agreement and its terms; and

²⁹⁴ Nidus Personal Planning Resource Centre and Registry 'Representation Agreement with Section 9 Broader Powers' <http://www.nidus.ca/PDFs/Nidus_FactSheet_RA_Section9.pdf> accessed 21 May 2013

²⁹⁵ Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship) <http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

- If the adult and the representative have a relationship based on trust.

There are four areas of authority that can be included in a Representation Agreement with Section 7 standard powers. These four areas are:

- a) Minor and major health care, which includes medications, tests, surgery, any treatment requiring a general anaesthetic, dental care, end-of-life comfort care.
- b) Personal care, such as, living arrangements, diet, exercise, taking part in activities, personal safety issues.
- c) Legal affairs, which include obtaining legal services and instructing a lawyer, settling an insurance claim, going to small claims court.
- d) Routine management of financial affairs, such as banking, government benefits, Revenue Canada, managing investments.

The representative in a s. 7 agreement is **not allowed** to make the following decisions:

- Abortion unless recommended in writing by the treating physician and at least one other medical practitioner who has examined the adult for whom it is proposed;
- Electroconvulsive therapy unless recommended in writing by the treating physician and at least one other medical practitioner who has examined the adult for whom it is proposed;
- Psychosurgery;
- Removal of tissue from a living human body for implantation in another human body or for medical education or research;
- Experimental health care (health care that deviates from standard professional practice) involving a foreseeable risk to the adult for whom the health care is proposed that is not outweighed by the expected therapeutic benefit;
- Participation in a health care or medical research program that has not been approved by a committee;

- Any treatment, procedure or therapy that involves using aversive stimuli to induce a change in behaviour.

In addition, the representative in a s. 7 agreement is not authorized to make a decision to refuse life-supporting care or treatment.

5.2.2 Enhanced Representation Agreements

An enhanced (section 9) representation agreement allows for an agreement which goes beyond the limited provisions of a standard section 7 agreement but requires the adult to have full mental capacity when it is signed. It can be as broad or detailed as the adult wishes it to be.

A representative appointed in an enhanced representation agreement has the same powers as one appointed in a section 7 standard agreement in addition to the authority to do the following:

- Physically restrain, move or manage the adult, or have the adult physically restrained, moved or managed, when necessary and despite the objections of the adult;
- Give consent, in the circumstances specified in the agreement, to specified kinds of health care, even though the adult is refusing to give consent at the time the health care is provided;
- Refuse consent to specified kinds of health care, including life-supporting care or treatment;
- Give consent to specified kinds of health care, including one or more of the following:
 - Abortion unless recommended in writing by the treating physician and at least one other medical practitioner who has examined the adult for whom it is proposed;
 - Electroconvulsive therapy unless recommended in writing by the treating physician and at least one other medical practitioner who has examined the adult for whom it is proposed;

- Psychosurgery;
- Removal of tissue from a living human body for implantation in another human body or for medical education or research;
- Experimental health care (health care that deviates from standard professional practice) involving a foreseeable risk to the adult for whom the health care is proposed that is not outweighed by the expected therapeutic benefit;
- Participation in a health care or medical research program that has not been approved by a committee;
- Any treatment, procedure or therapy that involves using aversive stimuli to induce a change in behaviour.
- Accept a facility care proposal under the *Health Care (Consent) and Care Facility (Admission) Act* for the adult's admission to any kind of care facility;
- Make arrangements for the temporary care, education and financial support of:
 - The adult's minor children, and
 - Any other persons who are cared for or supported by the adult;
- Do, on the adult's behalf, anything that can be done by an attorney acting under a power of attorney;

Giving the representative broader authorities does not mean they will act on them; rather, it ensures that someone you trust will have legal authority to carry out your wishes if you are incapable of giving or refusing consent.²⁹⁶ Currently, only practicing lawyers can consult with clients entering into enhanced representation agreements.²⁹⁷

²⁹⁶ Nidus Personal Planning Resource Centre and Registry, 'Representation Agreement with Section 9 Broader Powers' <http://www.nidus.ca/PDFs/Nidus_FactSheet_RA_Section9.pdf> accessed 21 May 2013

²⁹⁷ Heritage Law, 'Representation Agreements' <<https://www.bcheritagelaw.com/legal-services/estate-law-information/estate-planning/representation-agreements-vancouver/>> accessed 22 May 2013

Such types of support mechanism are progressive in that they leave it to the individual to choose his/her support and the areas in which he/she wants support. The act is also noteworthy because it extends the presumption of capability also to persons with intellectual and/or psychosocial disabilities. Also adults who would not be considered capable of managing their financial affairs under ordinary contract law are allowed to make representation agreements (as well as change and revoke them). When deciding whether an adult can make such an agreement, the 'understand and appreciate test'²⁹⁸ does not apply. Instead, consideration is given to whether the adult can communicate a desire to get help, can express preferences, is aware of the fact that concluding the representation agreement means that the representative may make decisions or choices that affect the adult, and whether the adult has a relationship with the representative that is characterised by trust.²⁹⁹

5.3 Additional supported decision-making resources

The above good practice models are already in place in the respective countries. This section features models of supported decision-making that are being proposed or being piloted in two jurisdictions: South Australia and Ireland.

South Australia

South Australia has piloted a supported decision making program aimed to assist people with a disabilities set up supported decision making agreements, in areas of health, accommodation and lifestyle decisions. The approach aims to maximise the autonomy and the exercise of rights by people with a disability, and is consistent with the UN Convention on the Rights of Persons with Disabilities, Article 12, 'Equal Recognition Before the Law'.³⁰⁰

²⁹⁸ i.e. that a person can understand the nature of a decision and appreciate the reasonably foreseeable consequences of their decision.

²⁹⁹ Representation Agreement Act, para 8. For further reading, see Michael Bach and Lana Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' 2010 <<http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>> accessed 30 May 2013

³⁰⁰ For more information, see Office of the Public Advocate, 'Supported Decision-making' <<http://www.opa.sa.gov.au/cgi->

The pilot project operated a Stepped Model of Supported and Substitute Decision Making.³⁰¹ In this model, there is not just one form of supported decision making within the total spectrum as different forms of supported decision making agreements may suit different people. With respect to Supported Decision Making the two key differences in the types of agreements are:

- (1) the presence or absence of recognition in legislation; and
- (2) who makes the appointment – the person themselves or a tribunal.

In the South Australian pilot project, there is no legislative recognition, and the supported person makes the appointment of the supporter. The stepped model:

Autonomous Decision Making

At the top of the stepped model is autonomous decision making. However, autonomous decision making does not necessarily mean individual decision making. Most people will choose to seek advice and support from others when making an important decision. For this reason decision making can be seen as “interdependent” as opposed to independent.

Assisted Decision Making

While definitions vary, in assisted decision making a person is regarded as having legal capacity, but requires assistance to collect information to make a decision. This can be communication assistance – for example a person who has had a stroke may need to communicate with a special device. For people who have an intellectual disability Assisted Decision Making may require information to be presented clearly in plain English with the use of diagrams if needed. Assistance can be provided by

[bin/wf.pl?pid=&mode=cd&file=../html/documents//11_Supported%20Decision%20Making>](#)
accessed 22 May 2013

³⁰¹ Office of the Public Advocate South Australia in Collaboration with the Julia Farr MS McLeod Benevolent Fund, ‘Developing a Model of Practice for Supported Decision Making’
<http://www.opa.sa.gov.au/documents/11_Supported%20Decision%20Making/2-Supported%20Decision%20Making%20Practice%20Manual%20%20v1.4%20June%202011.pdf.pdf>
> accessed 22 May 2013

anyone including service providers. Providing necessary assistance is a “reasonable accommodation” and is supported by Article 5 of the UN Convention. While a “supported decision maker” may offer assistance too, the presence of a supporter should not stop a service provider from providing assistance.

A non-statutory Supported Decision Making agreement

The appointment of a supporter is made by the person needing support. The person must want to have support making decisions, and have a trusting relationship with someone who will be their supporter. The person also must be able to cancel an agreement at any time if they are unhappy with its operation. Agreements can also specify a third person – a “monitor” – who can check to ensure that the agreement is operating as it should.

Without a specific law, an agreement acts as a record of the persons’ wish to receive support from another. It will not give the supporter any additional standing, and a supported person will not be obliged to use the agreement. This is the type of agreement used in the South Australian Supported Decision Making trial.

A statutory Supported Decision Making agreement

This has most of the same features as a non-statutory agreement, but in jurisdictions that have Supported Decision Making laws, this legal recognition has advantages in safeguarding the supported person, and giving a special status to supporters. A legislated form of agreement can create obligations on the supporter to act in the interests of the supported person, and also give their role legal recognition so that health services and community agencies can share information directly with supporters. Legislation can also include protections from liability for supporters and other parties assisting a person to make decisions provided that such actions are not in breach of the supporter’s duty to the supported person. A supported person is expected to use the agreement – if the person wishes to make decisions outside it then a person should cancel the agreement which the person has the power to do. The agreement is a significant document that cannot be ignored. In conducting the

South Australian trial, it was considered likely in the future that any widespread use of Supported Decision Making will require statutory recognition.

A tribunal appointed Supported Decision Making arrangement

Unlike the agreements already described, a person would not have the option of ending an agreement unilaterally as only the tribunal has the power to do this, and would be required to seek support in making decisions while the agreement is in place.

Representational Agreement

Such agreements are intended primarily to provide Supported Decision Making, and a person appoints their supporters through signing an agreement document as described previously. However, representational agreements also permit the supporter to make a substitute decision if the supported person is unable to make a decision themselves – for example, if the person became unwell and is in hospital. This model, as practiced in British Columbia allows for both supported and substitute decision making.

A tribunal appointed Co-decision maker

This is an arrangement used in Alberta. If an adult needs support with decisions a co-decision maker can be appointed by a court. The co-decision maker, who is usually a family member or close friend, and the adult, need to agree on major decisions. If there is a disagreement the decision of the adult (not the co-decision maker) takes precedence. If the arrangement is not working it may be followed up by the Public Guardian to determine if another person should be appointed co-decision maker or another form of decision making support is required.³⁰²

³⁰² Office of the Public Advocate South Australia in Collaboration with the Julia Farr MS McLeod Benevolent Fund, 'Developing a Model of Practice for Supported Decision Making' <http://www.opa.sa.gov.au/documents/11_Supported%20Decision%20Making/2-Supported%20Decision%20Making%20Practice%20Manual%20%20v1.4%20June%202011.pdf.pdf> accessed 22 May 2013

Ireland

The Irish Government has been considering the need to reform its law on capacity in line with the CRPD and is about to publish the Assisted Decision-Making (Capacity) Bill. A group of NGOs, including those representing older persons, persons with disabilities, people with mental health problems and acquired brain injury have developed essential principles to guide and shape new law on capacity in line with Article 12.³⁰³

According to these principles, everyone should be presumed to have the capability to make decisions. The main focus of the new law must be to support people to make their own decisions. The new law must include three different levels of support:

- a. The first level is where a person has the ability to **make decisions with only minimal support** e.g. easy to read information
- b. The second level is **supported decision-making**, where a person is supported by a person they trust to make a decision, and
- c. The third level is **facilitated decision-making**, this is used as a last resort where a person's 'will and preferences' are not known. Here, a representative has to determine what the person would want, based on what they know about that person and on their best understanding of their wishes.³⁰⁴

³⁰³ Amnesty International, 'Essential principles: Irish Legal Capacity Law' <<http://www.amnesty.ie/node/2558>> accessed 22 May 2013

³⁰⁴ Substitute decision-making of some form will probably still be required in some for people living with severe or profound impairment - Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship) <http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

6. Suggestions for enabling legal capacity for persons with disabilities in Kenya

The recommendations proposed herewith aim to respond to the findings in Chapter 4 of this paper. The key finding is that formal guardianship is not widespread in Kenya and the exercise of the right to legal capacity in Kenya is hindered by factors such as poverty and high unemployment rates among persons with disabilities, limited state support to persons with disabilities and their families, societal attitudes that continue to hold persons with disabilities as objects of care as opposed to rights holders, inaccessibility of the environment and lack of alternatives in the mental healthcare sphere.

In considering these recommendations, the state should recognize that there is a gender aspect to the manner in which the right to legal capacity plays out in the Kenyan context. Across the board, women with disabilities face compounded barriers in seeking to exercise their legal capacity on an equal basis with others. Article 6 of the CRPD on women with disabilities recognises that women and girls with disabilities are subject to multiple discrimination, and mandates States Parties to take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.³⁰⁵

The following recommendations would go a long way towards giving effect to Article 12:

Recommendations to the Law Reform Commission and the Ministry of Labour, Social Security and Services:

1. Develop a comprehensive policy on legal capacity that puts in place a supported decision-making paradigm that is suitable to the Kenyan

³⁰⁵ 'The fact that women's rights are not protected in so many areas contributes a lot to mental ill health'. Interview with Schizophrenia Foundation of Kenya (Nairobi, Kenya, 29 April 2013)

context. This should be done in a participatory and inclusive manner,³⁰⁶ and should:

- a. Define legal capacity broadly to include the capacity to hold a right and the capacity to act and exercise the right.
- b. Recognize the diversity of disability in tailoring support measures and in tailoring safeguards. Even within disability, some persons with disabilities are more marginalized than others,³⁰⁷ and hence different levels of support are required. An option is to have different levels of support:
 - i. One level could be where a person needs accommodations in order to make decisions, e.g easy to read information;
 - ii. The second level could be where a person is supported by a person they trust to make a decision, or where a person needs representation in order to ensure that third parties respect the person's decisions;
 - iii. The third level could be where a person appoints a person they trust to make certain decisions for them, say during a crisis;
 - iv. The fourth level could be in instances where it is difficult to discern a person's 'will and preferences'. In this case, decisions could be made based on what is known about the person and the best understanding of their wishes.³⁰⁸
- c. Establish legal obligations of supporters and provide for checks and balances against abuse and offer remedies against the same.
- d. Require that a database on persons currently under guardianship be established so as to reverse those decisions and consider how to put in place support measures that are in line with Article 12.

³⁰⁶ See for example the Irish process, Amnesty International, 'Citizen's Jury on Capacity Law' <<http://www.amnesty.ie/node/2552>> accessed 4 June 2013

³⁰⁷ In this regard, Article 12 is core to persons with intellectual disabilities and persons with psychosocial disabilities realizing their rights.

³⁰⁸ Amnesty International, 'Essential principles: Irish Legal Capacity Law' <<http://www.amnesty.ie/node/2558>> accessed 22 May 2013

Recommendations to Parliament

2. Repeal legislation that undermines the legal capacity of persons with disabilities by expressly providing for guardianship. Such laws include:
 - The Mental Health Act
 - The Civil Procedure Act and the Civil Procedure Rules
 - The Children’s Act

3. Amend the various sections in various legislation identified in this brief that contravene Article 12 of the CRPD. Such laws include:
 - The Constitution of Kenya
 - Age of Majority Act
 - Matrimonial Causes Act
 - Sale of Goods Act
 - Law of Succession Act
 - Traffic Act
 - Penal Code
 - Criminal Procedure Act
 - Sexual Offences Act
 - Evidence Act
 - Elections Act
 - HIV and AIDS Prevention and Control Act
 - Persons with Disabilities Act

Recommendations to the Ministry of Labour, Social Security and Services, the Ministry of Education, the Ministry of Health and the National Council for Persons with Disabilities

4. This briefing paper has demonstrated the inter-relatedness of human rights. Article 12 does not stand in isolation – it stands together with all the other human rights named in the Convention. Hence, the

approach should be comprehensive – fulfilling the other various rights in the convention including the right to education, work and employment and health would go a long way towards ensuring the realization of Article 12.³⁰⁹ In particular, it was emphasized that Article 24 on education and 27 on work and employment are key to an individual eventually being able to make decisions about their life. With regard to education for children with disabilities, it is important to recognize the diversity of disability, and to meet the specific education needs. For instance, children who are deafblind have for a long time not had access to education in Kenya due to lack of skilled communicators. There are direct and indirect actions that the state can take to effect Article 12. By the state realizing other articles of the Convention, the possibility of the autonomy of persons with disabilities being respected rises.

Article 54(2) of the Constitution requires the State to ensure the progressive implementation of the principle that at least five percent of the members of the public in elective and appointive bodies are persons with disabilities. The fact that persons with disabilities are disproportionately represented among the poorest in the country was emphasized often in the interviews. Employment offers a way out of poverty and out of dependence and is a critical measure towards ensuring that persons with disabilities live lives of their own choosing. Hence, the state should prioritize the implementation of this provision for persons with all types of disabilities. With regard to the employment of persons with high support needs, the State should consult with DPOs about how best to effect this.³¹⁰ Interviews revealed that persons with disabilities require greater leeway, for

³⁰⁹ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013); KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

³¹⁰ Interview with Kenya Association of the Intellectually Handicapped (Nairobi, Kenya, 6 May 2013)

instance to be exempted from laws that prohibit street entertaining.³¹¹

Recommendation to the National Council for Persons with Disabilities, the Kenya National Commission on Human Rights and the National Gender and Equality Commission

5. The state needs to create awareness with the aim of changing attitudes and ensuring that communities become inclusive of people with disabilities. Stigma is a significant barrier to persons with disabilities accessing their rights and this should be addressed through programmes aimed at educating members of the public. Persons with disabilities and their families should be specifically targeted for awareness raising. As identified in Chapter 4, a core barrier to persons with disabilities making their own decisions is that families tend to be overprotective of their family members with disabilities; something that could possibly be changed through awareness raising.³¹² Part of the reason why families are overprotective may just be because they have never thought of their family member with disabilities as a rights holder – only as a recipient of care. Hence, human rights sensitization is key in changing family perceptions and prejudices towards their family member with disabilities.³¹³ In working with families, it is important to be sensitive of the fact that most families are doing their best with limited support from the state and from the community.

³¹¹ Interview with Gatune, Street Entertainer (Nairobi, 16 May 2013)

³¹² Interview with Lawrence Mute, Member of the African Commission on Human and Peoples' Rights (ACHPR) and former commissioner at the Kenya National Commission on Human Rights (Nairobi, Kenya, 7 May 2013); Interview with Sense International (Nairobi, 16 May 2013)

³¹³ 'Sometimes when families take the money of a person with disabilities away and spend it, sometimes it's because they assume that they are helping the person'. KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

6. The state should build the capacity of key professionals on disability issues, and specifically on legal capacity. Such professionals include judges, magistrates, the police, prison staff and other actors within the justice system. The CRPD Committee in its concluding observations to state parties has identified that the judiciary should receive training on the recognition of the legal capacity of persons with disabilities and on mechanisms of supported decision-making.³¹⁴ One way to effect this in our context is to designate some magistrates as specialists on legal capacity issues and equip them to handle these cases, in a similar manner as happens with regard to children's matters. Avenues such as Continuous Legal Education for lawyers should be explored in building the capacity of lawyers on legal capacity. Social workers would also greatly benefit from being trained on the recognition of the legal capacity of persons with disabilities and on mechanisms of supported decision-making.³¹⁵ Once trained, social workers could pass the knowledge to the families they work with. They could also act as a safeguard because they have the likelihood of working closely with families and becoming aware of how persons with disabilities are treated in their homes.³¹⁶ Mental health professionals also need to be made aware of the right to legal capacity and of the social model of disability, and what both entail, particularly with regard to giving the power and control back to persons with psychosocial disabilities. Further, the state should build its own capacities on the CRPD and Article 12 in particular so that it becomes a repository of knowledge

³¹⁴ Concluding observations issued to Hungary - Committee on the Rights of Persons with Disabilities, 8th Session (17-28 September 2012)

<<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session8.aspx>> accessed 4 June 2013

³¹⁵ Concluding observations issued to Hungary - Committee on the Rights of Persons with Disabilities, 8th Session (17-28 September 2012)

<<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session8.aspx>> accessed 4 June 2013

³¹⁶ Interview with Lawrence Mute, Member of the African Commission on Human and Peoples' Rights (ACHPR) and former commissioner at the Kenya National Commission on Human Rights (Nairobi, Kenya, 7 May 2013)/ KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

on these issues, using all means possible including Article 32 of the CRPD.³¹⁷ On awareness raising and capacity building, it is important to recognize that there are already actors on the ground raising awareness, mostly DPOs and hence it may be useful for the state to work closely with DPOs.

Recommendations to the Ministry of Labour, Social Security and Services

7. It is commendable that the Social Assistance Act³¹⁸ has been enacted to provide for the rendering of social assistance to persons in need, and includes persons with disabilities as one of its target groups. The state should ensure that persons with disabilities are aware that they can apply for social assistance to the National Social Assistance Authority. Currently, support to persons with disabilities under the Cash Transfer Programme for Persons with Disabilities is available for up to 70 households in every constituency. This should be scaled up progressively to meet the demand as poverty is one of the core reasons why persons with disabilities are not able to exercise their legal capacity on an equal basis with others. The money paid out under the Cash Transfer Programme as it goes to the household; however, the Act makes it clear that the money is to be allocated to the person with disabilities. It is necessary to find ways to ensure that part of the money is indeed spent for the wellbeing of the person with disabilities, and that the whole amount does not end up being spent on household expenses to the exclusion of the family member with a disability. It is important to consider that a lot of times, caregivers are not able to engage in economic activities. Further, while it is commendable that the cash transfer programme targets the most

³¹⁷ 'We have had cases whereby we have called social services to come and intervene (with regard to a child with intellectual disabilities being abused) only for them to call us back and say that they do not know what to do with the child' KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

³¹⁸ Act Number 24 of 2013

vulnerable, there is merit in the view that ‘when you have no income mainly because of your disability, you are no different from a severely disabled person in terms of the decisions you can make over your life’.³¹⁹

8. Progressively develop alternative means of support for persons with disabilities who cannot depend on their family members for support. Also, families may be able to support their members with regard to some decisions, but not so well with regard to other decisions, and it is important for persons with disabilities to have alternative forms of support.
9. There is need for respite care services provided by the state. Even though many families willingly provide care to their loved ones with high support needs, the physical, emotional and financial consequences for the family caregiver can be overwhelming without some support, such as respite care. Respite care services would provide planned short-term and time-limited breaks for families and other unpaid care givers, which may prove beneficial to their overall quality of life.³²⁰ Further, the availability of respite care would go a long way towards reducing instances where persons with disabilities are locked up and/or tied up inside their homes by caregivers who experience themselves as having no alternatives in a setting where the caregivers are also responsible for providing financially for the family.
10. Both the National and County governments should work closely with persons with disabilities and their organizations in figuring out how supported decision-making would best work in the Kenyan context. On the ground, there are several Article 12 initiatives that have been started by DPOs and the state would benefit from collaborating with

³¹⁹ KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

³²⁰ Interview with United Disabled Persons of Kenya (Nairobi, 29 May 2013)

DPOs in order to enable them scale up their operations, and in order for there to be shared learning on how the state may pilot supported decision-making projects of its own. County governments should partner with local DPOs towards realizing Article 12 for persons with disabilities.

Recommendations to the National Council for Persons with Disabilities

11. The State should promote universal design to ensure that products, environments, programmes and services are usable by all people, to the greatest extent possible. In particular, persons with physical disabilities as well as persons who are blind indicated that a great barrier to their ability to carry out their decisions is the dependence that is imposed by inaccessible environment.³²¹

The State should enforce the existing laws on accessibility and the duty to accommodate within both the public and the private sectors.³²² With regard to making financial decisions, banks have a key role to play in making all their services accessible. In particular, persons who are blind and persons who are partially sighted should be able to have an unimpeded access to the services provided by the ATMs on an equal basis with the other clients.³²³ Signatures of blind people should be accorded equal recognition. The Central Bank of Kenya is the licensing body under Section 4 of the Banking Act; and a possible avenue for enforcing the accessibility of banks is to require that their services be accessible in order to qualify for the requisite annual licence.

³²¹ Interview with Women Challenged to Challenge (Nairobi, Kenya, 10 May 2013)

³²² Section 21 of the Persons with Disabilities Act and Article 54(1) c,d,e of the Constitution of Kenya

³²³ The Committee on the Rights of Persons with Disabilities has confirmed this obligation in a case brought against Hungary by Szilvia Nyusti and Péter Takács, <<http://www.ohchr.org/EN/NewsEvents/Pages/accesstobankingservices.aspx>> accessed 3 June 2013

12. In acknowledging the fact that families are for the most part the default supporters in our context, it may be necessary to have a code of conduct for family members on how best to support their family member with disabilities without infringing on their autonomy.³²⁴ The code would not create criminal liability over and beyond what is already in the existing laws of the country, but would guide families on how they may offer support to their family members with disabilities. The code could then be distributed upon registration as a person with disabilities. It could also be distributed by DPOs that work closely with families of persons with disabilities among other avenues.

Recommendations to Parliament and to the Ministry of Health and to Kenya National Commission on Human Rights

13. There is need to reform the mental healthcare system, and the ongoing review of the Mental Health Act is one avenue through which positive changes could be made in the mental healthcare field. The state should provide adequate, accessible and affordable quality mental health care. In this regard, it is necessary to invest more resources in the mental healthcare field. Further, the State should provide alternatives to medication in the mental healthcare field. A key finding is that legal capacity issues are magnified by unaddressed mental health needs in the country. One way of bringing mental health services closer to the people is to avail counseling services in all public schools and learning institutions, as well as in public offices.³²⁵ The reviewed Mental Health Care Act should provide for a variety of support measures including crisis and recovery supports, multidisciplinary home-based and assertive outreach care and a comprehensive range of relevant medical, psychological and social

³²⁴ KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

³²⁵ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013)

therapies for service users and their families.³²⁶ The act should also give advance directives legal standing.

The Act should also recognize the vital role of peer advocates in supporting individuals through mental health treatment and recognize the need for individual care plans that carefully set out the steps required to be put in place for recovery and community integration.³²⁷ The Act should also make it clear that mental health care should be provided within the community as far as possible. KNCHR did a report on mental health whose recommendations should also be considered and acted upon as appropriate.

The review of the Act may provide an avenue for initiating dialogue with traditional and faith-based healers who complement the formal mental health care system.

Recommendations to the Ministry of Labour, Social Security and Services, National Council for Persons with Disabilities and the Ministry of Information, Communication and Technology

14. The state should ensure that information on available services for persons with disabilities is accessible. Interviews revealed that people simply did not know about the availability of some of the services availed by the state. Examples are the Cash Transfer Programme for persons with disabilities, and community based mental healthcare facilities. One way of ensuring that information reaches persons with disabilities is to have avenues for making information reach DPOs which can then disseminate.

³²⁶ Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship) <http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

³²⁷ Dianne Chartres, *To Investigate Supported Decision-Making Practices, Capacity Building Strategies and other Alternatives to Guardianship* (2010 Churchill Fellowship) <http://capacityrights.org/uploads/3/1/8/0/3180011/2010_chartres_dianne.pdf> accessed 4 June 2013

Recommendation to the Law Reform Commission

15. Further consultations should happen on the issue of the insanity defence, and on the response of Kenya as a country to this in light of Article 12 of the CRPD. These consultations should include DPOs, the Kenya Police Service, members of the judiciary, Department of Public Prosecutions, Prisons Department and Mental Health Institutions where persons who are found 'guilty but insane' are placed among others.

Ministry of Labour, Social Security and Services and Ministry of Education

16. Some aspects of Article 12 may require skills that are not currently widely available in the country, such as skilled communicators to establish communication, for instance with persons who require more intensive support. Article 32 of the CRPD provides for international cooperation, which is an avenue that can be pursued to establish the transfer of such skills to Kenya.

Recommendation to the National Council for Persons with Disabilities, the Kenya National Commission on Human Rights and the National Gender and Equality Commission

17. It is necessary to have effective safeguards to ensure that the measures relating to the exercise of legal capacity are not abused. A well trained judiciary that understands the import of Article 12 would be one such safeguard, and would be invaluable in resolving the more serious conflicts that may arise under supported decision-making. Communities that are aware of the rights of persons with disabilities would also serve as effective safeguards against abuse of support

measures particularly with regard to persons with disabilities who require more intensive support who may face great barriers in accessing the formal justice system. Chiefs and other leaders who are situated at the local level should also be informed about the rights of persons with disabilities, as should social workers who operate within the community. Justice Advisory Centres established under the Legal Aid Bill should also be explored should the Bill become law. The predominant view was that it is better to strengthen the existing systems to make them better able to act as effective safeguards as opposed to establishing new institutions to deal with supported decision-making.³²⁸

In conclusion, these recommendations are preliminary and not prescriptive, and there is necessary to have further discussions on the issues. It is hoped that these recommendations have shown that there are a variety of options available to ensure the exercise of the right to legal capacity by persons with disabilities.

6.1 Way forward

This research focused mainly on the voices of persons with disabilities as far as the exercise of legal capacity is concerned. The views of other relevant actors have not been captured here and hence it is important that engagements on Article 12 continue to happen with regard to other actors including families of persons with disabilities, the judiciary, members of the legal profession, healthcare professionals (including persons working in Voluntary Counselling and Testing Centres), banks and other financial institutions, leaders of faith-based organizations, etc. The legal capacity policy should be informed by a diverse range of voices, with the voice of persons with disabilities and their organizations carrying significant weight in line with Article 4(3) of the CRPD.

³²⁸ Interview with Users and Survivors of Psychiatry – Kenya (Nairobi, Kenya, 1 May 2013); KNCHR Technical Committee Meeting on Legal Capacity (Nairobi 15 May 2013)

Issues of legal capacity also affect older persons, and their views have not been captured in the research done for this paper. Hence, further consultations for purposes of effecting Article 12 in Kenya should involve older persons.

Further, issues of legal capacity may present differently in rural areas, a geographical location that was not adequately captured in the course of this research. Hence, future consultations on legal capacity should aim to hear views of people living outside Nairobi and its environs.

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Conversation with Yotam Tolub, Attorney, Bizchut - the Israel Human Rights Centre for People with Disabilities on Skype (9 May 2013)

Email from Yotam Tolub, Attorney, Bizchut - the Israel Human Rights Centre for People with Disabilities to author (5 June 2013)