



**USERS AND SURVIVORS OF PSYCHIATRY – KENYA
DAY OF GENERAL DISCUSSION ON ARTICLE 19 OF THE UN CONVENTION ON
THE RIGHTS OF PERSONS WITH DISABILITIES**

**USP-K Submission on the right of persons with disabilities to live
independently and be included in the community**

About USP-Kenya

Users and Survivors of Psychiatry Kenya (USPK) is a national membership organisation whose major objective is to promote and advocate for the rights of people with mental health issues/conditions (people with psychosocial disabilities). USPK is affiliated with the World Network of Users and Survivors of Psychiatry (WNUSP) and the Pan-African Network of People with Psychosocial Disabilities (PANPEP).¹USPK thanks the Committee on the Rights of Persons with Disabilities (the Committee) for the opportunity to contribute to the Day of General Discussions on the right of persons with disabilities to live independently and be included in the community.

A. Purpose of the submission

1. In the present submission USPK wishes to call the Committee's attention to the specifically vulnerable position of persons with psychosocial disabilities in exercising the right to live independently in the community in Kenya. USPK urges the Committee to formulate general recommendations that enable states to implement the Convention so as to ensure persons with psychosocial disabilities have the right to live independently in the community. This submission focuses on key issues of concern regarding Kenya's implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) and the impact it has on the enjoyment of other key rights guaranteed in the CRPD. USPK hopes that focusing on Kenya will shed light on the circumstances of people with psychosocial disabilities in many developing countries around the world concerning article 19.

B. General facts on persons with psychosocial disabilities in Kenya

2. According to the 2009 Census, 1 330 312 million (3.5 per cent of the Kenyan population of about 39 million people) were reported to have a

¹ Further information is available at Users and Survivors of Psychiatry Kenya <<http://www.uspkenya.com/>>.

disability.² Of this number, 60 954 female persons and 75 139 male persons have a mental disability. The census used the blanket term 'mental disability' and did not make a distinction between persons with intellectual disabilities and persons with psychosocial disabilities.

3. It is estimated that with 46% of the population of Kenya live in absolute poverty, while 56% live on less than one US dollar a day.³ It is well established that there is a link between poverty and disability; indeed the majority of people with disabilities in Kenya, including those with psychosocial disabilities live in poverty.⁴

C. The right to choose one's place of residence on an equal basis with others

4. Article 19(a) calls upon States Parties to ensure that persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others.
5. The majority of persons with psychosocial disabilities in Kenya do not exercise their right to choose their place of residence on an equal basis with others for a variety of reasons. First, many people with psychosocial disabilities are institutionalized in various hospitals in Kenya, including in Kenya's Mental Health Referral Institution, Mathare Mental Hospital.⁵ It is well documented that institutionalization leads to loss of choice and control of an individual over the individual's life.⁶ At the same time, it is difficult to pinpoint the exact number of persons with disabilities who are institutionalized in Kenya.

Recommendation: USPK urges the Committee to obligate states to collect disaggregated data on persons with disabilities, including disaggregation by disability type, gender and age.

² Kenya National Bureau of Statistics 'Number of Persons with Disabilities'
<http://www.knbs.or.ke/index.php?option=com_content&view=article&id=155:number-of-persons-with-disability&catid=112&Itemid=638> accessed 16 February 2016

³Office of the High Commissioner for Human Rights Kenya Initial Report to the CRPD Committee, 31 August 2011, CRPD/C/KEN/1 p 7,8
<http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=29>accessed 16 February 2016

⁴Office of the High Commissioner for Human Rights Kenya Initial Report to the CRPD Committee, 31 August 2011, CRPD/C/KEN/1 p 8
<http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=29>accessed 16 February 2016

⁵In February 2011, a CNN investigation revealed how people with psychosocial disabilities in Kenya are 'dumped' in Mathari Hospital, where they face serious neglect,
<<https://www.youtube.com/watch?v=gM4meNCLYAA>>accessed 16 February 2016

⁶Human Rights Council 'Thematic study on the right of persons with disabilities to live independently and be included in the community' A/HRC/28.37 Para 21
<<http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session28/Pages/ListReports.aspx>> accessed 16 February 2016

6. Under Kenya's Mental Health Act 10 of 1989, disability justifies a deprivation of liberty contrary to article 14(1) b of the CRPD. Under section 10(3) of the Mental Health Act, a person who is voluntarily admitted in a mental hospital can only leave the hospital at the discretion of the person in charge of the mental hospital concerned. Section 14 allows involuntary detention for a person who is 'incapable of expressing himself as willing or unwilling to receive treatment'. A person received as an involuntary patient may be admitted in the hospital for a period not exceeding six months which period may be extended by the person in charge for a further period not exceeding six months.
7. Section 16 of the Act regulates emergency admission initiated by a police officer, administrative officer, chief or assistant chief, each of whom is authorized to take into custody any person whom they believe is suffering from mental disorder; is dangerous to himself or to others; acts or is likely to act in a manner offensive to public decency; and any person whom the officers believe to be suffering from mental disorder and is being cruelly treated or neglected by any relative or other person having charge of him. At no point does the Act make reference to persons with psychosocial disabilities giving consent to mental healthcare, a violation of articles 12 and 25(d) of the CRPD.
8. From the above, it is clear that Kenya's Mental Health Act is a big impediment to the right of people with psychosocial disabilities to choose their place of residence on an equal basis with others. This is compounded by the lack of alternatives to medical interventions in mental healthcare.

Recommendation: USPK urges the Committee to give concrete guidelines on how to carry out de-institutionalisation from mental health institutions to community based mental health care systems in low-income countries. The Committee should also provide guidance on how best to monitor de-institutionalisation in such settings. Secondly, the General Comment on article 19 should require that states develop a range of support services tailored for use by persons with psychosocial disabilities. Further, people with psychosocial disabilities and their organisations should be closely consulted and actively involved in measures undertaken to reform mental health laws.

9. People with psychosocial disabilities in Kenya fail to exercise their right to choose their place of residence on an equal basis with others because many of the people with psychosocial disabilities in Kenya are unemployed, and live with their families in a context of

dependency.⁷Unemployment among people with psychosocial disabilities is a big barrier to independent living, because it often leads to poverty, which significantly reduces the extent to which an individual can exercise choice. Hence, while the issue of youth living with their parents is not unique to persons with psychosocial disabilities in the Kenyan context, in many cases, people with psychosocial disabilities continue to live with their families much longer than people without disabilities, given their poor employment prospects and the lack of individualized support services.⁸ Further, people with psychosocial disabilities experience heightened control over their lives by family members; this situation is worse for women with psychosocial disabilities.⁹Hence, even in contexts without widespread guardianship mechanisms, persons with disabilities continue to experience curtailed decision-making prospects, including in the choice of where and with whom to live.

Recommendation: USPK calls upon the Committee to oblige States Parties to scale up social protection mechanisms that are aimed not generally to households but specifically to persons with disabilities.

10. There is limited state spending on social protection mechanisms in Kenya. While the majority of people with psychosocial disabilities would be able to work if provided with appropriate support and reasonable accommodation, a small number may not be able to participate in the competitive labour market. Their families may also be unable to engage in economic activities due to the demands of care work.¹⁰ This context of poverty without any state support makes it very difficult for persons with psychosocial disabilities to choose their place of residence and where and with whom they live on an equal basis with others.

Recommendation: USPK urges the Committee to clarify the link between article 19 and article 28 on the right of persons with disabilities to an adequate standard of living and social protection.

11. Finally on choice of place of residence, it is important to note the relationship between article 19(a) and article 28(d) on access to

⁷E Kamundia 'Choice, Support and Inclusion: Implementing Article 19 of the CRPD in Kenya' (2013) 1 *ADRY* 49

⁸Kenya National Commission on Human Rights 'How to Implement Article 12 of the Convention on the Rights of Persons with Disabilities Regarding Legal Capacity in Kenya: A Briefing Paper' <<http://www.knchr.org/ReportsPublications/ThematicReports/GroupRights.aspx>> accessed 16 February 2016

⁹Mental Disability Advocacy Centre 'The Right to Legal Capacity in Kenya' <http://mdac.info/sites/mdac.info/files/mdac_kenya_legal_capacity_2apr2014.pdf> accessed 16 February 2016

¹⁰E Kamundia 'Choice, Support and Inclusion: Implementing Article 19 of the CRPD in Kenya' (2013) 1 *ADRY* 49

housing.¹¹ While independent living in the community does not mean merely having a house in which to live and includes many other factors, access to housing is key to the enjoyment of article 19.¹² The right to housing remains unfulfilled for many people in Kenya, with or without disabilities. Kenya has limited public housing programmes; housing development and provision remain in the hands of the private sector. The result is that low cost housing remains unavailable for the majority of low-income urban dwellers, among whom persons with disabilities are disproportionately over-represented.¹³ This affects the extent to which people with disabilities in Kenya can access the right to choose their place of residence, and to choose where and with whom to live.

Recommendation: USPK urges the Committee to elaborate on the obligations of states parties to implement the right to access to public housing programmes, with a focus on access to housing by those whose needs are most urgent and whose ability to enjoy all rights is most in peril, including persons with psychosocial disabilities

D. The right to access a range of community support services

12. Article 19(b) requires states to ensure that persons with disabilities have access to a range of in-home, residential and other community support services including personal assistance necessary to support inclusion in the community and to prevent isolation or segregation from the community.

13. In Kenya, support for inclusion in the community often comes from family, including the extended family. Increasingly, people are moving from rural settings to urban settings as a result of (among other reasons), government policies that enhance economic development in urban areas. The impact of the rural urban migration is that the natural supports that people enjoy in rural communities are disappearing, leaving people with psychosocial disabilities vulnerable to being homeless in urban settings.¹⁴

Recommendation: USPK calls upon the Committee to make a statement on the need for states to examine state policies, checking for the potential of state policies to impact negatively on natural supports that exist in the community for persons with disabilities. This would require that states involve persons with

¹¹Human Rights Council 'Thematic study on the right of persons with disabilities to live independently and be included in the community' A/HRC/28.37 Para 9<<http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session28/Pages/ListReports.aspx>> accessed 16 February 2016

¹²E Kamundia 'Independent living for people with disabilities in Kenya: Charting the way forward' in P Kenna (ed) *Contemporary housing issues in a globalized world* (2014) 159, 174

¹³E Kamundia 'Independent living for people with disabilities in Kenya: Charting the way forward' in P Kenna (ed) *Contemporary housing issues in a globalized world* (2014) 159, Page 173

¹⁴E Kamundia 'Independent living for people with disabilities in Kenya: Charting the way forward' in P Kenna (ed) *Contemporary housing issues in a globalized world* (2014)

disabilities and their representative organisations in the development of new policies and in the review of old policies.

14. In addition, family based support for people with psychosocial disabilities is usually supply driven; provided on the carer's terms rather than based on the will and preference of the individual. In part this is because Kenya does not provide incentives or any manner of compensation to families for their role as carers. Overreliance on family based support creates a context of dependency that makes it difficult for people with psychosocial disabilities to exercise choice and control not only with regard to issues arising under article 19, but also with regard to exercising the right to legal capacity as provided for under article 12 of the CRPD.

Recommendation: USPK urges the Committee to require that States Parties develop a range of state funded support services tailored for use by persons with psychosocial disabilities. Further, USPK urges the Committee to highlight to States Parties the need to raise awareness among families and within the wider society on the rights of people with psychosocial disabilities, particularly their rights to exercise choice and control over their own lives.

15. Being physically located in the community (as opposed to being institutionalized) does not equate to being included in the community. Kenya has limited states funded support services for people with psychosocial disabilities. As a result, people with psychosocial disabilities, particularly those who require more intensive support find themselves living on the margins of society. In instances where they are not institutionalized, persons with psychosocial disabilities who require intensive support are often locked up in houses by family members who experience themselves having no options.¹⁵ This isolation marks persons with psychosocial disabilities who are segregated in homes as prime targets of exploitation and abuse, including sexual exploitation.

Recommendation: USPK urges the Committee to require that States Parties ensure that community based rehabilitation in the mental health sphere is carried out in a manner that ensures participation and inclusion in the community. In this regard, there should be human rights based indicators to evaluate the extent to which community-based rehabilitation in the mental health sphere leads to participation and inclusion in the community. Further, USPK considers that it would be necessary for the Committee to provide concrete examples of interventions that should be developed by States Parties, geared towards enhancing the capacity of families to provide support to their family member with a psychosocial disability.

¹⁵World's Untold Stories 'Kenya's mentally ill locked up and forgotten'
<<http://edition.cnn.com/2011/WORLD/africa/02/25/kenya.forgotten.health/>> accessed 16 February 2016.

16. Persons with psychosocial disabilities in Kenya have set up peer support groups, in part to prevent isolation or segregation from the community.¹⁶ However, most peer support groups are privately funded, and are not available throughout the country. Further, persons with psychosocial disabilities in Kenya lack a range of support services that they may need, including 'crisis respite and planning, non-medical support to deal with altered perceptions, assistance to meet practical needs of everyday life, advocates for decision-making support and living support networks to help make connections in the community'.¹⁷

Recommendation: USPK calls upon the committee to provide further guidance on support services that are geared towards persons with psychosocial disabilities that can work in low-income settings.

E. The right to access community services and facilities on an equal basis with others

17. Article 19(c) requires states to ensure that 'community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs'. The services referred to under section 19(c) include 'education, health, vocational training and support in finding and maintaining employment, transportation'¹⁸among others.

18. In the Kenyan context, many people, disabled and non-disabled do live on the fringes of society with regard to access to community services and facilities. However, people with psychosocial disabilities do experience heightened discrimination with regard to access to community services, particularly education and employment. This is compounded by the stigma that exists in Kenyan society against persons with disabilities in general.¹⁹

Recommendation: USPK urges the Committee to clarify the obligation to establish reasonable accommodation measures to ensure that people with

¹⁶Kenya National Commission on Human Rights 'How to Implement Article 12 of the Convention on the Rights of Persons with Disabilities Regarding Legal Capacity in Kenya: A Briefing Paper' <<http://www.knchr.org/ReportsPublications/ThematicReports/GroupRights.aspx>> accessed 16 February 2016

¹⁷Human Rights Council 'Thematic study on the right of persons with disabilities to live independently and be included in the community' A/HRC/28.37 Para 9 <<http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session28/Pages/ListReports.aspx>> accessed 16 February 2016

¹⁸Commissioner for Human Rights 'The Right of People with Disabilities to Live Independently and be Included in the Community' COMM (2012) 3 <https://wcd.coe.int/ViewDoc.jsp?id=1917847#P188_14524> accessed 16 February 2016

¹⁹Office of the High Commissioner for Human Rights Kenya Initial Report to the CRPD Committee, 31 August 2011, CRPD/C/KEN/1 p 7,8 <http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=29> accessed 16 February 2016

psychosocial disabilities have access to community services, including education and employment on an equal basis with others.

F. Recommendations

In summary, USPK recommends the Committee to include in its General Recommendation the following recommendations; for States to:

- i. collect disaggregated data on persons with psychosocial disabilities;
- ii. ensure that persons with psychosocial disabilities and their organisations are closely consulted and actively involved in measures undertaken to reform mental health laws;
- iii. give concrete guidelines on how to carry out de-institutionalisation in the mental health context in low income countries, and how best to monitor de-institutionalisation;
- iv. raise awareness among families and within the wider society on the rights of people with psychosocial disabilities, particularly their rights to exercise choice and control over their own lives;
- v. scale up social protection mechanisms that are geared not generally to households but specifically to persons with disabilities;
- vi. scale up access to public housing programmes, with a focus on access to housing by those whose needs are most urgent and whose ability to enjoy all rights is most in peril, including persons with psychosocial disabilities;
- vii. examine state policies that impact negatively on natural supports that exist in the community;
- viii. ensure that states develop a range of support services tailored for use by persons with psychosocial disabilities;
- ix. establish community based mental health care systems and increasingly phase out the provision of mental healthcare in institutional settings (taking into account the connection between Article 19 and article 25);
- x. Ensure that community based rehabilitation in the mental health sphere is carried out in a manner that ensures participation and inclusion in the community. In this regard, there should be human rights based indicators to evaluate the extent to which community-based rehabilitation in the mental health sphere leads to participation and inclusion in the community;
- xi. establish reasonable accommodation measures to ensure that people with psychosocial disabilities have access to community services, including education and employment on an equal basis with others;
- xii. actively build inclusive communities including through removing barriers (including attitudinal barriers) and transforming mainstream services to be inclusive, including in rural communities; and
- xiii. Allocate budgets specifically towards implementation of article 19.

USPK would once again like to thank the Committee for its dedication and commitment towards the rights of persons with disabilities to live independently in the community, and for the opportunity to participate in the Day of General Discussion on this issue.

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