

AN ADVISORY ON REGISTRATION OF PERSONS WITH PSYCHOSOCIAL DISABILITY IN KENYA

27TH JULY 2017

INTRODUCTION AND EXPERTISE

1. Article 10 of the Constitution recognizes public participation as national value and principle for the implementation of the Constitution. Similarly, article 4 (3) of the UN Convention on the Rights of the Persons with Disabilities (CRPD) obligates States Parties to the Convention to actively involve persons with disabilities and their representative organizations in all decision-making process including in policy making and its implementation.
2. Accurate data and statistics are integral to effective policy formulation and implementation of human rights and development goals. Following its review by the Committee on the Rights of Persons with Disabilities in August 2015, Kenya launched a national action plan on implementation of concluding observation (2015-2022).¹The action plan accentuates among others the collection and dissemination of disaggregated data by age, disability and sex.
3. Similarly, the Sustainable Development Goals (SDGs) emphasizes collection and data disaggregation by disability as a strategy to ensuring no one is left behind. The SDGs and the Third Medium Term Plan (MTP 3) reinforce each other providing opportunities to address inequalities and leave no one behind. Additionally, in two years, Kenya will be conducting a national population and housing census.
4. Against this backdrop, Users and Survivors of Psychiatry-Kenya (USP-Kenya) submits this advisory on registration of people with psychosocial disability highlighting the following:
 - ❖ Challenges faced by people with psychosocial disability while registering as persons with disability,
 - ❖ Absence of accurate and concrete statistics and how this may adversely impact on addressing inequalities people with psychosocial disability face,
 - ❖ Recommendations on how to address existing gaps and calls upon implementation by the National Council for Persons with Disabilities (NCPWD), Ministry of East African Community, Labour & Social Protection (MEAL), Ministry of Health (MoH), the Kenya National Bureau of Statistics (KNBS), the Kenya National Commission on Human Rights (KNCHR) and the National Gender and Equality Commission (NGEC).
5. USP-Kenya is a Non-Governmental Organization (NGO) that was established and registered in Kenya in the year 2007.
6. It is a membership organization whose major objective is to promote and advocate for the rights of people with psychosocial disabilities (mental health conditions) in Kenya. The organization is

¹ Ministry of East African Community, Labour & Social Protection, 'National Plan of Action on implementation of recommendations made by the Committee on the Rights of Persons with Disabilities in relation to the initial report of the Republic Kenya (September 2015-June 2022).

affiliated with the World Network of Users and Survivors of Psychiatry and its African affiliate the Pan-African Network of People with Psychosocial Disabilities.

7. USP-Kenya has been operating in Kenya for the past 9 years and has transformed the lives of persons with psychosocial disabilities in Kenya especially through influencing policy and legislation, rights-based advocacy and through participatory public education programs using different media such as TV, radio, newspapers, magazines and e-platforms on mental health issues. The organization has also participated in international conferences and other forums.

DEFINITION AND OBLIGATIONS

8. 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 disability. ²Of this number, 60,954 female persons and 75, 139 male persons have a mental disability.

DEFINING DISABILITY AND PERSONS WITH DISABILITY

9. Article 260 of the Constitution defines disability to 'include any physical, sensory, mental, psychological or other impairment, condition or illness that has, or is perceived by significant sectors of the community to have a substantial or long-term effect on an individual's ability to carry out ordinary day-to-day activities'
10. The Persons with Disabilities Act 2003, defines disability 'as a physical, sensory, mental or other impairment, including any visual, hearing, learning or physical incapability, which impacts adversely on social, economic or environmental participation'.³
11. The CRPD which Kenya is a signatory ⁴to defines persons with disabilities to include 'those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.⁵

OBLIGATIONS

12. The Persons with Disabilities Act 2003, mandates the National Council for Persons with Disabilities (NCPWD) to register persons with disabilities.⁶
13. The Statistics Act 2006 mandates the Kenya National Bureau of Statistics (KNBS) to periodically conduct the population and housing census every ten years and maintain a comprehensive and reliable national socio-economic database.⁷
14. The CRPD obligates all state parties to collect statistical data, disaggregate as appropriate and use it to identify and address the barriers faced by persons with disabilities in exercising their rights.⁸

² 3.5% remain contested given the World Health Organization 2011 report provides that 15% of the world population has a disability.

³ Section 2, Persons with Disabilities Act 2003.

⁴ Kenya signed and ratified the CRPD in 2007 and 2008 respectively.

⁵ Article 1, CRPD.

⁶ Section 7 (1) (c) (i).

⁷ Section 4 (2) (d); (e).

⁸ Article 32, CRPD.

15. The national action plan on implementation of the CRPD concluding observations tasks the obligation to ensure collection and disaggregation of data by disability to a multi-sectoral body including: Ministry of Health (MoH), KNBS, NCPWD, MEAL and Disabled Persons Organizations (DPOs).

THE PERSONS WITH DISABILITIES REGISTRATION CYCLE



CHALLENGES FACED BY PERSONS WITH PSYCHOSOCIAL DISABILITY WHILE SEEKING REGISTRATION

16. People with psychosocial disability face manifold challenges while registering as persons with disability.

SOCIAL MODEL VS MEDICAL MODEL OF DISABILITY

17. Registration of persons with disabilities includes at least four stages which are entwined. Without a certified and verified medical report by the MoH one cannot be registered as a person with disability. Unfortunately, this stage remains the greatest impediment to registration of persons with psychosocial disability. While the law⁹ and the registration form for persons with disabilities clearly recognize people with mental disability¹⁰, most medical practitioners interpret it as an illness and not a disability. This has been reported in various counties including Nairobi, Kiambu, Nakuru, Nyeri and Machakos. This interpretation borrows mainly from the medical model of disability unlike the social model that interprets disability as an interaction between an

⁹ See definitions above.

¹⁰ Appendix 1

impairment and the environment. It also highly recognizes the visible disabilities such as physical, visual and hearing impairment leading to disproportional marginalization of those with invisible disability such as people with psychosocial disability.

LACK OF PROPER POLICY GUIDELINE ON THE REGISTRATION PROCESS

18. Limited or lack of proper policy guideline on the registration process specifically the medical assessment process continues to create unnecessary barriers to registration of persons with psychosocial disability. The Persons with Disabilities (Registration) Regulation, 2009 provides that no fee shall be charged while applying for registration either as a person with disability or as a representative organization of persons with disabilities.¹¹
19. Contrary to this regulation, persons with disabilities including those psychosocial disabilities incur costs at the initial stage of medical assessment. In 2015, the Kenya National Commission on Human Rights released a report on status of implementation of rights of persons with disabilities in Kenya.¹²The report identified among others discrepancies in medical assessment fee as one of challenges people with disability face. While some hospitals have waived the costs, others charge up to Kshs.1000. For people with psychosocial disability, this challenge is compounded by a restrictive order that only psychiatrists can assess and certify their medical reports despite having trained nurses in level 5 hospitals. With only 88 psychiatrists,¹³ Kenya lacks adequate human resource in the mental health sector. This restriction poses additional monetary and psychological burden to people with psychosocial disability who are forced to people to travel further to seek services in more affordable hospitals and only in those hospitals that have psychiatrists.

STIGMA AND LACK OF AWARENESS

20. Stigmatization and lack of awareness remain a key challenge to registration of persons with psychosocial disability. Most people with psychosocial disability are not aware of the registration process and others are deprived of this right by families who lock them in houses or involuntary admit them in mental institutions. Through its awareness programme, USP-K has assisted approximately 220 people with psychosocial disability secure registration by NCPWD. This is just a meagre given the total number of people with psychosocial disability as recorded in 2008 census.

DIGITIZATION OF REGISTRATION PROCESS

¹¹Regulation 4 on fees states:

- (1) Subject to this regulation, no fee may be charged in respect of an application made under regulation 3
- (2) A fee of fifty shillings shall be payable for the for issue of a duplicate copy of the certificate of registration if the original is defaced, damaged or lost and the duplicate copy so issued shall bear the words "Duplicate Copy".

¹²Kenya National Commission on Human Rights (2014), 'From norm to practice, a status report on implementation of the rights of persons with disabilities in Kenya', available at <<http://www.knchr.org/Portals/0/Reports/Disability%20Report.pdf>> accessed on 14 August 2017.

¹³ Health experts warn of mental illness crisis, Elizabeth Mereb (May 18 2016) available on <<http://www.nation.co.ke/news/Health-experts-warn-of-mental-illness-crisis/1056-3207914-4og&u9z/index.html>>

21. In the last four years, government has been investing heavily on technology to improve transparency and improve service delivery. Registration processes such as issuance of birth certificate, identity card and passports have been digitized. Despite digitization and provision of services in one stop shop-the Huduma Centre, persons with disabilities go through a tedious manual registration process. Additionally, while NCPWD has devolved some of its services to ease registration, verification of medical assessment forms can only be done by a specific officer at the national level at MOH. Persons with disabilities are therefore forced to consistently travel to check their registration unlike in other registrations where one can easily track their registration online or receive short message service (SMS). This imposes disproportional monetary and psychological costs to persons with disabilities including those with psychosocial disability.

MENTAL DISABILITY VS INTELLECTUAL DISABILITY

22. Finally, conflating of mental and intellectual disability impedes the process of maintaining accurate and concrete data of people with psychosocial disability. The NCPWD registration form treats both mental and intellectual disability as one form of disability.

RECOMMENDATIONS

THE NATIONAL COUNCIL FOR PERSONS WITH DISABILITIES

23. Review registration form and separate mental disability and intellectual disability
24. Provide a regulation on standardization of registration fee in all hospitals or waiver of the same.
25. Digitize registration of persons with disabilities and mainstream within other services at Huduma Centre
26. Together with organizations of persons with psychosocial disability, create awareness among persons with psychosocial disability and their families.
27. Specifically design a campaign that targets registration of people with psychosocial disability in communities and those in mental institutions such as Mathari Hospital.

MINISTRY OF HEALTH

28. Together with NCPWD build the capacity of doctors on the rights of people with psychosocial disability. Persons with Psychosocial disability and their representative organizations should be included in this process.
29. Devolve the verification of medical assessment reports to reduce costs, backlogs and promote availability of services within the community.
30. Review the requirements that only psychiatrists should assess people with psychosocial disability

KENYA NATIONAL BUREAU OF STATISTICS

31. Incorporate and use Washington Group short set of questions on disability in 2019 national population census in order to collect, concrete and accurate statistics on people with disabilities.
32. Ensure disaggregation of data by disability type, age, gender and geographical location in 2019 national population census.

**KENYA NATIONAL COMMISSION ON HUMAN RIGHTS AND NATIONAL GENDER AND EQUALITY
COMMISSION**



33. As the designated independent monitoring body, KNCHR and NGEC should monitor collection and dissemination of accurate and concrete disaggregated data by disability, gender, sex and geographical location.

CONCLUSION

In the spirit of leaving no one behind, USP-K calls upon the Ministry of health, National council for persons with disabilities, Kenya national commission on human rights, National gender and equality Commission and the Kenya national bureau of statistics to implement the recommendations provided in this advisory. Recognition and registration of people with psychosocial disability is integral to planning and implementation of rights of persons with psychosocial disability. Without registration persons with psychosocial disability will not benefit from affirmative action policy, tax exemption and social programmes among others.

APPENDIX 1 : REGISTRATION FORM

(ATTACH PHOTO)
NATIONAL COUNCIL FOR PERSONS WITH DISABILITIES
INDIVIDUAL REGISTRATION FORM

| Registration No. (For Official use only) | | | | | | | | | |
|--|--------------------------------------|------------|--|--------------------------------|--------------------------------------|----------|------------------------------------|--|--|
| Date of registration | Day | Month | Year | | | | | | |
| PERSONAL DETAILS (BLOCK LETTERS) | | | | | | | | | |
| A01 Full name | | | | | | | | | |
| A02 ID/Birth Certificate No | | | | | | | | | |
| A03 Postal Address (the most stable) | Box No. _____ | Code _____ | City/Town _____ | | | | | | |
| A04 Cellphone Number | | | | | | | | | |
| A05 Nationality | | | | | | | | | |
| A06 Name of next of kin | | | | | | | | | |
| A07 Relationship to next of kin | | | | | | | | | |
| PERMANENT ADDRESS/AREA OF IDENTIFICATION | | | | | | | | | |
| A08 County..... | | | | B12 Home Location..... | | | | | |
| A09 Sub County..... | | | | B13 Home Sub Location | | | | | |
| A10 Home Division..... | | | | | | | | | |
| A11 Constituency..... | | | | | | | | | |
| DEMOGRAPHIC INFORMATION | | | | | | | | | |
| A12 Sex | <input type="checkbox"/> 1 Male..... | | <input type="checkbox"/> 2 Female..... | | | | | | |
| A13 Date of birth | Day: | | Month: | | Year: | | | | |
| A14 Marital Status | <input type="checkbox"/> 1 Married | | <input type="checkbox"/> 2 Divorced | | <input type="checkbox"/> 3 Separated | | <input type="checkbox"/> 4 Widowed | | <input type="checkbox"/> 5 Never married |
| DISABILITY (Mark appropriate box. If major cause = 1, then B03 should be blank) | | | | | | | | | |
| B01 Nature of disability | B02 Major cause | | | B03 At what age? (Years) | B04 Severity of the disability | | | | |
| | By birth | Accident | Illness | | Severe | Moderate | | | |
| | 1 | 2 | 3 | | | | | | |
| 1 Albinism..... | 1 | 2 | 3 | | 1 | 2 | | | |
| 2 Physical | 1 | 2 | 3 | | 1 | 2 | | | |
| 3 Mental..... | 1 | 2 | 3 | | 1 | 2 | | | |
| 4 Visual | 1 | 2 | 3 | | 1 | 2 | | | |
| 5 Hearing..... | 1 | 2 | 3 | | 1 | 2 | | | |
| 6 Epilepsy..... | 1 | 2 | 3 | | 1 | 2 | | | |
| 7 Blind..... | 1 | 2 | 3 | | 1 | 2 | | | |
| 8 Deaf/using sign language..... | 1 | 2 | 3 | | 1 | 2 | | | |
| 9 Deaf/able to talk normally | 1 | 2 | 3 | | 1 | 2 | | | |
| 10 Other (specify)..... | 1 | 2 | 3 | | 1 | 2 | | | |

The Washington Group Short Set of Questions on Disability

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
 - a. No - no difficulty
 - b. Yes – some difficulty
 - c. Yes – a lot of difficulty
 - d. Cannot do at all

2. Do you have difficulty hearing, even if using a hearing aid?
 - a. No- no difficulty
 - b. Yes – some difficulty
 - c. Yes – a lot of difficulty
 - d. Cannot do at all

3. Do you have difficulty walking or climbing steps?
 - a. No- no difficulty
 - b. Yes – some difficulty
 - c. Yes – a lot of difficulty
 - d. Cannot do at all

4. Do you have difficulty remembering or concentrating?
 - a. No – no difficulty
 - b. Yes – some difficulty
 - c. Yes – a lot of difficulty
 - d. Cannot do at all

5. Do you have difficulty (with self-care such as) washing all over or dressing?
 - a. No – no difficulty
 - b. Yes – some difficulty