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Introduction

- 1 This is a research proposal concept that aimed at collecting comparative data on Orphaned and Vulnerable Children (OVC) with disabilities. The proposed research was conducted in a collaborative effort between the Kenya Umbrella for Children with Disabilities (KUCD) located in Makindu, Mathare Special School for the Mentally Challenged, located in Mathare Valley, the Department of Special Need Education at Kenyatta University (KU) and the French Institute for Research in Africa (IFRA). The aim of the study was to carry out a baseline survey on various OVC with disabilities in the Makindu area of Makueni County as a representative region of the rural Kenyan population, and Mathare Valley which is an urban informal settlement.
- 2 The research is in cognisance of the fact that Persons with Disabilities (PwDs) in Kenya, and in most parts of Africa, continue to face multiple forms of discrimination at home, in the community and society at large. They are faced with low quality and segregated education, chronic unemployment; poor access to public facilities and coupled with poor attitudes and limited inclusion. Most disabled persons, regardless of their age and gender, are prevented from making decisions that affect their daily lives. They experience oppression and violation of basic human rights on a daily basis. This is contrary to Section 68 of the 2010 Constitution of Kenya which spells out that PwDs are entitled to enjoy all the rights and fundamental freedoms set out in the Bill of Rights, and to be full participants in society.

- 3 The Constitution of Kenya in Chapter four on Citizenship—a general principle on the rights of every citizen as being entitled to the rights, privileges and benefits of citizenship, subject to the limits set out in the Constitution. Chapter 3 Section 13 (2) k on National Values and Culture—ensures progressive implementation of the principle that at least 5% of the members of public elective or appointive bodies shall be persons with disabilities. Such provisions in law can only be viewed and understood in the context of the development of Special Education in Kenya. The plight of children, youth and adults with disabilities in Kenya were in the past decades, seen against the backdrop of persons with visual impairments, mentally handicapped, hearing impairments and physical handicaps. Since the 1940s these dictated the development of infrastructure to support them.
- 4 Recognising and in reference to Constitution of Kenya Section 68 (2) that PwDs have a right to:
 - Respect and human dignity, including to be treated, addressed and referred to, in official or private contexts, in a manner and in words that are not demeaning or derogatory;
 - Have access to education and to institutions and facilities for persons with disabilities that are as integrated into society as a whole as is compatible with the interests of those persons;
 - Have reasonable access to all places accessible to the public, to public transport and to information and communications;
 - Use of Kenya sign language, Braille and other appropriate means of communication; participate in decision-making at all levels;
 - Have equal rights to inherit, access, and manage property;
 - Have access to materials and devices to overcome constraints arising from those disabilities; and
 - Treatment and opportunities in all spheres of life that are both fair and equal to those of other members of society.
- 5 It is envisaged that the state shall take legislative and other measures, including special provisions for women, to ensure that PwDs enjoy all these rights.
- 6 The establishment of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is a response of the international community to the long history of discrimination, exclusion and dehumanization of PwDs. In its preamble UNCRPD raises concern that, despite the various instruments and undertakings, PwDs continue to face barriers in their participation as equal members of society in all parts of the world (UNCRPD, 2006). The Convention views disability as a “pathology of society,” that is a result of the failure of societies to be inclusive and to accommodate individual differences.
- 7 Having signed and ratified the UNCRPD, Kenya is constitutionally bound by the provisions in the Convention and as such needs to facilitate independent living of persons with disability. This requires universal design and access to infrastructure and utilities. Universal design is the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design and excludes assertive devices.
- 8 Persons with disabilities are present and are the most marginalized in all societies (UN/OHCHR/IPU, 2007). Many are hidden or excluded from society, either in their homes or in institutions because of social stigma. There may be barriers such as physical, attitudinal, cultural, legal, regulatory, policy, communication that limit their

opportunity to participate in a variety of activities. Some disabilities may not be immediately apparent or visible. In all communities, persons with disabilities are denied opportunities to: School and education, Access to information; Suitable transportation system; Employment; Access to facilities; Respect and/or understanding; Accessibility to ICT Utilities by way of their design; Accessible infrastructure; Access to protection and safety; Health facilities; Cultural life, recreation, leisure and sport. Recognizing this, the World Health Organization (WHO, 2011) provides a paradigm shift in its definition of persons with disability and defines a disabled person as an “individual with an impairment that requires an accommodation to perform functions required to carry out life activities”. WHO also provides a strategy to address disability by requiring society and governments to remove barriers, create access through accommodation and universal design, and promote wellness and health. It also gives a method to address disability through provision of supports, eg, assistive technology, personal assistance services, job coach. Its provision moreover spells out the source of intervention as peers, mainstream service providers, consumer information services whose entitlements include eligibility for accommodations seen as a civil right. Finally, WHO assigns a role to an individual with disability of a consumer or customer, empowered peer, research participant, decision-maker and underscores the domain of disability as a socio-environmental issue involving accessibility, accommodations, and equity.

Rationale and Background Information

- 9 The National Council for Persons with Disabilities (NCPD) was set up in November 2004, marking a milestone in the history of PwDs in Kenya. The Council, a semi-autonomous government agency, operates under the Ministry of Gender, Children and Social Development. Its purpose was to put in place systems and structures that would ensure that the Persons with Disabilities Act of 2003 is implemented.
- 10 In 1946, the plight of children, youth and adults with disabilities attracted the attention of the then colonial government in Kenya when special schools for the blind were built followed by mental retardation facilities in 1948, the school for the deaf in 1958 and those for the physically handicapped in 1962. After independence and in 1964 the government formed the Kenya Education Commission to investigate, among other things, the formulation and implementation of national policies regarding the educational needs and capacities of children and assess the monetary and human resources required to service those needs. The Commission was to also look at the care and rehabilitation of the disabled in the country.
- 11 The early efforts made by the Government of Kenya in accommodating her citizens with disabilities were further enhanced through the enactment of the Disabilities Act of 2003. The Act in Article 12 (1) criminalizes the denial of access to opportunities for employment to Persons with disabilities. It further states in Article 12 (2) that the same conditions of employment shall apply to such category of persons. Article 13 (2) exempts persons with disabilities from all tax accruing from self, formal, or informal employment. The rationale behind this provision lies in the fact that persons with disabilities incur extra costs arising from their disability. Under the same article the National Council for Persons with Disabilities (NCPD) is mandated to take affirmative action and secure the reservation of 5% of all employment opportunities including

casual, emergency and contractual employment in both public and private sectors to persons with disabilities.

- 12 Presently, however, cases are reported of employers or recruitment firms failing to interview PwDs on account of their disabilities. Most of them give an excuse of lack of expertise and facilities to accommodate them in the workplace. In addition, Kenya has few, if any human resource practitioners specially trained in disability and access to the workplace environment. The Persons with Disabilities Act of 2003 outlaws denial of employment for lack of facilities. A barrier-free and disability-friendly environment is a right under the Act. In order to ensure full access to employment, the Act provides for tax exemption of 25% of total amount paid per each employee or apprentice with a disability. It further gives 50% tax exemption on any modification made towards reasonable accommodation for the employee.
- 13 In a quest to compensate years lost in school and late inclusion into society, the Act proposes that the retirement age for PwDs be sixty years. Recently, the retirement age for public servants has been raised to 60 years. Suggestions have been made as to amend the PDA to provide for the retirement of PwDs at age 65.
- 14 The National Council for Persons with Disabilities (NCPD) commits to carry out its functions in ways that best serve the interest of persons with disabilities through:
 - formulating and developing measures and policies designed to achieve equal opportunities for persons with disabilities
 - cooperating with the government during the national census to ensure that accurate figures of persons with disabilities are obtained
 - issuing orders that require the adjustment of buildings that are unfriendly for use by persons with disabilities
 - recommending measures to prevent discrimination against persons with disabilities
 - encouraging and securing the rehabilitation of persons with disabilities within their own communities and social environment
 - registering persons with disabilities and institutions and organizations giving services to persons with disabilities
 - raising public awareness regarding persons with disabilities.

Participating Institutions

- 15 Kenyatta University (KU) collected scientific data through a multi-disciplinary team that addressed issues such as: Identification, prevalence and causes of disabilities among OVC; Oral testimonies and case stories of OVC with disabilities and the psychological implications of the same; Cultural and social biases against OVC with disabilities; Spatial mapping and environmental issues related to OVC with disabilities among other emerging issues.
- 16 KU is a public entity mandated to undertake capacity building, research and community outreach. In executing this mandate, the university brings together researchers, stakeholders, communities, NGOs, Donors, Governments, the private sector and other actors to solve problems affecting society. Through strong and appropriate synergy and collaboration with the mentioned stakeholders the university has what it takes to pursue the objective of a consultancy on the magnitude of a national scale. The diversity of her training programmes in sociology, counselling psychology, gender and development, special needs education and health among others

gives the university the locus to investigate, assess and propose solutions to a diversity of challenges affecting the society.

- 17 Kenya Umbrella of Children with Disability (KUCD) acquired data collection skills from Kenyatta University. The staff will also be expected to implement the findings of the survey in Makindu and Mathare areas. KUCD is a Community Based Organization that was initiated way back in 2008 and was officially registered under Ministry of Gender and Social Services, in 2011. It was started by community members in support of the children with disabilities amongst them. This was after it was observed that they were being marginalized in the community. They saw the need for concern, care and support for them. It was registered to enable the community to empower and curb the growing number of persons with disability in the entire district.
- 18 The main concern of KUCD as an organization is to address the plight of the most vulnerable, in provision of services, health, food, awareness, child rights, HIV prevention and awareness. By 2011 KUCD had provided two wheelchairs for its members. About fifty other members have others benefited from with counselling services and information on disability prevention and awareness.

Statement and objectives

- 19 Kenya is a signatory to the achievements of the Millennium Development Goals (MDGs). The MDGs set time-bound targets by which progress in reducing extreme poverty; hunger, disease, lack of adequate shelter and exclusion—while promoting gender equality, health, education, and environmental sustainability can be measured.
- 20 However, the MDGs cannot be achieved if the persons with disabilities are not included. MDG 1 focuses on the eradication of extreme poverty which is one of the main challenges of our time, and is a major concern of the international community. Ending this scourge will therefore require the combined efforts of all governments, civil society organizations and the private sector in addressing the various issues on disabilities. This may include: Knowledge, Attitude and Practices on disabilities; Causes of disabilities, Prevalent types of disabilities; Existing intervention and rehabilitation programmes; Differences between urban and rural settings; Availability of resources; and Gender and Disabilities among others. These are the concerns of this survey.
- 21 We carried out a baseline comparative survey on the above stated areas of concern and also build capacity of the KUCD to intervene in response to our findings. This includes establishing centers for capacity building for stakeholders such as households, on issues related to OVC with disabilities in the Makindu and Mathare areas. The aim of this baseline survey was to establish levels of disability and inclusion into society of Orphaned and Vulnerable Children in the Makindu and Mathare areas. The research objectives of the study were to:
 - Determine the prevalence of various disabilities among OVC and the intervention and rehabilitation programmes and their effectiveness in Makindu and Mathare areas and make a comparative study;
 - Determine the differences in disabilities in urban and rural settings;
 - Establish the main causes, knowledge, attitude and practices of PwDs in these areas;

- Determine cultural and social biases and existing indigenous knowledge (witchcraft, marriage, marginalization, genetic transfer, education, health and poverty) of PwDs in the areas;
- Establish the number of Educational and Assessment Centers for PwDs and their trained staffing and effectiveness;
- Determine the effectiveness and availability of Instructional, Learning and Assistive materials and their psychological implications on persons with disabilities;
- Carry out a Training Needs Assessment and establish a capacity building service on disabilities for all the stakeholders key among them KUCD.

Justification

- 22 According to the AFUB (2007) and GoK (2003), the total number of people with disabilities in Kenya is estimated at 3,280,000 people, which reflects the global average of 10% (WHO, 2011). According to the World Bank, 20% of the world's poor are disabled people. At a poverty level of 56% of the population the living conditions of the disabled persons in the country raises many concerns. Kenya, through the social pillar of Vision 2030 (GoK, 2007) started implementing a welfare system to support sectors of the population who are less advantaged such as those who are unemployed, aged or have disabilities. In addition, the Ministry of Education has adopted an integration policy, which provides that children with physical and mental disabilities be placed in normal schools.
- 23 The study served to document the level of implementation and impact of such government programmes using Makindu and Mathare Valley as pilot project sites especially with regard to the right to make decisions on issues affecting their lives. Special attention was paid on the level to which the barriers and obstacles faced by PwDs affect their dignity, autonomy, equality and inclusion.
- 24 NCAPD (2008) reports that over the years, Kenya has unsuccessfully attempted to determine the disability status through national censuses and studies by civil societies, non-government organizations and government.
- 25 This study fed into evidence-based data on the nature and extent of disabilities as well as other factors that affect PWDs in Makindu and Mathare Valley.

Methodology

Data collection

- 26 The task entailed conducting of comparative baseline survey on disability in order to provide information to guide in mainstreaming disability among OVC in Kenya with a pilot project in Makindu and Mathare areas. The task called for the application of an Action research method and approach. Given the nature of the areas of focus, the consultants therefore utilized a highly participatory method to collect qualitative and quantitative data and information. The specific methods used in the exercise are outlined below.
- 27 Secondary data was collected through an intensive desk study. This was conducted through a review of relevant documents from District headquarters involving; Assessment and placement of children with disabilities, Intervention and Rehabilitation

programmes in the selected areas, possible causes if available from local hospitals and Health centers; PwDs' in-school and out of school. The analysis paid particular attention to disability responsiveness of all the policies including those related to engagements and representation of children and youth with disabilities in local organizations and employment.

- 28 Other documents reviewed included current strategic plans and operational manuals. This information formed part of the secondary data that was part of the baseline report.
- 29 Primary data was generated mainly from the staff in the administrative headquarters, administrative staff and staff in hospitals and schools including persons working with children and youth with disabilities. In order to gather this information, the team utilized the following tools;
- 30 Questionnaire for selected administrative, medical and teaching staff. This helped elicit information on the awareness, sensitivity and responsiveness to disability.
- 31 Focus group discussion guides with selected parents, opinion leaders and the Youths and children with disabilities. The discussions helped assess the impact of knowledge, attitude and practices on mainstreaming disability activities.
- 32 Observational checklist to assist the consultants to make observation on institutional practices that have a bearing on creating awareness, sensitivity and responsiveness to disability.
- 33 A disability audit in the district was particularly useful in investigating the extent to which disability has so far been mainstreamed in terms of physical and social infrastructures.

Data Analysis

- 34 The collected data was analyzed according to: Causes; Types and Prevalence; Assessments, Placements and Interventions; Gender and Disability.
- 35 Quantitative data was coded then cleaned and checked for consistency. The data analysis was then done using measures of standardization such as frequencies and percentages, measures of central tendency such as mean, mode and medium and measures of comparison such as chi square and others as the case demands.
- 36 Qualitative data was categorized, thematically classified and presented using appropriate descriptive terms and sections based on areas of concerns. The final sections of the analysis employed triangulation where quantitative and qualitative data was presented in a complementary manner.

Conclusion

- 37 At the end of this survey it was noted that:
 - Issues that have remained unaddressed through the national and other census were made visible through this pilot survey.
 - It is important that other regions and areas of Kenya require support to enable them carry similar in depth surveys to make visible challenges affecting OVC with disabilities.

- Findings generated from this survey acted as an advocacy tool for interventions from public, private and other sectors to address the plight of OVC with disabilities in Kenya and beyond.

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