A SHADOW REPORT SUBMITTED TO THE

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Emerging Concerns on Rights of Persons Living with Disabilities (PLWDs) 2011-2015

PREPARED AND SUBMITTED BY:

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A Note about the Cluster of Persons Living with Disabilities (PWDs)

- 1.1 This report has been generated as a result of consultation with various actors both individuals and organizations working on the rights of Persons living With Disabilities (PWDs). The National Union of Disabled Persons of Uganda (NUDIPU) was the convener of this cluster whose information feeds into the National Stakeholders' Forum report on UPR. The cluster of persons with disabilities began the compilation of its report by getting a training on February 15th 2016 on the UPR mechanism. This training was aimed at bringing all the participating Disabled People's Organizations (DPOs) to the same level of knowing what goes on in the UPR mechanism reporting and other processes.
- 1.2 The training was followed by a consultative process whereby the participating organizations had to provide information on the status of human rights in Uganda basing on their work and reports thereof. The reports were then read and synthesized by a small team consisting of officers from the National Union of Disabled Persons of Uganda (NUDIPU) and East Africa Centre for Disability Law and Policy (CDLP), the outcome of which was a compilation of emerging issues pertaining to persons with disabilities in Uganda as far as human rights protection by government of Uganda is concerned.
- 1.3 After deliberations among the cluster members, the following issues were agreed upon as emerging concerns for persons living with disabilities in Uganda. The report recognizes the positive aspects that have been undertaken by the Government of Uganda in the past 5 years to enhance the rights of PWDs and Minorities. It further highlights the emerging concerns and proposes recommendations aimed at improvement.

Emerging Concerns on Rights of Persons Living with Disabilities (PWDs) in Uganda -2011-2015

II. STRUCTURAL ISSUES RELATING TO THE IMPLEMENTATION OF THE RIGHTTO ACCESS TO INFORMATION

Low Budgetary Allocation to PWD issues

2.1 In Uganda, 19% of the Ugandan population is estimated to have some form of disability according to the Uganda Demographic and Health Survey (UDHS 2011) which makes it imperative to reflect the same in the national budget. The current budgetary allocations are meagre situate in only the Ministry of Gender, Labour and Social Development being allocated, Ministry of Health to cater for disability and rehabilitation, and Ministry of Education, Science, Technology and Sports given 1% of the ministry budget for special and inclusive education in the country.

2.2 Moreover, the aggregate spending (as percentage of total government spending) to the three sectors has consistently declined in the recent past. And although ministerial budget statements adequately analyze the short falls, hardly any measures are put in place to address these shortfalls or prioritize allocations to PWDs in subsequent financial years. This is further compounded by shortfalls in budgetary allocations to local Governments in charge of delivering basic essential services to PWDs.

2.3 Despite the good policies, legal environment and the accompanying strategies for disability issues, the amount of public resources directly allocated for disability programs is insufficient. There is considerable discrepancy between what is promised through government policies and what is provided for in the annual budget. The lack of funds targeted to specific issues related to PWDs has further contributed to the discrimination and marginalization of PWDs in Uganda since the policies and programmes geared towards promoting equal opportunities for vulnerable populations including PWDs are meagerly funded.

- a) At least 10% of all funds extended to Uganda as grants should go to addressing disability issues;
- b) Increase the PWDs budgetary allocation to the Ministry of Gender, Labour and Social Development, Ministry of Health and Ministry of Education, Science, Technology and Sports;
- c) Increase funding to the National Council for Disability;

d) Establish further mainstreaming of disability funding in other ministries with particular attention to Ministry of Agriculture since the sector employs a substantial number of PWDs;

Inadequate Statistics Relating to Persons Living with Disabilities

2.4 There is a lacuna in the statistics on disability in Uganda yet this is needed for research, planning, targeting and disaggregating services for persons with disabilities and decision making on policy matters concerning PWDs. This is tagged to the lack of disaggregated data about PWDs from Uganda bureau of statistics, the birth and death registry, immigration department and National Planning Authority.

2.5 Measuring the disability prevalence is problematic in part due to the lack of a uniform definition of disability in the Ugandan laws, which is not even aligned to the definition in the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The Persons with Disabilities Act (2006) defines disability as "a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environmental barriers resulting in limited participation". By defining that the impairment must result in "a substantial functional limitation of daily life activities of daily life activities", this definition falls short of the notion enshrined in the CRPD, which makes no qualification for impairment. There are more examples of attempts to define disability in the Ugandan laws that must be harmonised, say the National Social Security Fund Act (1985), the Workers Compensation Act (2000) and the Employment Act (2006).

2.6 Urgent action is needed to improve the coverage, quality and transparency of data, and to ensure that there is nationally representative evidence on the burden and specific vulnerabilities and needs of Persons with disabilities on which to base policy decisions to promote their wellbeing.

- a. Harmonize the PWD definitions from the different laws to comply with the CRPD comprehensive understanding of PWDs to avoid exclusion;
- b. Design and disseminate a uniform data collection/data tracking tools criteria in government Ministries Departments and Agencies to track uniform data on disability. PWDs should be participate effectively in the design and utilization of the tools;

- c. Undertake a national comprehensive study/baseline survey to establish the current status of disability;
- d. Take steps to include Disabled Persons Organizations (DPO) in the design, implementation, compilation, monitoring and evaluation of the census with a focus on ensuring questions on the identification and situation of persons with disabilities through a rights based perspective. Ensure training on the rights of persons with disabilities and including communication and accessibility of census takers with the participation of DPOs.
- e. Systematically collect data disaggregated by gender, age, type of disability, ethnicity, urban/rural population etc. across all sectors (e.g. education, health, access to justice, legal capacity, violence, employment, institutionalisation, housing, political participation, social protection, poverty reduction, gender equality, sustainable energy, climate change etc.) necessary for optimizing and improving the various services facilitating effective decision making, and conduct training for staff of the Uganda Bureau of Statistics and National Planning Authority (NPA) on disaggregation of data concerning persons with disabilities, necessary for optimal UN human rights instruments implementation and monitoring as well as implementation, monitoring and reporting of the SDGs.

Rights of Women Living with Disabilities

2.7 Discrimination faced by women with disabilities is still widespread. **Within the My Story My Rights project framework**¹ both women and men with disabilities report discriminative attitudes and abuses they experience from service providers, governmental representatives and communities. However, women with disabilities are disproportionately affected; abusive attitudes on a daily basis very often lead them to become victims within the community and within the family/clan circle. The sense-making sessions of the project "My Story My Rights" showed that women are twice more abused or exploited by their family or community members:

- A. Around 30% of female responses in regard to the barriers they experience in their daily lives come for "Negative Attitudes of Others",
 "Abuse/Violence/Exploitation" and "Exclusion";
- B. Women with mental disabilities experience very often abuse and discriminative attitude being under guardianship. They become delegitimized

¹ This is a project that focuses on the experiences of PWDs with particular regard to their human rights and in relation to various articles of the CRPD. The project is in line with the obligations enshrined under article 33(3) of the CRPD which is to the effect that 'civil society, in particular PWDs and their representatives shall be involved and participate fully in the monitoring process'.

by their guardians and they lose their legal right to exercise choice and control over their bodies, as well as autonomy and decision-making. During sensemaking sessions it has been reported that most of people who act on their behalf do not follow their will and preferences. There is also lack of informed consent during treatment as the medical practitioners consider them as being 'mad'.

2.8 Although there is a Domestic Violence Act (2010), this law does not establish a system of mandatory reporting with regard to cases of domestic violence. Moreover, it does not specifically address itself to women and girls with disabilities. The situation is further made more precarious by societal stereotypes that discriminate in provision of education to women with disabilities, and their employability despite the fact that some are educated.

Scarcity of Assistive technologies

2.9 Strengthening self-reliance and resilience of Persons Living with Disabilities cannot be divorced from provision of assistive technologies. Uganda's commitment to improving the lives of PWDs should be viewed in its extension of and making available assistive technologies to enable PWDs earn a living and sustain themselves and their families. Currently, such technologies are expensive and cannot be easily acquired by the poor households having children with disabilities. Additionally, they are scarce and can only be imported on order which is practically impossible for the poor communities hosting PWDs.

- a) Increase funding or subsidize local companies engaged in producing or importing assistive technologies to make them affordable to the PWDs without discrimination based on financial strength;
- b) Increase funding to Research and Development (R&D) initiatives in software and hardware inventions in PWD related technologies in Uganda and also consider putting tax waivers on imports of assistive technologies;
- c) The government of Uganda should provide free assistive technology devices to learners with disabilities in primary and secondary schools as well as tertiary institutions since computer literacy has become a compulsory component of the education curriculum. The assistive technology devices being referred to here may include screen readers and screen magnifiers, alternative keyboards, speech-to-text software applications, and e-book readers;

- d) Compel by law commercial entities to adopt disability compliant assistive technology for PWDs to ease their accessibility to services provided by these companies such as Bank ATMs.
- e) Allot representation of the PWDs on the National Information Technology Authority of Uganda to represent the views of the PWDs.

Employment of Persons with Disabilities

2.10 A study done by Uganda National Association of the Deaf in 2012 found out that the Public service commission has no guidelines on employment of PWDs in regard to advertising of job vacancies, selection, interviews and induction. The same situation was reported in the District Service Commissions, where recruitment of PWDs is done at the discretion of officers there rather than following any written policy. Available practice is by exclusion with one of the grounds of termination being mental disabilities arising during subsistence of the employment. Positively the PWD Act has a chapter on disability and employment to offer guidance on the same. It is however ambiguous a law decreeing confusing centers of power to implement. Whereas Section 17 of the Persons with Disabilities Act (2006) provides that "Private employees, apprentice or learner on full time basis shall be entitled to tax deduction of fifteen percent of all payable tax upon proof to the Uganda Revenue Authority," this has since been lowered to 2%, which is no longer attractive enough.

Recommendations to Government of Uganda;

- a) Undertake a comprehensive study of labour laws with the aim of amending them to cater for the rights of persons living with disability in employment.
- b) Revise upwards the incentives given to private employers (the percentage of tax reduction) for giving jobs to PWDs;
- c) Undertake to provide reasonable accommodation (support services) to PWDs at work.

Accessibility - both infrastructural and communicative

2.11 PWDs in Uganda observe that public communication is often not disability friendly. This is evident in the absence of sign language interpreters in public meetings and on national television. Government information is also rarely availed in accessible formats like braille, large print and easy-to-read format. Many public roads are not accessible due to lack of cubs and ramps for wheelchair users, existence of open manholes that poses significant risk, and the absence of beepers at signal

boxes to facilitate the crossing of people with visual impairment. Access to public institutions, including hospitals, is often restricted due to lack of ramps, elevators with wide doors and disability friendly applications that announce the floors users are at, lack of accessible toilets (with wide doors and handles on which to hold in case of wheelchair users).

2.12 The situation is no different in the Justice, Law and Order sector (JLOS) characterized by inaccessibility to judicial facilities with absence of sign language interpreters in courts, police stations and prisons and where available it is at times defective. For instance, in one case in a court in Masindi District, the judicial officer realized that the person who had volunteered to provide sign language interpretation services in fact was not doing it properly, and decided to adjourn proceedings until accurate interpretation was procured by the person with a disability.

2.13 There is inadequacy of sign language interpreters, as well as for a mechanism of professional certification of such interpreters. There is no official professional certification of sign language interpreters in the country, which makes it difficult to suitably standardize and guarantee principles and excellence of sign language interpretation provided in different contexts.

2.14 In relation to access to information, as NUDIPU gas noted before, 'the Uganda Constitution (1995) places Sign language under national objectives rather than under substantive articles, which affects its legal enforcement. Section 21 of the Persons with Disabilities Act (2006) restricts the alternatives in which public information must be provided to sign language, Braille and tactile formats. However, there is no recognized system of communication in Uganda for people with intellectual disabilities. While the Persons with Disabilities Act (2006) and the Access to Information Act (2005) provide for access to information by persons with disabilities, national service providers lack sign language interpreters and consistency in the interpretation of the two laws. Furthermore, Television and Telephone companies are mandated under Section 21 (2) of the Persons with Disabilities, but most ICTs in Uganda are not disability friendly. E.g. the computers and telephone sets imported do not have speech software for people with visual impairments'

Recommendations:

- a. Undertake tangible steps to guarantee accessibility to persons with disabilities to all judicial facilities, including court buildings, police stations and prisons, and of all data within the justice system, including through Braille, sign language, easy to read formats, etc., as well as the establishment of procedural and age-appropriate accommodations;
- b. Conduct training, awareness raising and provide information to court staff, judges, prosecutors and staff of law enforcement agencies on their obligations to provide procedural accommodations and access to justice of persons with disabilities and, how to support them in their role as complainant, witness or defendant;
- c. Devote substantial resources into training of sign language interpreters and establish a certification system to guarantee better readiness and improved value of sign language interpretation in public services;
- d. Ratify and implement the Marrakesh VIP Treaty;
- e. Take steps to ensure recognition of Ugandan Sign Language as a legally enforceable right;
- f. Enact legislation to ensure that persons with disabilities enjoy the right of access to information, including provisions for: recognition and use of Ugandan sign language; brailling of public information, such as government documents, government newspapers and other publications;
- g. Require all television stations to provide a Ugandan sign language insert and sub-titles, on the basis of real time captioning, in all the major newscast programmes and in all special programs of national significance.

Right to Health for PWDs

2.15 Negative attitudes towards PWDs in health centres still persist: 10% of all respondents (197 in total) mentioned *'Healthcare'* as the most important theme in their stories. The most common barriers in relation to this theme are:

- *'Lack of access to medical services'*: respondents noted challenges in: provision of medical information in an inclusive way, medical workers who lack of information, knowledge, and skills on how to treat PWDs and inaccessible medical facilities.
- *'Abuse/Violence/Exploitation':* respondents noted with concern the widespread discrimination, harassment or disrespect of persons with disabilities when seeking healthcare services at medical facilities.
- *'Lack of assistive devices':* respondents cited the unavailability of assistive devices that would allow them to reach medical facilities (wheel

chair, crutches etc.), and the absence of language interpreters to facilitate the communication of a person with a disability with the medical personnel as key constraints.

• **Obsolete drugs:** Drugs for persons with mental disabilities are obsolete, recommended not any more as medical treatment. In Uganda, they continue to be used by the health sector yet they only catalyse the problem and not necessary cause healing.

The above problems have been compounded by underfunding of the disability and health budget-disability is lumped under the non-communicable diseases which is poorly funded. Some of the treatment related ointments used by PWDs to mitigate the effects of the disability are expensive and out of reach by the poor PWD communities. A case in point it the Vaseline/sunscreen oils used by albinos to deter the effects of sun rays.

- a. Expedite the enactment of the Mental Health Act;
- b. Review of all laws with a view of implementing the court ruling on use of derogatory words in relation to persons with mental disabilities;
- c. Undertake a national programme of immunization of pregnant mothers against germen measles (rubella) since it is a cause of many disabilities in children-such as deafness, blindness and deaf-blindness;
- d. Revise teaching curriculums of all heath care providers and institutions to introduce sign language and rights of PWDs;
- e. Halt the importation and sale of obsolete drugs to PWDs;
- f. Amend the Persons with Disabilities Bill in order to provide for a CRPD compliant definition of disability, which should similarly be adopted in all relevant existing laws and regulations;
- g. Urgently adopt progressive regulations in line with Article 9 of the CRPD to operationalize the Building Control Act, in close consultation and with the active involvement of persons with disabilities, through their representative organizations, as well as establishing monitoring and complain mechanisms and dissuasive sanctions for non-compliance;
- h. Amend the Public Procurement and Disposal of Assets Act to expressly incorporate accessibility standards as one of the systematic criteria for awarding construction tenders;
- i. The Persons with Disabilities Bill of 2014, which seeks to repeal the Persons with Disabilities Act of 2006 still retains significant elements of the medical model as opposed to the social model advanced by the CRPD. For instance,

although Clause 2 of the Bill refers to disability in terms that appear to reflect the social model, this definition then makes reference to a list of impairments contained in Schedule 3 of the Bill.

Right to Education and PWDs

2.16 The access to education remains one of the most important issues for youth and children with disabilities: the data from the project my Story My Rights show that around 20% of respondents (male and female) mention this theme as the most important issue in their stories. Besides, most experiences of respondents in relation to this theme are '*negative*' (63%). The barriers which the respondents experience in regard to this include;

- *'lack of access to education/accessibility':* respondents revealed that schools are poorly equipped to assess or meet their needs noting that there is low provision of inclusive educational services, lack of trained and open-minded teachers and lack of accessible buildings which are easy to access by persons with disabilities.
- *'negative attitudes of others'/'abuse, violence, exploitation'*. This barrier implies stereotyping of PWDs as being unable to study on the equal basis with other students. The respondents reported very often experiencing abuse and negative attitudes of peers or teachers during school years.
- Most of the children with disabilities reported experiencing discrimination and stigmatisation within their families and communities are hidden from the public eye so that the family could avoid being associated with the disability. In addition, the children with disabilities in schools that were visited feel unsafe and insecure because there isn't adequate protection for them.

2.17 For PWDs, the education sector is riddled with low provision of inclusive educational services, inadequate/insufficient human resource of trained and openminded teachers characterised by lack of accessible buildings which are not easy to reach by persons with disabilities. Most of the children with disabilities are hidden from the public eye so that the family could avoid being associated with the disability. In addition, the children with disabilities in schools that were visited feel unsafe and insecure because there isn't adequate protection for them.

Recommendations:

- a) Increase funding to the Faculty of Special Needs and Rehabilitation in Kyambogo University to increase skilled human resource in handling special needs learners;
- b) Increase funding for extensive research on disability and education-special needs education;
- c) Introduce special needs on the curriculum /syllabus teacher training colleges and institutions;
- d) Review the subvention grants guidelines with a view of providing appropriate allocation to schools with Persons Living With Disabilities;
- e) Review the transfer procedure of special needs education teachers to halt their transfer to schools without PWDs;
- f) Increase funding to public Universities with policies on disabilities to implement them;
- g) Provide Learning aids and assistive technology to learners at subsidized costs to ease affordability. technology devices, and training of teachers to make them disability friendly;
- h) Expedite the adoption of National Policy on Inclusive and Special Needs Education.

Political Participation rights for PWDs

2.18 Persons with Disabilities in Uganda contend that the law on election of PWDs should be reviewed so that it caters for everybody to participate in voting their representatives in parliament and Local Councils, rather than using the current system that uses electoral colleges. There should also be an increase in the representation of PWDs in government programs and institutions. Currently there are only five members of parliament for PWDs and two councilors (male and female) representing PWDs in Local Councils. On constitutional bodies, disability representation is only categorically mentioned in the law that establishes the Equal Opportunities Commission. Special groups left out include people with psycho-socio disabilities; deaf blindness etc because of non-compliance with the CRDP definition of disability.

Recommendations;

a) Review the electoral law governing electoral colleges to allow all PWDs where possible vote for their representatives in Parliament;

- b) Repeal discriminatory legislation and amend the Elections Act to eliminate restrictions of persons with psychosocial disabilities and persons with intellectual disabilities to stand for election;
- c) Ensure accessibility of all materials and information to enable persons with all kinds of impairment to effectively participate in the electoral process, including through Braille, sign language interpretation, easy to read formats, and other augmentative and alternative modes of communications;
- d) Adopt measures to encourage political parties across the spectrum to mainstream disability in their political agenda and programming;
- e) Provide sustained capacity building programmes for representatives of persons with disabilities, particularly at the district level, to improve their capacity to influence key legislative agendas to advance the rights and welfare of persons with disabilities. Modify legislation in order to require MPs and councilors representing persons with disabilities to periodically consult their constituents especially with regard to key matters requiring their input.