BASELINE SURVEY ON SOCIAL INCLUSION, ATTITUDES AND ACCESS TO SRH SERVICES FOR PERSONS WITH DISABILITIES

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UMBRELLA OF ORGANISATIONS OF PERSONS WITH DISABILITY IN THE FIGHT AGAINST HIV&AIDS AND FOR HEALTH PROMOTION (UPHLS)

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LIST OF ACRONYMS AND DEFINITION OF KEY TEMRS

AIDS: Acquired Immune Deficiency Syndrome
AKA: Akagoroba k'ababyeyi / A platform where mothers come together to share Ideas on social / economic issues & knowledge on fighting malnutrition
CHWs: Community Health Workers
CNF: Conseil National des Femmes / National Women Council
CNJ : Conseil National des Jeunes / National Youth Council
DPOs: Organizations of Persons with Disabilities
FGD: Focus Group Discussion
FP: Family Planning
HIV: Human Immunodeficiency Virus
HMIS: Health Management Information System
IEC: Information Education and Communication
LODA: Local Administrative Entities Development Agency
MIGEPROF: Ministry of Gender and Family Promotion
MUSA: Mutuelle de Santé
NCPD: National Council of Persons with Disabilities
PWDs: Persons with Disabilities
RBC: Rwanda Biomedical Council
SDGs: Sustainable Development Goals
SRH: Sexual Reproductive Health
SRHR: Sexual Reproductive Health and Rights
STI: Sexually Transmitted Infections
UBUDEHE: Social and economic classification of Rwandan households / population
UMUGANDA: Practice that takes root from Rwandan culture of self-help and Cooperation, in traditional Rwandan culture, members of the community would call upon their family, friends and neighbours to help them complete a difficult task.
UNCRPD: United Nations Convention on the Rights of Persons with Disabilities
UPHLS: Umbrella of Organizations of Persons with Disabilities in the fight against HIV&AIDS and for Health Promotion
VSO: Voluntary Services Overseas
WASH: Water Sanitation and Hygiene
WGSS: The Washington Group Short Set of Disability Questions
WHO: World Health Organization

EXECUTIVE SUMMARY

Sexual and Reproductive Health and Rights (SRHR) encompass the right of all individuals to make decisions concerning their sexual activity and reproduction: free from discrimination, coercion, and violence. Specifically, access to SRHR ensures individuals are able to choose whether, when, and with whom to engage in sexual activity; to choose whether and when to have children; and to access the information and means to do so.

The SRHR Baseline Survey on knowledge, attitudes and behaviours of youth with disabilities in accessing SRH services was conducted by UPHLS team of experts, in Rwanda between February and April 2019 at grass root level in four regions of Rwanda. The purpose of the study was to develop a baseline on disability and SRHR to support UPHLS advocacy approaches with strong evidence based strategies in regards to national health policy framework that have to be inclusive of persons with disabilities.

The baseline had a main objective of assessing knowledge, attitudes, behavior and practice on SRH services among Persons with disabilities in Rwanda. The study was conducted in 12 districts of Rwanda based on regional balance (Rusizi, Nyamasheke, Karongi, Ngororero and Rubavu Districts in Western Province; Musanze and Gicumbi District in Northern Province; Nyagatare District in Eastern Province, Huye, Gisagara, Nyaruguru and Nyamagabe Districts in Southern Province), using qualitative method as follows: (i) Focus Group Discussions (FGDs) administered on 144 young people with different forms of disabilities and (ii) 12 Key Informant Interviews with opinion leaders at district and sub-district levels including health centers.

CONTEXT

The United Nations have put in place the Convention on the Rights of Persons with Disabilities (UNCRPD) which serves to protect, to respect and to promote their rights throughout the world1. However, there is still some way to go in terms of translating the convention into actual facts.

The government of Rwanda has put in place a law protecting persons with disabilities. The Article 1 stipulates that without prejudice to provisions of this law, there may be instituted particular laws protecting persons who are disabled due to various circumstances. The following article stipulates that disability shall mean the condition of a person's impairment of health ability he or she should have been in possession, and consequently leading to deficiency compared to others. And a disabled person is any individual who was born without congenital abilities like those of others or one who was deprived of such abilities due to disease, accident, conflict or any other reasons which may cause disability[2].

Universal access to sexual and reproductive health (SRH) is key to improve the quality of life for everyone. Inequalities between communities still persist and are considered an "unfinished agenda" and a challenge to the attainment of the Sustainable Development Goals (SDGs), particularly those targeting health security and reducing inequalities among persons with disabilities. SDG target 3.7: by 2030, ensure universal access to sexual and reproductive health care services, including services for family planning, information and education, and the integration of reproductive health services into national strategies and programmes. SDG target 5.6: ensure universal access to sexual and reproductive health and reproductive rights as agreed in accordance with the Programme of Action of the International Conference on Population and Development and the Beijing Platform for Action and the outcome documents of their review conferences[3].

Rwanda made commitment during the London Global Disability summit in 2018 to Tackling stigma and discrimination – commitments that includes greater legislation at national level;

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[1] Convention on the Rights of Persons with Disabilities
[2] Law N° 01/2007 of 20/01/2007 relating to protection of disabled persons in general
[3] Fact sheets on sustainable development goals: health targets. WHO, 2017

quotas on representation and visibility of people with disabilities; and high-profile media campaigns.

UPHLS seeks to address the denial of human rights of persons with disabilities in Rwanda. It aims to legitimize the SRH needs of disabled persons as rights holders as declared in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Its role in strengthening SRHR include the use of UNCRPD and Rwanda reproductive health policies as tools for our advocacy to ensure human rights of disabled persons are recognized in Rwanda by ensuring that all national SRH programs and policies reach and serve disabled persons for social inclusion by SRH programs designed to reach the general community especially in rural area.

1 INTRODUCTION

The baseline study report gathers evidence on SRH and identifies major gaps in SRHR knowledge / attitudes/ behavior among PWDs, which will be used for evidence-based advocacy and policy engagement. The study explored SRH vulnerabilities and needs for young people with disabilities, experiences of accessing SRH services and what access challenges they face within the community. Girls, boys, young women and men with disabilities between 15 to 35 years with physical, intellectual / mental disabilities, visual impairment or hearing impairment were engaged in the study.

During the baseline survey, we adopted a qualitative peer-to-peer approach to explore the sensitive nature of the survey topic, with focus group discussions (FGDs) engaged to gather information on overarching themes and general experiences young people with disabilities had in relation to SRH and access to services and products.
Between 6 and 12 informants with similar types of disability, closer age groups, and/or gender were invited for focus group discussion (FGD). Measures were taken to ensure that FGDs and interviews are organized in accessible locations & with Sign language interpreters whenever necessary.

2 AIM OF THE STUDY

The main objective of the baseline survey was to assess knowledge, attitudes, behavior and practice on SRH services among youth with disabilities in Rwanda.

3 METHODS

Data collection

Based on the information gained through the comprehensive document review, the data was collected using individuals' interview guide at National, District and Sector level; focus groups discussion at community level and observation. The in-depth interview was used to explore in detail the key informant's own perceptions and accounts. These interviews resembled conversations, although they focused on the researcher's needs for data. They

differed from everyday conversation because we were concerned to conduct them in the most rigorous way we can in order to ensure reliability and validity. These interviews used an open-ended, discovery-oriented method, which allowed us to deeply explore the respondent's feelings and perspectives on the subject.

Questions were worded so that respondents expound on the topic, not just answer "yes" or "no." We used active listening skills to reflect upon what the speaker is saying and we tried to interpret what is being said and seek clarity and understanding throughout the interview. Interviews were typically audio-recorded and complemented with written notes (field notes taken by the interviewer). Written notes included observations of both verbal and non-verbal behaviors as they occur, and immediate personal reflections about the interview. These in-depth interviews involved not only asking questions, but systematically recording and documenting the responses to probe for deeper meaning and understanding. Both the researcher and the users of the findings will be as confident as possible that the findings reflect what the research set out to answer, rather than reflecting the bias of the researcher.

Questionnaires

The Washington Group Short Set of Disability Questions (WGSS) was used prior interviews with all targeted informants. The individual questionnaire and focus group guide were used to collect data on attitudes and knowledge of decision makers, local authorities in targeted Districts, services providers, community members, families and care givers as well as persons with disabilities themselves on social inclusion, attitudes & access to SRH services. The questionnaires contained open-ended questions and have been piloted to identify if the questionnaires are well structured and the reaction of respondents. The observation tools such as DISC were used to appreciate the accessibility of SRH services.

Recording/ transcribing interviews

Whenever necessary a transcriber was used to write notes at the same time as the interviewer was speaking and used audiotape when necessary (whenever an audiotape was used the respondent's prior permission was sought).

Sample size

The sampling method used in this study is the Purposive sampling. We grouped participants according to preselected criteria relevant to our research question. A Sample size of 120 participants was chosen for this study, this sample size depended on the research topic and potential respondents, resources and time available.

Ethical aspects

As researchers, we have responsibilities to our research participants and the persons to whom we will present our findings. We have considered the following principles:

- Respect the rights of the individual
- Beneficence (doing good)
- Not doing harm
- Justice (particularly equity)

The context in which we were working in, and the aim of our research was carefully considered. UPHLS informed local authorities in writing about the survey before the start of field work. We considered writing consent form whenever it was found to be relevant and we ensured confidentiality (data collectors' maintained clear boundaries between what they were told by participants and what they told the participants). The ways in which confidentiality might be breached were carefully considered before data collection begun and explicit strategies were put in place for protection.

4 RESULTS

4.1 KNOWLEDGE ABOUT SRH AND DISABILITY

During the baseline survey, the following has been identified in terms of knowledge about SRH and disability:

- Apart from youth with intellectual disabilities and some special cases with the blind and the deaf, other groups of youth with disabilities (males and females) in schools, self-help groups or Paralympic sports clubs (like Umutara Deaf School in Nyagatare District, cooperative called "COOPAP Nyange" in Musanze District, Gicumbi Stars in Gicumbi District, Nkanka Deaf School in Rusizi District, Twisungane Simbi in Huye District, etc.) have basic information on reproductive system, family planning, HIV&AIDS, Condom use, preventing early pregnancies, puberty stage, hygiene, antenatal and postnatal care, etc.
- Youth with disabilities (males and females) out of schools have limited information on SRH and they reported sexual education within family being a taboo to be talked about for most of their parents;
- Youth with intellectual disabilities consulted together with their care givers (like those in Center called "Wir Fur Rwanda" in Gisagara District and those in Ineza Kabaya in Ngororero District) have shown very limited information on SRHR;
- During the baseline survey, all the engaged groups of youth with disabilities had no idea on SRH related policies and its engagement process

4.2 AVAILABILITY, ATTITUDES AND USE OF SRH SERVICES BY YOUTH WITH DISABILITIES

The following services are available at the visited health centers:

- Some components of Sexual and Reproductive Health services are available at the health center like Family planning, HIV voluntary counselling and testing, Condom distribution, etc.
- Community health workers provide information on family planning to the community (especially to mothers) and they refer to health centers those in need;

Note: Family planning services provided at the Health center depends on the nature of the center, if it is a faith based center like those managed by Catholic Church, they only provide

natural family planning methods. Modern contraceptive methods are provided in other health centers.

Services mostly provided at the visited health centers include:

- Short and long-term contraceptive methods;
- STIs (Sexually Transmitted Infections) and HIV education, information, counselling, prevention, care and treatment;
- Information, education and communication on menstrual cycle in youth corners;
- Referral for further diagnosis and treatment

Health centers are not capturing disability disaggregated data in SRH or any other services because their supervising entities are not requesting it and, with no related indicators in health management information system to report to.

Very few Persons with disabilities are using health services at visited health centers and some data can be captured using RBC HIV registers which are not also used on regular basis. When asked to estimate, Heads of visited health centers estimated persons with disabilities served at health center to be less than 1% of the total population served in the catchment area of the health center. Physical and mental disabilities are the mostly received categories at the health centers.

Note: Some healthcare providers reported that they try deciding for deaf people when they can’t understand what those clients are asking about.

Through information shared by Community Health Workers or Health Centers, young mothers with physical disabilities who have access to family planning (FP) services are empowered to make lifesaving choices such as delaying motherhood, spacing pregnancies and avoiding unintended pregnancies.

Following are some of the challenges faced by PWDs in accessing SRH services:

- Youth with disabilities engaged during the baseline survey in Gicumbi, Gisagara and Ngororero Districts reported the lack of appropriate care for persons with mental health issues and adapted referral mechanisms to SRH services;
- No budget is allocated to disability friendly SRH services provision at visited health centers

- All visited health centers lack disability friendly training & IEC materials on SRH, they had just IEC materials for general population;

Local authorities report the following challenges that are limiting PWDs to access health services SRH included:

- Physical challenges in accessing health services, public institutions and facilities especially for wheelchair users and those with limited mobility;
- Lack of assistive devices (e.g. white canes, crutches, hearing devices, etc.);
- Limited rehabilitation services (and where those services are available you find the cost to be expensive to persons with disabilities most of whom are very poor);
- Many persons with mental problems without support or hard to reach people in SRH especially in the following visited Districts: Gicumbi, Gisagara, Nyaruguru, Nyagatare and Rusizi Districts
  - The Health Promotion and disease prevention Officer at Rusizi District shared an issue of poor mind-set of some community members thinking that mental health don't need medical intervention;
  - He goes on with another issue of people with mental disabilities in the District with no personal identification and no known address;
  - The Director of Health in Gisagara District said that, sometimes people with mental disabilities get impregnated without their consent and that is most of the time identified late for appropriate care / follow up and, added that we lack skills on how to care for them things become worse. Their follow up is so complicated!
- Lack of transportation means for wheelchair users (most wheelchairs used by persons with physical disabilities are not convertible to fit in public buses);
- Communication barriers (especially for the deaf);
- Lack of disaggregated data on disability and SRH but some cases recorded like in Gisagara Districts include high mental illness & physical disabilities
- The Director of Health in Nyamagabe said that youth are not using SRH services in general due to fear, low self-esteem, not seeing importance of SRH, etc.
- The Director of Health in Nyamasheke Districts added that the use of SRH services is still low in the general population. So that can be worse among youth with disabilities due to additional barriers faced but, unfortunately the lack of data on disability and SRH can't allow people to measure that;

- The Health Promotion and Disease Prevention Officer in Rusizi District reported that the lack of structures to capture disaggregated data on disability in health services is limiting them to know how persons with disabilities are accessing or using SRH services;
- Local authorities that were interviewed during this study share same views on the need of collecting data on disability and SRH for this vulnerable group of persons with disabilities in order to plan accordingly.

The following support to PWDs is reported by the local authorities in visited Districts:

- Nyamagabe District is trying to provide social support to PWDs on rehabilitation services. Example: The Director of Health reported that she has requested over 8 + 5,9 million since November 2018 from social protection's budget to cover rehabilitation services' cost for some PWDs that brought their requests to the District;
- The Health promotion and Disease Prevention Officer in Rusizi District reported that the District is providing some support to PWDs through their cooperatives and participation in Paralympic sports;
- The Director of Health in Gisagara District reported that stigma towards PWDs is decreasing in the District, awareness on disability is going on and PWDs are being prioritized at Health centers;
- The Director also reported that some development partners like Hopes & Homes are providing family support to children with disabilities;
- The Director of Health in Nyamasheke District reported that through partnership with development partners the District is supporting access to inclusive education and rehabilitation of persons with disabilities at Gatagara Center (VSO in this case), treatment of eye diseases (Fred Hollows) and all new building have to cope with accessibility standards;

Local authorities in some of the visited Districts shared also the following information:

- Disability has been considered in the development of Nyamasheke District Development Strategy and persons with disabilities have been involved through their elected representative at District level to capture their needs per area of intervention;
- The Director of Health in Nyamagabe District said that the District has seen the need to include PWDs in development programs but it seems that the community has not yet captured it as a priority (the example given here is when the community is consulted to determine which social / economic category to put in the population and you find PWDs being forgotten as a priority. This has an impact on who is being selected for social protection scheme where community health insurance is provided to the most vulnerable households).

Note: Too often even programmes with the best intentions have treated persons with disabilities as a "target" – passive recipients of services. In fact, persons with disabilities constitute a significant stakeholder group that should have a place at the table whenever health programmes are planned and decisions are made. Their involvement is the best assurance that programmes will meet needs effectively

The following are channels used by local authorities to share programs' information to PWDs:

- The commonly used channel to communicate with persons with disabilities at District level is through the meeting with elected representatives of person with disabilities at different levels of local governance;
- Some programs like "Umuganda or Akagoroba k'ababyeyi (AKA)" and local authorities at cell and village levels are also used
- Community leaders, self-help groups of PWDs and Community health workers are another way of transmitting messages to PWDs

4.3 INTERNAL AND EXTERNAL FACTORS FAVORABLE & UNFAVORABLE TO INCLUSION IN SRH SERVICES

	Favorable factors to social inclusion in SRH services	**Unfavorable factors to social inclusion in SRH services**
Internal factors	- Some Districts that try to provide social support to PWDs on rehabilitation services	- Fear among PWDs to access SRH services & stigma in family; - Discrimination towards persons with disabilities by community members - Most of them living in abject poverty
External factors	- Most of the visited health centers in Nyamagabe, Rusizi, Nyamasheke, Rubavu, Musanze, Gicumbi, Nyagatare, Huye, Gisagara, Nyaruguru, Ngororero and Karongi Districts are now prioritizing outreach services / mobilization of the community on the use of long-term contraceptive methods, HIV/AIDS control, Antenatal and Postnatal Care - Sensitizing and seeking ways of motivating the youth (including those in schools) to come at Health centers during the weekend - Referring mothers going to health center for post-natal services to family planning services - Global commitments from London Disability Summit held in 2018	- Physical challenges especially for wheelchair users and those with limited mobility which make them more vulnerable due to the need of being carried to and from the health centers; - Lack of adequate / adapted SRH information, education and communication channels; - Limited social protection and lack of health insurance; - Few girls with disabilities in Sexual relationship that participated in the survey feel being used instead of getting married because of having a disability; - Other girls with disabilities feel stigmatized, not getting married or seduced because of their disabilities; - Negative attitude / limited capacity of healthcare providers on disability rights and communication barriers where special needs of persons with disabilities need to be considered like Sign Language - Some care givers of young persons with mental disabilities engaged in the baseline survey reported cases of rape - Case like that of one of member of FGD held in Ineza Kabaya had a child but no idea on whose the father due to nature of her mental health)

4.4 SUMMARY OF SRH BARRIERS AND NEEDS OF YOUTH WITH DISABILITIES PER CATEGORY OF DISABILITY

Youth by type of disability	Gender	Barriers faced by the group	Needs in SRHR
Youth with intellectual disabilities	Female	- Lack of information on SRHR - Poor social protection system - Limited or little freedom to exercise their rights in terms of SRH	- Provide IEC materials and guiding tools on SRH in line with children learning - Training on disability rights for healthcare providers - Development of comprehensive social protection system
	Male		
Youth with physical disabilities	Female	- Physical accessibility of health centers - Long queue in waiting hall - Expensive sanitary pads	- Accessibility of Health centers - Prioritization when there are long queue in waiting hall - Low cost or reusable sanitation pads
	Male	- Physical accessibility of health centers including washroom / toilets	- Upgrade of health centers in terms of physical accessibility
Youth with visual disabilities	Female	- Lack of confidentiality (especially being obliged to be accompanied by their helper) - Expensive sanitary pads	- Training on disability rights for healthcare providers - Low cost or reusable sanitary pads
	Male	- Lack of information on condom use	- Adapted training on condom use
Youth with speech and hearing disabilities	Female	- Lack of confidentiality due to communication barriers - Expensive sanitary pads	- Healthcare trained on Sign language - Low cost or reusable sanitary pads
	Male	- Communication barriers - Limited customer care	- Healthcare training on Sign language - Training on disability rights

5 RECOMMENDATIONS

Recommendations from the Healthcare providers:

- There should be mechanisms to support persons with disabilities not in category 1 of Ubudehe to get the community health insurance known as "MUSA";
- Responsible institutions should consider building the capacity of healthcare providers on disability rights and Sign language;
- HMIS and data collection registers at health centers should have indicators on disability and, get updated to capture disaggregated data on disability;
- Development partners should consider initiatives that can help to lift PWDs out of abject poverty;
- There is a need to deal with physical accessibility all over the trip chain inside the health center;
- The community should be trained on disability rights;
- Support health centers to get personal identification of persons with mental disabilities or their domicile to be traced for SRH related services and decisions that need consent;
- Responsible parties should mobilize and interest youth with disabilities to go for SRH services;

Recommendations from local authorities:

- The community should be mobilized on the rights of persons with disabilities;
- Recommendation from the Director of Health in Nyamasheke District: There is a need to set up a mechanism with skilled people knowledgeable in disability and SRH to guide health sector personnel in serving persons with disabilities and, together with local authorities they can find ways to integrate this mechanism in the national health system. That should be done in a balanced way in terms of demand and supply of SRH services;
- He goes on with the following: Learn from the youth corners at health centers and create disability friendly SRH corners at Health centers and mobilize Persons with disabilities to use them;
- The Director of Health in Nyamasheke District said also that there is a need to build the capacity of different stakeholders in terms of disability and SRH;

- The Director of Health in Gisagara District recommended that stakeholders should find ways to share information on disability and SRH as well as reinforcing partnership with the District;
- He added that development partners should support at least one health center to become a model in terms of accessibility and providing disability friendly health services (SRH included) in their minimum package of services;
- The Disability Mainstreaming Officer in Gisagara District recommended to focus on the training of the Blind and the Deaf on Sexual and Reproductive Health as well as training service providers on Sign language and disability rights;
- He said also that there is a need to support the installation of accessible / disability friendly toilets at health facilities to facilitate persons with disabilities who may be blocked to attend health centers by the fact that they will not be able to use the toilets once at the center. These toilets should serve as a demonstration for decision makers at Districts level to learn from them;
- The Director of Health in Nyamagabe District said that the youth with disabilities should be organized in order to educate them on SRH and mobilized to use the services. They shall also be assisted and followed up closely as special groups and consideration should be made to include other programs related to SRH like HIV, drug abuse, income generating, sports, etc.;
- The Health Promotion and Disease Prevention Officer in Rusizi District said that a Study on health conditions like hygiene, nutrition, etc. should be conducted among PWDs

Recommendation from youth with disabilities who participated in the survey:

- Training on SRH and intensified grassroots advocacy to reach out to PWDs in communities on SRHR;
- Disability friendly IEC materials on SRH;
- Low cost / affordable sanitary pads;
- Disability friendly SRH centers;

Recommendations from the Disability Organizations:

- UPHLS should scale up distribution of adapted IEC materials on SRH starting with all DPOs;

- NCPD should identify and provide assistive devices / rehabilitation services to most vulnerable persons with disabilities who need them so they can be able to move and go for different services including SRH;
- NCPD and UPHLS should advocate to LODA for the integration of sanitary pads into the minimum package of social protection;
- Disability actors should lobby stakeholders in SRH or WASH for the training of females with disabilities on hygiene and use of sanitary pads;
- MIGEPROF, CNF, CNJ, NCPD and disability actors should secure livelihood of females with disabilities so they can cover their SRH basic needs;
- Government should consider special social protection services for most vulnerable persons with disabilities especially those who have severe disabilities;
- UPHLS should build the capacity of DPOs in terms of SRH so DPOs can find ways to integrate SRH education under their outreach services;

6 REFERENCES

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