Disability mainstreaming toolkit

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Foreword

While the Government of Rwanda is ensuring that all development programs and plans are inclusive for all; this guide for inclusive HIV and AIDS services indicates the practical approaches to significantly promote the inclusion of Persons with Disabilities (PWDs) and accelerate the attainment of the Sustainable Development Goals (SDGs).

The guide is built based on the provisions from the Rwandan Constitution, Rwandan Legal frameworks on disability, the UN Convention on the Rights of PWDs (UNCRPD), the National Council of Persons with Disabilities' guides on Mainstreaming Disability among other relevant documents. While the guide recognizes that all health care interventions are relevant and should continue to receive support; it also recognizes that interventions should prioritize the inclusion and consideration of disability as a crosscutting issue.

This guide illustrates key challenges and practical recommendations to include PWDs and ensuring that people of Rwanda are healthy and able to contribute to social and economic development. Therefore it emphasizes strong collaboration to address all the social determinants of health with appropriate levels of commitment and support from the Government, Cooperating Partners, health workers and other key stakeholders within the Disability Movement.

I therefore, urge all the people involved in the implementation of the Ministry of Health Policies and Plans to fully dedicate themselves to the use of this guide for the inclusion of PWDs.

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Acknowledgement

It has been a pleasure to work with different personnel from the National Council of Persons with disabilities, WE-ACTx for Hope, UWEZO Youth Empowerment, Rwanda National Union of the Deaf and Rwanda Union of the Blind and others who provided a lot of information and expertise in disability mainstreaming; and participated in the whole process of developing this important document.

We are very grateful to the Ministry of Health for their collaboration, understanding, financial and technical support they are providing to UPHLS through the preparation and implementation of projects that targets disability mainstreaming into HIV response in Rwanda.

Finally, we greatly appreciate the support of Organizations of Persons with Disabilities who provided the best of their team. Many thanks go to all of you who gave time and participated in development of this document since the design process, literature review, discussions, proposed strategies to remedy the situation, etc. We hope that, by listening to your voices and words, this guide will bring positive changes in the lives of persons with disabilities.

Blaise Shyirambere, J. Gabriel M. Kayumba, Madeleine Kamayugi and Alexis Uyisabye

Executive Summary

People with Disabilities face difficulties than non-disabled Rwandan n accessing HIV and AIDS services. Despite the efforts made by the Government of Rwanda in removing barriers to accessing health services for all citizens including persons with disabilities, there are still significant gaps in ensuring full and effective realization on the desired inclusion.

It is in this framework that the Umbrella of Organizations of Persons with Disabilities in the fight against HIV and AIDS and for health promotion, (UPHLS) in collaboration with the National Council of Persons with Disabilities (NCPD), Disability member Organizations (DPOs) and other stakeholders working in HIV response, under financial support of the Ministry of Health, developed a disability mainstreaming guide for persons with disabilities in HIV&AIDS services.

The purpose of this guide is to serve as a reference for health policy makers, program developers and health care providers in health institutions and in the community in ensuring full participation of people with disabilities in HIV&AIDS services provision. This guide throws more lights on the existing provisions in the Rwandan disability legal framework and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

An in depth demonstration of challenges faced by various categories of disability have been addressed ranging from attitudinal, physical and institutional barriers that have limited access to HIV&AIDS information, unfriendly communication between health service providers and clients with communication barriers, unfriendly health equipment like consultation tables, weighing balance that cannot be adjusted to people with short stature, and wheelchair users as well as compromising privacy of people with disabilities due to involvement of third parties during their participation to HIV and AIDS services provision.

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Abbreviation / Acronyms

AIDS: Acquired Immune Deficiency Syndrome
BCC: Behavior change communication
CHMIS: Community Health Management Information Systems
COGE: Comité de Gestion
COSA: Comité de Santé
DPOs: Disabled People Organizations
FSW: Female sex workers
HC: Health Center
HIV: Human Immunodeficiency Virus
HMIS: Health Management Information System
IEC: Information, Education Communication
HSP: Health Strategic Plan
HSWG: Health Sector Working Group
HSSP: HEALTH SECTOR STRATEGIC PLAN
M&E: Monitoring and evaluation
MOH: Ministry of Health
MINEDUC: Ministry of education
MINECOFIN: Ministry of finance
MININFRA: Ministry of infrastructure
MTI: Medical Technology and Infrastructure
MUSA: Mutuelle de Santé
NCPD: National Council of Persons with Disabilities
NHP: National Health Policy

NISR:	National institute of Statistics in Rwanda
NSP:	National strategic plan
NST:	National Strategy for Transformation
PWDs:	Persons/People with disabilities
RBC:	Rwanda Biomedical Center
RHA:	Rwanda Housing Authority
RNUD:	Rwanda National Union of the Deaf
RUB:	Rwanda Union of the Blind
SDGS:	Sustainable Development Goals
SPIU:	Single Project Implementation Unit
TWG:	Technical Working Group
UNAIDS:	United Nations Program on HIV and AIDS
UNECOSOC:	United Nation Economic and Social Council
UNCRPD:	United Nations Convention on the Right of Persons with disabilities
UNRWA:	United Nations Relief and Works for Palestine
UPHLS:	Umbrella of Organizations of persons with Disabilities in the Fight HIV&AIDS and for Health Promotion
WE-ACTx:	Women Equity and Access to Care and Treatment
WHO:	World Health Organization

Background

Globally, it is estimated that 1 billion people (15% of the world's population) have a disability. Of those aged over 15 years, approximately 110 - 190 million (2.2 -3.8%) experience significant disabilities; Disability is increasing in prevalence due to ageing populations, trauma, accidents and the increase in chronic health conditions, including HIV (World report on disability, Geneva: WHO and World Bank; 2011). Persistent discrimination against and exclusion of PWDs, in particular women and girls with disabilities, increases their vulnerability, including their risk of HIV infection (Disability and HIV, UNAIDS 2017).

Overall, 446,453 persons with disabilities aged 5 and above are living in Rwanda according to the 2012 Census, out of which 221,150 are male and 225,303 are female. The count of persons with disabilities by province reflects the geographical distribution of the population in general, with the largest number being found in the Southern Province (122,319) and the lowest in Kigali City (32,170). For the same reason, the number of persons with disabilities is higher in rural areas than in urban areas. When excluding children under five, for whom the identification of activity limitations poses problems, the disability prevalence rate is 5%. There is only a small difference by gender, with a prevalence rate of 5.2% for males (aged five and above) and 4.8% for females (Social economic characteristics of persons with disabilities. 4th Population and Housing Census, Rwanda, 2012).

People with disabilities have been excluded and neglected in all of the sectors responding to HIV. HIV prevalence data among people with disabilities are scarce. Data from sub-Saharan Africa suggest an increased risk of HIV infection of 1.48 times in men with disabilities and 2.21 times in women with disabilities compared with women without disabilities. Access to HIV prevention, care, treatment and support and sexual and reproductive health and rights services is equally important, and in some cases even more important, for people with disabilities compared with their peers without disabilities. (Disability and HIV, UNAIDS 2017)

In Rwanda, HIV prevalence has been stable since 2005 and remains at 3 percent among adults age 15-49 (4 percent among women and 2 percent among men). HIV prevalence is higher in urban areas than in rural areas (6 percent and 2 percent, respectively). HIV prevalence increases with age and is highest among women age 40-44 (8 percent) and men age 45-49 (9 percent). (Final Report; Demographic and Health Survey 2014-2015, NISR, 2016)

While the Millennium Development Goals were silent on disability, the new Sustainable Development Goals feature a strong will to "leave no one behind", including people with disabilities (Trans- forming our world: the 2030 agenda for sustainable development. New York: United Nations; 2015). Similarly, the CRPD (Convention on the Rights of PWDs; New York: United Nations; 2006) calls on state parties to ensure the rights of people with disabilities to participate

and be included in all spheres of life, including specific articles relating to the right to access health services, including sexual and reproductive health, and rehabilitation services.

Including disability in HIV response requires commitment to counteract underlying inequality and discrimination across all sectors and a shift towards integrating HIV with disability and rehabilitation services. Disability as a cross-cutting issue in the response to HIV also calls for broader social, cultural and economic development that is person-centred, is disability-inclusive and addresses the unique barriers that face people with disabilities, in particular women and girls with disabilities, and people living with HIV. (Inclusion made easy: a quick program guide to disability in development. Melbourne: Christian Blind Mission. 2012)

Chapter I: Introduction

A number of questions about HIV and AIDS and disability remain unanswered. How can individuals with disabilities best be reached by HIV and AIDS Response programs? Should they be included in general AIDS outreach campaigns and services? Are special initiatives and targeted approaches needed? If so, will this entail greater expense? If there are greater expenses, where should such funding come from? Calls for the inclusion of individuals with disabilities in HIV and AIDS outreach efforts are regularly countered with concerns that HIV and AIDS activities are already stretched to the breaking point and that funding to develop new disability-specific activities is not available. (Inclusion guide of people with disabilities in HIV and AIDS response, MoH/RBC, 2012)

The UN Convention on the Rights of Persons with Disabilities (CRPD) states clearly that persons with disabilities have the same rights as all other persons. This means that persons with disabilities have equal rights to access all services, including education, health, relief and social services, microfinance, infrastructure, protection, and emergency response. To ensure persons with disabilities can claim their rights, services must be provided without discrimination, and necessary and appropriate modifications or adjustments (Disability inclusion guides, UNRWA, 2017).

Purpose, targeted audience and use of this guide

The purpose of this guide is to create a consistent understanding of key disability inclusion principles and practices; provide advice on how to mainstream disability inclusion in HIV and AIDS related policies and services; and help policy makers, planners, coordinators, monitoring &

evaluation teams, managers, services providers to operationalize provisions under the Convention on the Rights of Persons with Disabilities and Rwandan laws on disability.

Policy makers, planners, coordinators, monitoring & evaluation teams, managers and services providers should use this guide to:

- Gain a better understanding of disability and have clarity on the inclusion principles and practices.
- Better understand how to identify, interact with and assist persons with disabilities.
- Identify entry points for disability mainstreaming at all stages of the service provision.

This guide provides information about approaches to disability inclusion within HIV and AIDS response in Rwanda. This document provides tools that can be used for identifying the particular service provision needs of persons with disabilities in a health sector or context, actors can apply the principles and recommendations in this document to develop specific project and program's level actions to further enhance the inclusion of persons with disabilities in HIV and AIDS programs and services.

Understanding disability

Article 1 of the CRPD stipulates that "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers hinder their full participation in society on an equal basis with others." While "disability" is often

equated to "impairment", there is in fact a distinction between these concepts. The CRPD definition considers disability not simply as a health condition or impairment in isolation, but as the interaction of a person's impairment along with the barriers in their environment that together leads to a situation in which their full and equal participation in society is hindered.

Definition of key words and concepts

Disability:

A disability is the result of interactions of individual impairments they be physical, sensory, mental, intellectual and or psychosocial with the environmental barriers: Physical, attitudinal, social and institutional barriers.

Accessibility:

Accessibility refers to facilities to physical environment, to transportation, to information and communications, including information and communications technologies and systems that enable persons with disabilities to live independently and participate fully in all aspects of life.

Communication:

Communication includes languages, display of text, Braille,sign language, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.

Language:

Language includes spoken and signed languages and other forms of non-spoken languages;

Discrimination:

Discrimination on the basis of disability means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

Toolkit:

A set or collection of tools, supplies, instructional matter, etc., for a specific purpose:

Mainstreaming disability

Why mainstreaming?

- PWD have normal needs, not special needs: previously, idea that PWD are different, medical, need specific interventions;
- Implication of social model of disability: if society disables, then the answer is to remove barriers and include;
- Distinction from targeted or special services, which might be stigmatising, segregating, expensive, limited reach;
- Participation reduces negative attitudes, cheaper, more sustainable, does not require diagnosis / PWDs to self-identify

As borrowed from UN ECOSOC paper on gender, but substituting disability: "Mainstreaming disability is the process of assessing the implications for PWDs of any planned action, including legislation, policies and programmes, in all areas and at all levels." (Mainstreaming disability in health and development, 2011, WHO)

Disability mainstreaming is the inclusion of PWDs or the inclusion of a disability perspective in development. It aims at helping to eliminate barriers, promote equality and prevent discrimination so that persons with and without disabilities can benefit equally from development measures and interventions. Mainstreaming should not be seen as an end but rather as a process to achieve equality. It should be reflected across all sectors. A cooperation with disabled people's organisations (DPOs) as a way to build capacities and to monitor and evaluate the participation of PWDs has been proven efficient in the past. (Disability Mainstreaming
Practical Information and Advice, 2016, Austrian Development Cooperation)

Legal framework on disability

- UNCRPD: Established on 15/12/ 2006 and Ratified by Rwanda in 2008: (art 9 on Accessibility), art 25 on Health).
- Rwanda constitution (articles 16, 51,139),
- Law n° 01/2007 of 20/01/2007 relating to protection of disabled persons in general,
- Law n°02/2007 of 20/01/2007 relating to the protection of disabled former war combatants,
- Ministerial order N° 01/Cab.M/09 of 27/07/2009 determining the modalities of constructing buildings providing various public services to ease the access of persons with disabilities,

- Ministerial order n°20/19 of 27/7/2009 determining the modalities of facilitating persons with disabilities access medical care,
- Ministerial Order Nº 01/09/MININFOR of 10/08/2009 determining the modalities of facilitating persons with disabilities in matters relating to communication,
- Rwanda Building Code,
- National Disability Mainstreaming Guides

Chapter II: Disability mainstreaming in HIV related Policies

In the Rwanda HIV and AIDS National Strategic Plan 2013 - 2018, among the innovations to address challenges and sustain best practices, we have to elaborate tools for specific groups (IEC tools adapted to all types of disability, M&E tools for FSW, tools for discordant couples).

The current health care model is primarily designed for the "average person", and thus presents significant barriers for persons with disabilities in terms of access to appropriate services since they do not fully comply with what are considered "normal standards". In addition, although persons with disabilities are not and do not consider themselves unhealthy, in many cases they require specific, regular and more intense health care assistance than other citizens. The health system does not seem to meet the needs of persons with disabilities, which can vary considerably according to the type of impairment or severity of disability. In many cases, the disability is not even taken into account because health care professionals do not know how to deal with it. (Disability mainstreaming guides "for a Rwandan empowering and inclusive society", 2014, NCPD)

Rwanda started the process of inclusion of PWDs in the policies and programs. Particularly efforts have been made in HIV&AIDS programs and policies. However little efforts have been done in terms of policies and programs to include PWDs .

The following has been realized so far:

- Art 139 of the constitution recognizes the rights of Persons with disabilities
- Establishment of the National Council for Persons with Disabilities
- Ratification of CRPD in 2008 and ensures its domestication
- Ministerial order N°20/19 of 27/7/2009 determining the modalities of facilitating PWDs access medical care
- Categorization of PWDs conducted to provide data and rights of PWDs as per the law
- Ministerial order N°20/19 of 27/7/2009 determining the modalities of facilitating PWDs access medical care
- Categorization of PWDs conducted to provide data and rights of PWDs as per the law

Challenges / gaps in policies and proposed strategies

The field of HIV/AIDS and disability is rapidly developing, but the majority of HIV/AIDS policies, guides and programs is still missing directions, resources and commitments to ensure the related interventions are disability inclusive.

Challenges	Proposed strategies
Apart from considering disability in a medical / individual model, there is a lack of clear guidance on disability mainstreaming in Rwanda HIV and AIDS National Strategic Plan and 3rd Health Sector	Disability being complex and the interventions required to overcome disability disadvantages are multiple, systemic, and vary depending on context, it should be considered as a cross-cutting issue in the Rwanda HIV and AIDS National Strategic Plan.
Currently, most health financial systems only cover a limited range of technical aids and health products – in some cases, even the most essential ones are not funded – designed to increase the independence and social participation of persons with disabilities.	Enforce disability related laws and setting up systems to facilitate the financing of special medical treatments (like the provision of all necessary assistive devices and other disability related health needs).
Health sector policies lacks data on disability	MoH in collaboration with NISR and NCPD should avail data on disability and HIV/AIDS

Challenges	Proposed strategies
Limited capacity of health professionals in providing disability friendly health services	Disability Mainstreaming should be taken into consideration in curriculums for health Professionals to be
Lack of mechanisms to monitor and evaluate the inclusion of PWDs in the implementation of health policies	❖ Ensure national HIV and AIDS M&E system has necessary resources to measure the inclusiveness PWDs in HIV response ❖ Strengthen monitoring mechanisms and enforce rights of PWDs
The community based health insurance policy implementation does not consider the ministerial order (N°20/19 of 27/7/2009)	Responsible parties should ensure enforcement of disability laws and ministerial orders (e.g. ministerial order N°20/19 of 27/7/2009) as well as setting up strategies for their implementation in an accessible way for all types of disability

Challenges	Proposed strategies
Limited consideration of UNCRPD and ministerial orders' provision on disability in the development and implementation of health sector policies (2015) and NSP (2013 – 2018)	Responsible parties should consider UNCRPD, laws and Ministerial orders' provisions on disability in the elaboration and implementation of health policies and strategies.
Inadequate health facilities / inaccessible services, materials / infrastructure to facilitate PWDs	MOH, MININFRA and other responsible parties to ensure accessible services and infrastructure as stipulated in Ministerial order N°20/19 of 27/7/2009 and in Rwanda housing code. Such as adjustable beds, ramp for wheelchair users, sign post, handrails, tactile floors for the blind, accessible toilets, etc.
Protocol for disability friendly services in district hospitals not yet developed as stipulated in health sector policy 2015	Develop and implement the protocol for disability friendly services for all types of disability.

Chapter III: Disability mainstreaming in programs / projects' planning, coordination, monitoring and evaluation

According to UNCRPD motto slogan " nothing for us about us without us" the inclusion of persons with disabilities in health programs will help to promote the rights of persons with disabilities and ensure the socio economic status of PWDs. Despite some of the initiatives, the table below shows the challenges and proposed recommendations to ensure effective and efficient inclusion of PWDs at institutional level.

Challenges / gaps in policies and proposed strategies

Challenges	Proposed strategies
Limited capacity of planners on disability mainstreaming	Capacity building and awareness raising on disability mainstreaming for planners
Lack of data on disability and HIV	MoH in collaboration with NISR and NCPD should avail data on disability and HIV/AIDS
Limited availability of disability friendly tools, materials and equipment in health settings.	Build the capacity of procurement and finance departments of health institutions on disability mainstreaming
Most drug notices of medicines including condoms procured are not accessible to the blind	Responsible parties should ensure procurement / availability of medicines and condoms with consideration of their accessibility to PWDs. Ex: Notice with Braille options.
Lack of M&E mechanism to monitor the inclusion of PWDs in the implementation of HIV response	Establish M&E mechanism to monitor and evaluate the inclusion of persons with disabilities in HIV response

Challenges	Proposed strategies
Some data collection tools do not capture data on disability.	Disability being a crosscutting issues, there should be an adaptation of all data collection tools to capture data on disability
No consideration of disability as a crosscutting issue in HIV&AIDS planning and program implementation as stipulated among the crosscutting areas in the NST from which the HSSP IV is drawn.	Disability should be considered as a cross-cutting issue in HIV&AIDS planning and program implementation
The Ministerial Order provisions on mutual health insurance for PWDs is not implemented equitably	MoH should ensure full and effective implementation of Mutual health insurance provisions for PWDs as stipulated in the ministerial order

Challenges	Proposed strategies
Lack of disaggregate Data on disability and HIV	Adapt HMIS and data collection tools used by the service providers to capture disaggregated data on disability
Limited provisions for specific teaching and learning resources on HIV and AIDS for PWDs	Add specific teaching and learning resources on HIV&AIDS for PWDs to all capacity building initiatives targeting HIV&AIDS service providers
Some health facilities are not complying with what is stipulated in the Rwanda building code of 2015 (by the RHA)	Responsible parties should ensure that all health facilities are complying with the provisions in the 2015 RHA building code
No clear disability mainstreaming mechanisms to implement, monitor and evaluate HIV/AIDS policies & programs	Public servants should elaborate clear mechanisms to monitor and evaluate the inclusion of persons with disabilities in HIV response.

Chapter IV: Disability mainstreaming in services provision at Health facilities

Persons with Disabilities are among most vulnerable categories that need specific assistance according to their type of disability, therefore special consideration is needed. This section describes how PWDs should be mainstreamed in service provision at health facilities.

Lack of expertize among health care providers in HIV&AIDs, community health workers and other professional in the provision of health services to different categories of persons with disabilities is challenging. For instance, health care providers are not able to communicate effectively with the deaf due to lack of sign language skills.

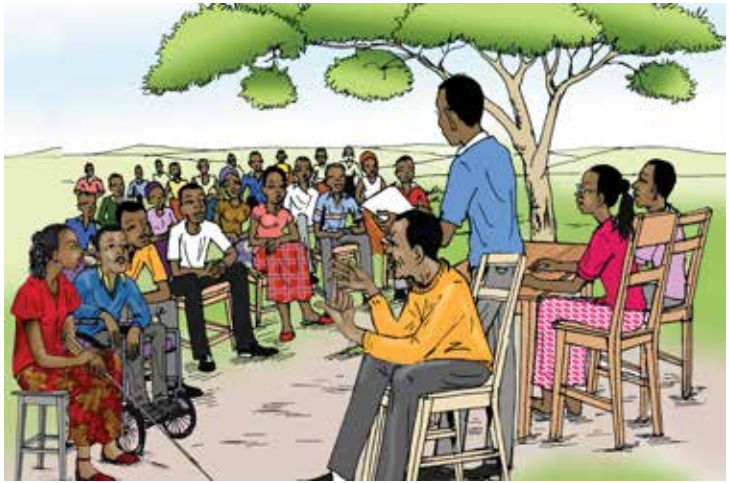
Challenges	Proposed strategies	Target group
Most Health service providers lack practical ways to serve PWDs	MoH, RBC and NCPD to provide capacity building for Health service Providers on disability inclusion and special needs of PWDs.	All
Most communication materials are not accessible for PWDs	• Increase the availability of documents with braille for the blind, video with subtitles for the deaf, etc. • Adapt more communication materials and ensure inclusive ways of communication during information sharing	Blind, deaf and intellectual
Disability mainstreaming is not well understood in most decision making structures at health centers' level.	• Capacity building of HCs' COSA and COGE members on disability mainstreaming. • Consider disability as a crosscutting issue since the planning phase	All

Challenges	Proposed strategies	Target group
Overall layout of some health facilities is not set in a reasonable and logical way (trip chain)	Establish a logical trip chain (arrange services in a logical way from the entrance up to the last service)	All
Most Health facilities lack disability inclusive procedures and policies	Ensure that procedures and policies (internal rules and regulations) in Health facilities have provisions to ensure disability friendly service provision	All
Most health facilities lack disability friendly equipment (Beds, Weighing scales, consultation tables, etc.)	Adjust existing equipment to make them disability friendly where possible and purchase accessible ones where needed.	Physical

Challenges	Proposed strategies	Target group
Most health facilities are not physically accessible	• Upgrade the existing physical infrastructure referring to standards set in the Rwanda building code (ramps, toilets etc. • New health facilities should comply with the Rwanda Building code	All
Limited prioritization for PWDs in waiting rooms	Prioritization of PWDs in Health facilities as stipulated in Ministerial Order N°20/19 Of 27/7/2009	Persons with physical disabilities
Inaccessible to WASH services (e.g. rest rooms, wash rooms, etc.)	Upgrade and avail reserved restrooms & washrooms for PWDs	Physical, blind, little people

Chapter V: Disability mainstreaming in service provision at community level

At community level, community health workers supported by technical supervision from health centers provide Health care services. The table below describes the package of services provided at community level and how they should be made accessible to Persons with Disabilities.



Challenges Proposed strategies Target group

Challenges	Proposed strategies	Target group
Community health workers lack skills and knowledge about disability issues	Responsible parties should provide basic and practical skills on disability mainstreaming.	All types of disability
Apart from columns in VCT and ART registries set to capture data on disability at HCs, HMIS is not capturing disaggregated data on disability	HMIS should capture disaggregated data on disability to allow decision makers gain more insight on disability inclusion in HIV services	All types of disability
Physical accessibility of places where outreach campaigns are held	Build the capacity of health professionals involved in community interventions on specific needs of PWD	Physical
Discrimination, Sexual and physical violence	- Raise awareness in community about life conditions of PWDs - Social impact mitigation	All types of disability

Conclusion

The government of Rwanda has made important achievements in the promotion of the health of the Rwandan population. Even though there is a remarkable effort of the government of Rwanda, some policies / regulations are not considering disability as a crosscutting issue in HIV response and, many actors lack knowledge on disability mainstreaming which is hindering the inclusion of persons with disabilities in HIV and AIDS interventions.

To tackle these issues, UPHLS developed this disability mainstreaming tool, which will guide policy makers, planners, managers, M&E and community health services providers in HIV and AIDS to take into consideration persons with disabilities in their work / program. In this guide there are suggested recommendations focused on different departments working in health, especially HIV services depending on types of disabilities and the way forward to address the issue of exclusion of PWD in HIV service provision.

We hope that this document comprises most of the practical ways to mainstream disability into HIV and AIDS service provision and, that it will serve the inclusion of persons with different categories of disability in HIV response in Rwanda.

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