HIV/AIDS, Disability and Discrimination:

A Thematic Guide on Inclusive Law, Policy, and Programming

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ABOUT ONE BILLION STRONG

One Billion Strong (OBS) is an international, non-governmental organization working to advance the rights of persons with disabilities and to facilitate participation, equality and inclusion in society. The mission of OBS, so named to indicate the substantial world population of persons with disabilities, is to ensure that the obligations set forth in the United Nations Convention on the Rights of Persons with Disabilities are made accessible to all through participatory education and implemented through innovative advocacy and example. OBS is managed by an international Board of Directors, an Advisory Board, and an Honorary Board of First Ladies.

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Foreword

The global fight against HIV/AIDS took off in 2002 with the establishment of the Global Fund to Fight AIDS, TB, and Malaria. The United States became the Fund's largest donor and then took an even bigger step forward in 2003 with the creation of PEPFAR, the President's Emergency Program for AIDS Relief. In less than three years, global spending on the prevention and treatment of HIV/AIDS went from hundreds of millions to multiple billions of dollars. There was a desperate scramble to get services and life-saving drugs to those with greatest need. Remarkable success followed, but many of those in need did not have access to such services. Notable among those with limited access were persons with disabilities.

The Convention on the Rights of Persons with Disabilities (CRPD) was adopted in 2006 by the UN General Assembly to expand legal rights and access to public services for persons with disabilities. Though not directed specifically at the special challenges of HIV, the CRPD is the law in more than 110 countries around the world, many of which are seriously impacted by the HIV epidemic. This Guide is intended to show government officials, advocates, and persons with disabilities how to use the CRPD in the creation of an enabling legal framework to protect the rights of persons with disabilities and all persons living with and affected by HIV and AIDS.

The Guide identifies the mutually reinforcing link between the human rights principles present in both the CRPD and the UN 2011 *Political Declaration on HIV and AIDS.* It challenges government officials and their many partners to draw upon these common principles as they develop legal and institutional frameworks to combat the stigma and discrimination that so often undermine universal access to programs of prevention, care, and treatment of HIV/AIDS.

We welcome this publication and commend One Billion Strong for its efforts to combat discrimination against persons with disabilities.

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List of Acronyms

AAAQ	Available, accessible, acceptable, quality framework
ADA	Americans with Disabilities Act
AIDS	Acquired immunodeficiency syndrome
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled people's organizations
NGO	Non-governmental organization
HIV	Human immunodeficiency virus
ICCPR	International Covenant on Civil and Political Rights
IPU	Inter-Parliamentary Union
NHRI	National human rights institution
OBS	One Billion Strong
OHCHR	Office of the High Commissioner for Human Rights
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary counselling and testing
WHO	World Health Organization

Introduction

HIV infection permeates all strata of society. Persons with disabilities are as likely as other members of society to become infected with HIV. In some instances, they are at higher risk of infection than others. HIV infection is a disabling condition and requires domestic laws and institutions such as legislatures, AIDS councils and national human rights institutions to ensure that HIV/AIDS and disability responses are mutually reinforcing. Research shows that marginalized and socially isolated groups who experience discrimination and other human rights violations in society are far more likely to face barriers in their access to HIV prevention, treatment, care and support than other populations. Persons with disabilities are among the most vulnerable groups in society, yet HIV-related laws, policies, programmes and institutional frameworks all too often fail to take their needs into account.

Disability Inclusion and HIV and AIDS Response

The 2011 Political Declaration on HIV and AIDS adopted by the UN General Assembly celebrates the adoption of the Convention on the Rights of Persons with Disabilities and underscores the need "to take into account the rights of persons with disabilities as set forth in the Convention, in particular with regard to health, education, accessibility and information, and in the formulation of our global response to HIV and AIDS."

Source: Political Declaration on HIV and AIDS: Intensifying Our Efforts *to Eliminate HIV and AIDS*, G.A. Res. A/65/L.77, U.N. Doc. A/res/65/277, 23 (July 8, 2011).

Disability laws and policies have important implications for protecting the rights of persons living with HIV. Treatment for HIV now offers the opportunity for long-term survival, and, whether symptomatic or not, persons living with HIV must be recognized as persons with disabilities. Given the need to protect the human rights and fundamental freedoms of all persons, persons living with HIV should be regarded as falling within the protective framework of disability law and policy.

I. Purpose of Guide

The purpose of *HIV/AIDS, Disability and Discrimination: A Thematic Guide on Inclusive Law, Policy, and Programming* is to support efforts to make HIV response inclusive and accessible to persons with disabilities. At the same time, it also highlights the interrelationship between disability inclusion and the rights of persons living with and affected by HIV who are entitled to the protections of international standards on the rights of persons with disabilities. Particular attention is given to HIV-related law, policy, and institutional reform by providing information on how to ensure that HIV prevention, treatment, care and support is accessible to all persons with disabilities. This Guide offers effective strategies for disability inclusive programming across the continuum of HIV prevention, treatment, care and support.

This inclusive approach is in keeping with human rights principles regarding non-discrimination, equality, accessibility, and participation set forth in the UN Convention on the Rights of Persons with Disabilities (CRPD) [1] and reflected in all core UN human rights treaties. The challenge is to ensure that HIV programming and health interventions more generally are inclusive of and accessible to persons with disabilities. Inclusion will not only respect the human rights of persons with disabilities, including persons living with HIV, it will increase the impact of programmes and save lives.

II. Using the Guide

HIV/AIDS and Disability: A Thematic Guide on Disability Inclusive Law, Policy, and Programming is intended to serve as a user-friendly tool for designing and implementing HIV interventions that are accessible to persons with disabilities. It is primarily intended for use by staff of AIDS responders, disabled people's organizations (DPOs), networks of persons living with HIV, human rights and HIV and AIDS service organizations, other civil society organizations, and national AIDS programmes. It may be used in training workshops at national and international levels, including training health professionals to enhance their understanding of the health rights of their clients with disabilities. Government institutions and other partners of national institutions may also find it useful, including legislators and policymakers, officials involved in national AIDS programmes and relevant departments and ministries, such as health, foreign affairs, justice, interior, employment, welfare and education. Independent national human rights institutions and faith-based organizations will also find this material helpful.

The guide is designed to be used both as a reference and an education tool, providing substantive narrative on specific topics and also incorporating active-learning exercises that can be used in a group setting to generate concrete solutions for making HIV/AIDS programmes inclusive of persons with disabilities. Each part stands alone and may be read and used independently depending on the needs of the reader.

III. Structure of Guide

The Guide is structured into five parts. Part I provides an overview of the global context for considering HIV and AIDS in the context of disability. Part 2 analyzes the international legal framework required for protecting the rights of persons with disabilities and persons living with HIV, together with the legal framework required to ensure effective HIV programming. Part 3 examines the institutional mechanisms at the national level which contribute to an inclusive, rights-based HIV and AIDS response. Part 4 identifies common barriers in disability inclusive programming and strategies for addressing barriers to

[1] Convention on the Rights of Persons with Disabilities, G.A. Res 61/106, U.N. DOC A/RES/61/106 (Dec. 13, 2006).

inclusion. Part 5 contains participatory exercises to allow stakeholders to consider and discuss key concepts and strategies around HIV and disability. Annexes provide additional information for further reference.

Part 1: Disability and HIV/AIDS

Introduction

Acquired immunodeficiency syndrome (AIDS) is the sixth largest cause of death in the world.[2] There are an estimated 34 million persons living with HIV.[3] HIV prevalence is growing among the most marginalized groups in society and growing most rapidly among young people, especially women and girls. UNAID's goal of zero discrimination, zero new HIV infections, and zero AIDS-related deaths through universal access to effective HIV prevention, treatment, care and support is a considerable challenge. It requires attention to the specific barriers that risk groups face in accessing HIV programming.

Vulnerability to HIV that may be experienced by persons with disabilities is a major concern due to prevailing social, legal, and economic conditions commonly affecting this substantial subset of the world's population. The *World Report on Disability*, released by the World Health Organization and the World Bank in 2011, states that there are some one billion persons with disabilities worldwide.[4] Persons with disabilities are increasingly recognized as a group particularly vulnerable to HIV infection which is tied to their extreme marginalization in society.[5]

[2] WHO, *Global Health Risks Report: Mortality and burden of disease attributable to the selected major risks* 19 (2009).
[3] UNAIDS, *How to get to zero: Faster. Smarter. Better*. 6 (2011).
[4] WHO/World Bank, *World Report on Disability*, 2011.
[5] *See, e.g.*, Nora Groce, "HIV/AIDS and Disability," 8 Health and Human Rights, 215-225 (2005); Nora Groce, et al, HIV/AIDS and Disability: Capturing Hidden Voices (New Haven, Connecticut:

I.I Defining the Relationship between HIV/AIDS and Disability

The interrelationship between HIV and disability is only now emerging as an important area of focus in HIV response. Few studies have addressed this issue, and as a result, this relationship is poorly understood. While there are specific country conditions that will impact the nature of any public health epidemic, it is well established that HIV disproportionately affects marginalized populations in any given society. For example, vulnerability to HIV infection is generally most pronounced among women, children, young people, persons living in poverty, prisoners, sex workers, men who have sex with men, injecting drug users, and refugees and internally displaced persons.[6] It is only recently that persons with disabilities figure among those considered at risk for HIV infection.[7]

> "The relationship between HIV and disability has not received due attention, although persons with disabilities are found among all key populations at higher risk of exposure to HIV. People living with HIV may develop impairments as the disease progresses, and may be considered to have a disability when social, economic, political or other barriers hinder their full and effective participation in society on an equal basis with others."
>
> Source: UNAIDS, WHO and OHCHR, *Policy Brief: Disability and HIV*, at 1, April 2009.

Persons with disabilities often face multiple risk factors that increase exposure to HIV infection. For example, many persons with disabilities live in poverty and have little or no access to employment and these factors link, in turn, to sexual violence and exploitation, particularly against women with disabilities. They may also be subjected to exploitative forms of labor which cause or exacerbate conditions leading to disability and risk for HIV infection. Persons with disabilities have limited or no access to education and experience multiple forms of discrimination in society. These risk factors impact the extent to which persons with disabilities can participate in society and present barriers to health-related services that are oftentimes insurmountable.

World Bank Group/Yale School of Public Health, 2004), *available at* http://globalsurvey.med.yale.edu.

[6] WHO, UNICEF, UNAIDS, *Global HIV/AIDS Response: Epidemic update and health sector progress towards universal access, Progress Report*, 2011.

[7] For example, *Taking Action against HIV*, includes persons with disabilities among its categorization of at risk individuals. *See* IPU, UNAIDS, UNDP, *Taking Action Against HIV: A handbook for parliamentarians* iii (2007).

The link between disability and persons living with HIV must likewise be understood and appreciated. Persons living with HIV are likely to develop impairments as the disease progresses. This compounds the extent to which they experience social stigma and discrimination. Additionally, the combination of disability and HIV infection results in a particular experience that is distinct and unique, both in terms of discriminatory impact and specific needs. Disability and HIV create the basis for multidimensional discrimination and disadvantage and requires measures to ensure inclusion and accommodation in the development and application of HIV and AIDS response and in laws, policies and institutions. HIV infection should be recognized as a disability, whether or not symptoms have developed. This is reflected in national law and policy in an increasing number of countries and is consistent with the understanding of disability under international law.[8]

1.2 Stigma and Discrimination in the Context of HIV and Disability

Stigma, or negative or pejorative beliefs, feelings and attitudes associated with HIV infection and disability, is a common experience across all cultures. The drivers of HIV-related stigma and disability-related stigma run in parallel in many respects. Stigma results in internalized shame and self-blame. It also fuels isolation from family and community and contributes to the failure of society to recognize the worth and respect the dignity of affected individuals.

Stigma invariably increases vulnerability to discrimination and other human rights infringements. Persons with disabilities often face serious discrimination based on attitudes, perceptions, misunderstandings, and lack of awareness about disability. In the context of HIV, the myth that persons with disabilities are asexual may lead health educators and HIV/AIDS outreach workers to exclude them from accessing important and potentially life-saving information about safe sex. In other instances, the myth of HIV cure through "virgin cleansing" may heighten risk of sexual violence for women and girls with disabilities who may be assumed to be virgins.[9]

[8] *See* United Kingdom, The Equality Act, c. 15, 2010 (amended 2012); United States, Americans with Disabilities Act of 1990, P.L. 110-325, 1990 (amended in 2008).
[9] *See* Nora Groce and Reshma Trasi, "Rape of individuals with disability: AIDS and the Folk Belief of Virgin Cleansing," 363 LANCET at 1663-1664 (2004).

Table 1: HIV and Disability Stigma

HIV-Related Stigma	Disability-Related Stigma
Fear of HIV infection through casual contact	Fear of acquiring disability through casual contact
Considered less than human	Considered less than human
Individual blamed for HIV infection	Individual blamed for disability
HIV infection caused by curse	Disability caused by curse
Exclusion from social events	Exclusion from social events
Undeserving of education	Unable to be educated
Unworthy/undeserving of employment	Unable/incapable of employment
Sexually deviant	Asexual

In some instances, there is a common experience of discrimination for persons with disabilities and persons living with HIV: both groups are subjected to discrimination in employment, immigration, social protection benefits, and are at risk of being subjected to coercive treatments such as involuntary sterilization, medical testing, and forced institutionalization.

1.3 Social and Cultural Understandings of Disability and HIV

Disability and HIV status are cross-cutting issues with human rights implications that must be addressed holistically. The social model understanding of disability reflected in international norms and standards, including in the CRPD, best expresses the impact of social and cultural norms in limiting human rights enjoyment and undermining public health goals. Socially constructed barriers facing persons with disabilities and persons living with HIV require identification and removal in order to ensure human rights protection and to realize public health goals. Such barriers manifest in attitudinal, legal, policy, and institutional exclusion, as well as ineffective HIV responses.

Like disability, traditional approaches to HIV have tended to be framed narrowly, within a medical model perspective. This focus concentrates on medical intervention and treatment, and does not take into account the broader social and cultural context of the HIV epidemic. An understanding of the unique barriers that persons living with HIV and persons with disabilities experience in society shifts attention away from purely medical approaches, towards a broader, rights-based focus. To this end, HIV response is not simply about providing a continuum of health-related supports and services, whether for persons with disabilities, persons living with HIV, or other marginalized groups; it is also about developing programming, laws, and policies that promote inclusion in all aspects of society. Reframing HIV status and disability in terms of socially constructed barriers compels a rights-based approach in order to achieve a comprehensive HIV response.

The international human rights framework that has developed around HIV/AIDS and around disability should be regarded as mutually reinforcing and complementary. Together, these norms and standards create a basis for ensuring equality of access to the HIV support continuum for persons with disabilities, persons living with HIV, and other highly vulnerable groups.

Part 2: Building Supportive Law and Policy Frameworks for Disability Inclusion

Introduction

The human rights of persons with disabilities are an essential element of any HIV/AIDS strategy.[10] In addition, international standards on disability are directly relevant to ensuring the legal rights of persons living with and affected by HIV.

Human rights within the context of HIV and AIDS are universal, indivisible, interdependent, and interrelated. All civil, political, economic, social and cultural rights are important when thinking about the interrelationship between HIV, human rights, and disability.

[10] *See* Susan Timberlake and Jason Sigurdson, "HIV, Stigma, and Rates of Infection: A Human Rights and Public Health Imperative," 4 PLos Med. (Jan. 2007).

2.1 International Standards Relating to Persons Living with HIV and Disability

Significant developments have taken place with regard to human rights protection along the HIV/AIDS-related prevention, treatment, care and support continuum. International expressions of rights-based approaches to HIV/AIDS underscore the relevance of existing human rights standards to persons infected and affected by HIV and provide guidance on the application of such standards to HIV response. Two important instruments in this context are:

- International Guidelines on HIV/AIDS and Human Rights[11]
- Declaration of Commitment on HIV/AIDS[12]

The adoption of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006, and its rapid ratification around the world, is a major development for protecting the human rights of persons with disabilities, including persons living with HIV. The CRPD has important implications for protecting the rights of persons with disabilities within the context of HIV *and* creates a detailed framework of protection for persons living with HIV as well as persons affected by HIV, such as children who have lost parents to AIDS or family members of persons living with HIV.

CRPD provisions relating to and supporting the right to health for persons with disabilities include: the right to the highest attainable standard of health, provisions on non-discrimination and equality, accessibility, participation, education, respect for privacy, freedom from violence and abuse, the freedom to receive and impart information, and the right to marry and found a family, among others. All of these rights are relevant for HIV response and clearly affirm the position that persons with disabilities may not be discriminated against in their access to programming, nor may they be discriminated against on the basis of their HIV status. Such protection from discrimination applies equally to persons in a relationship with someone who has HIV or AIDS. Furthermore, the rights set forth in the CRPD support the meaningful participation of persons with disabilities and their representative organizations in the design and implementation of HIV prevention, treatment, care and support.

2.2 Equality and Non-Discrimination

International human rights law guarantees the right to equality before the law and the right to be free from discrimination. The human rights protections afforded to all persons under human rights law are equally applicable to persons living with HIV and to persons with

[11] International Guidelines on HIV/AIDS and Human Rights, HR/PUB/06/9 (2006 Consolidated Version) [hereinafter HIV Guidelines].
[12] Declaration of Commitment on HIV/AIDS, U.N. Res. A/RES/S-26/2 (Aug. 2, 2001).

disabilities. A central element that cuts across all substantive rights is equality and non-discrimination.

Discrimination in the Context of HIV/AIDS and Disability

- Persons living with HIV experience discrimination when they are not provided with equal access to health services.
- Persons with physical disabilities experience discrimination when they are unable to have HIV testing because the medical facility is not accessible.
- Children who have lost a parent to AIDS experience discrimination when they are segregated from their community and forced to live in institutional settings.
- Women with disabilities face discrimination when they are denied access to health services on the basis that they do not need such services.
- Persons living with HIV and persons living with disabilities experience discrimination when they are not provided with reasonable accommodation by their employers.

The *International Guidelines on HIV/AIDS and Human Rights* recognize that groups singled out for discriminatory measures in HIV-related contexts include persons with disabilities. The right to equality and non-discrimination prohibits discrimination in law and in practice in any field regulated and protected by public authorities. States are required to review, and as needed, repeal or amend their laws, policies, and practices to eliminate differential treatment based on arbitrary HIV/AIDS-related status.

International Standards of Human Rights Protection for Persons with Disabilities and Persons Living with HIV	
International Guidelines on HIV/AIDS and Human Rights	**Convention on the Rights of Persons with Disabilities**
Guideline 5: Anti-discrimination and other laws to protect persons living with HIV, persons with disabilities, and other vulnerable groups.	**Articles 4 & 5**: Modify/abolish discriminatory laws against persons with disabilities; guarantee equal legal protection against discrimination and take measures to ensure reasonable accommodation is provided.
Guideline 9: Action to change attitudes of discrimination and stigmatization associated with HIV.	**Article 8**: Action to raise awareness about disability rights, combat harmful stereotypes, and promote understanding.
Guideline 10: Public and private sector standards of conduct regarding HIV issues.	**Article 4**: Measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise.
Guideline 11: State monitoring and enforcement mechanism to guarantee HIV-related rights.	**Articles 33 - 40**: National and international level monitoring mechanisms to enforce disability rights.

The Scope of Disability Rights Protection in the CRPD

Article 1 states: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." In addition, the CRPD recognizes in the Preamble that "disability is an evolving concept" and "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society."

- The reference to "persons with disabilities" is not exhaustive.
- The term "persons with disabilities" could refer to a broader group of people at the national level.
- The diversity of disability is recognized and disability is not restricted to only one type of impairment, such as physical disability.
- Accordingly, all persons with disabilities, whatever their impairment, are entitled to equal rights.
- It is impermissible to exclude certain categories of persons with disabilities, such as persons living with HIV, from exercising their human rights.
- Persons associated with persons with disabilities, such as children who have parents with HIV, are protected from discrimination on the basis of disability because the CRPD protects against "all forms of discrimination."

Source: Convention on the Rights of Persons with Disabilities, Preamb. (e) & arts. 1, 2, 3, 5.

The CRPD is the first human rights convention to explicitly recognize disability as a prohibited ground of discrimination, together with the obligation to ensure that reasonable accommodation is provided to facilitate human rights enjoyment by persons with disabilities. The CRPD obliges States Parties to address all forms of disability-based discrimination in law, policy, and practice and makes clear that persons with disabilities are entitled to the same human rights as other human beings.

Notably, the CRPD applies to all persons with disabilities and includes persons living with HIV. In prohibiting "all forms of discrimination, including denial of reasonable accommodation,"[13] States are thus obliged to take positive measures to ensure that persons with disabilities are able to access public health services of any kind. Reasonable accommodation is defined in the CRPD as:

> [N]ecessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.[14]

[13] CRPD, *supra* note 1, art. 2.
[14] *Id*.

Thus, it is important to recognize that the failure to provide persons living with HIV with reasonable accommodation in the context of HIV treatment, care and support, or other areas of life (such as employment, education, property ownership) is prohibited and constitutes disability discrimination.

Failure to Provide Reasonable Accommodation is Discrimination

- Failure to provide a physically accessible environment at an HIV testing center for a person who uses a wheelchair.
- Failure to make arrangements to ensure that HIV counseling for a soldier living with HIV is confidential.
- Failure to provide HIV information in accessible formats to a person who is blind or has low vision.
- Failure to provide information in an accessible format about the use of antiretroviral drugs to a person living with HIV who cannot read.
- Failure to provide sign language interpretation or other means of communication access at an HIV testing center for a person who is deaf or hard of hearing.
- Failure to provide flexible work arrangements for a person with HIV infection to receive treatment.

The concept of reasonable accommodation is a core element of the duty of States to respect, protect, and fulfil the non-discrimination mandate on the basis of disability. The duty to provide reasonable accommodation in order to satisfy the obligation of non-discrimination includes the following:

- Identifying and removing barriers that impact the enjoyment of human rights for persons with disabilities;
- Making modifications or adjustments that are necessary and appropriate and that do not impose a disproportionate or undue burden;
- Responding to the specific, individual circumstances of the person with a disability;
- Finding solutions to address barriers that are appropriate to the individual with a disability;
- Recognizing that some accommodations may entail cost-free changes to standard practices while others may require resources to be spent on supports, equipment, or modifications; and
- Understanding that disability accommodations apply to ensuring the enjoyment of all human rights for all persons with disabilities, including persons living with HIV.

2.3 Specific Substantive Rights

Beyond equality and non-discrimination, other human rights - civil, political, economic, social and cultural - are relevant to persons with disabilities and persons living with HIV. Illustrative examples include the right to privacy, providing protection against mandatory testing, and the requirement that HIV status be kept confidential. These are important protections given the stigma associated with HIV status. The right to liberty and freedom of movement protects against quarantine, detention, segregation, or isolation in a special hospital ward based on HIV status or forced institutionalization of persons with disabilities. The right to social security, assistance, and welfare guarantees the right not to be denied these benefits on the basis of HIV status or disability. The right to be free from torture and other cruel, inhuman, and degrading treatment or punishment is likewise of relevance and requires, for example, that States combat sexual victimization of persons with disabilities that may result in HIV transmission or sexual violence that occurs in prison.

2.4 Permissible Restrictions and Limitations

Under international human rights law, States may impose limitations and restrictions on certain rights, in narrowly defined circumstances. Any limitations and restrictions must be necessary to achieve specific overriding goals, such as public health, the rights of others, morality, public order, the general welfare in a democratic society, or national security.[15] In addition, in order for such restrictions to be legitimate under human rights law, the State must establish that the restriction is: (1) carried out in accordance with the law; (2) based on a legitimate State interest; and (3) proportional to the State's interest and the least restrictive means.[16] It should be noted that some rights, such as the right to life or right to be free from torture or other inhuman and degrading treatment or punishment, may not be restricted under any circumstances.

[15] International Covenant on Civil and Political Rights, G.A. Res. 2200A (XXI), U.N. Doc. A/6316, art. 4 (Dec. 16, 1966).

[16] Restrictions must be grounded in specific legislation which is accessible, clear and precise; based on a legitimate interest; and proportional to that interest and constituting the least intrusive and least restrictive measure available and actually achieving that interest. *See* Paul Sieghart, *AIDS and Human Rights: A UK Perspective*, British Medical Association Foundation for AIDS, London, 1989, pp. 12-25. *See also* Paul Sieghart, *International Human Rights,* 85-103 (1984).

Governments must Respect, Protect, and Fulfil the Rights of Persons with Disabilities in the Context of HIV/AIDS

Respect: The obligation to "respect" human rights means that States must not interfere with the exercise and enjoyment of the rights of persons with disabilities.

Example: Governments may not arbitrarily deny to an HIV-infected individual with a disability the same standard of medical treatment offered to other citizens.
Example: Governments may not deny equal access to antiretrovirals to a woman living with HIV.

Protect: The obligation to "protect" human rights means that the State is required to protect everyone, including persons with disabilities, against abuses by non-State actors, such as individuals, businesses, institutions, or other private organizations.

Example: Governments must ensure that private health care providers do not discriminate against persons with disabilities and that they provide reasonable accommodations to facilitate their access to HIV/AIDS education and other services.
Example: Governments must ensure that employers do not discriminate in hiring or retention on the basis of HIV status.

Fulfil: The obligation to "fulfil" human rights means that States must take positive action to ensure that everyone, including persons with disabilities and persons living with HIV, can exercise their human rights.

Example: Governments must undertake measures to extend coverage of HIV/AIDS programming to persons with disabilities. While resource constraints may mean that coverage will not reach the entire population immediately, governments must ensure that they are progressively working to meet the needs of all people, including persons with disabilities.
Example: Governments must undertake measures to ensure that children affected by HIV and AIDS have equal access to education.

2.5 Applying International Standards to HIV and AIDS Response

Ensuring the protection and promotion of human rights in the context of HIV is important in preventing the spread of HIV infection and in minimizing or mitigating the social and economic impact of the pandemic. Obligations to promote and protect HIV-related human rights are clearly defined in international instruments. The *International Guidelines on HIV/AIDS and Human Rights*, together with the CRPD, outline human rights obligations that should be applied in the context of HIV and AIDS and disability. They are the principal instruments of relevance in assessing the application of human rights to the lives of persons living with HIV and persons with disabilities.

2.6 Social Stigma as a Basis of Discrimination

Social stigma on the basis of disability and HIV status seriously undermines public health responses and creates major barriers to the full participation of persons with disabilities and persons living with HIV in society. Given the importance of integrating HIV strategies across sectors, the stigma and discrimination it fosters is a major impediment to inclusion and an effective HIV response.[17]

Laws to Address Stigma

Australia: The Anti-Discrimination Act of New South Wales makes it unlawful for an individual "to incite hatred towards, serious contempt for, or severe ridicule of" anyone infected with HIV or thought to be HIV infected.

China: The Law of the People's Republic of China on the Protection of Persons with Disabilities provides that insults, disparagement of and infringement upon the dignity of persons with disabilities is prohibited.

Source: New South Wales Anti-Discrimination Act 1977, Part 4F HIV/AIDS Vilification § 492ZXB (1), (May 30 2012); Law of the People's Republic of China on the Protection of Persons with Disabilities, Ch. 1, art. 3, (entry into force, July 1, 2008).

Vilification and harassment, where an individual is subject to comments, ridicule, or other demeaning conduct on the basis of HIV-status or disability, are all too common in school, the workplace, and the community at large. Persons with disabilities and persons living with HIV require protection against harassment. Children living with or affected by HIV, and all children with disabilities, require special protection in educational settings.

Laws and policies have an important role to play in helping to avoid or remedy disability and HIV-related stigma and discrimination.[18] The CRPD protects against all types of disability discrimination, requires States to guarantee the right to non-discrimination under the law and to undertake measures to address stigma.[19] At the same time, law and policy can reinforce stigma and discrimination against persons with disabilities and persons living with HIV and must be reviewed and amended or abolished insofar as they violate human rights standards.

2.7 Highest Attainable Standard of Health

[17] *See* Bunmi Makinwa and Mary O'Grady, HIV/AIDS: FHI/UNAIDS Best Practices in Prevention Collection (2001); and UNAIDS HIV–Related Stigma, Discrimination and Human Rights Violations, UNAIDS/05.05E, (April 2005).
[18] *See* Michael Ashley Stein et al., Health Care and the UN Disability Rights Convention, 374 LANCET 1796 (2009); Janet E. Lord et al., Lessons from the Experience of the UN Convention on the Rights of Persons with Disabilities, 38 J.L. MED. & ETHICS 564 (2010).
[19] CRPD, *supra* note 1, arts. 4, 5 and 8.

States are required under international human rights law to take steps to prevent, treat and control epidemic diseases, such as HIV-infection, as part of the general right to the highest attainable standard of physical and mental health.[20] This right is to be provided to all persons without discrimination.

Protecting against Discrimination

Specific protection from discrimination based on HIV or health status or disability may be found in constitutional provisions, general or context-specific anti-discrimination legislation, disability-specific legislation, HIV and AIDS legislation, among others:

Constitutional Protection: In the South African case of *Hoffmann v. South Africa Airways*, the Constitutional Court held that the airline's policy of refusing to hire persons with HIV was a violation of the protection of equal rights under the constitution.

HIV and AIDS Legislation: In the Philippines, the AIDS Control and Prevention Act of 1998 provides that "discrimination in all its forms and subtleties, against individuals with HIV or persons suspected of having HIV shall be considered inimical to individual and national interest…" The statute prohibits discrimination in the workplace, schools, travel and habitation, public service, credit and insurance services, hospitals and health institutions, and in burial services.

General Anti-Discrimination Legislation: In South Africa, the Promotion of Equality and Prevention Unfair Discrimination Act No. 4 of 2000 prohibits discrimination in all sectors of society on the basis of HIV status.

Disability Legislation: In the United States, the Americans with Disabilities Act of 1990 prohibits discrimination against persons with disabilities in employment, public services, public accommodations, and telecommunications. Significantly, in the case of *Bragdon v. Abbott*, the United States Supreme Court considered a case of a dental patient infected with HIV who brought claim of discrimination under the Americans with Disabilities Act (ADA) against the dentist who refused to treat her because of her health status. The court held that a person infected with HIV who is asymptomatic is still considered a disabled person and enjoys the protections of the ADA. In 2008, Congress amended the ADA, making it easier for people with HIV/AIDS to demonstrate that they are persons with disabilities who are covered by the statute. People with HIV/AIDS can demonstrate that they are disabled on the basis that their unmedicated HIV/AIDS substantially limits the functions of their immune system.

Source: *Hoffmann v. South Africa Airways*, (CCT17/00) [2000] ZACC 17; Philippines, the AIDS Control and Prevention Act of 1998, Republic Act 8504; South Africa, the Promotion of Equality and Prevention Unfair Discrimination Act, PEPUDA Act No. 4 of 2000; The Americans with Disabilities Act of 1990, P.L. 110-325, 1990 and ADA Amendments Act of 2008*; Bragdon v. Abbott*, 524 U.S. 624, (1998).

The right to health is guaranteed to all persons with disabilities, including persons living with HIV. The CRPD requires States to provide reasonable accommodation to ensure equal access to HIV-related prevention, treatment, care and support.[21]

[20] International Covenant on Economic, Social, and Cultural Rights, G.A. Res. 2200A (XXI), U.N. Doc. A/6316, art. 12 (Dec. 16, 1966).
[21] CRPD, *supra* note 1, arts. 5 and 25.

An important analytical framework used to deepen understanding of the content of the right to health requires that health services, goods and facilities, including the underlying determinants of health, shall be *available, accessible, acceptable, and of good quality*.[22] This framework applies to HIV-related services, goods and facilities and should be understood and interpreted within the context of the CRPD. For example, Article 9, Accessibility, is a cross-cutting provision that must be applied in the context of health and HIV-related services. It thus requires State Parties take appropriate measures to ensure equal access to HIV facilities and services, including physical premises, and communications and HIV-related information.[23] States must ensure access to services for the prevention (such as condoms) and treatment of HIV (such as drugs) and to voluntary and confidential testing with pre- and post-test counselling.

Health and HIV-related Rights under the CRPD

The CRPD guarantees the right of persons with disabilities, including persons living with HIV, to the highest attainable standard of physical and mental health which includes:

- Non-discrimination and the provision of reasonable accommodation in relation to health and rehabilitation.
- Non-discrimination and the provision of reasonable accommodation in contexts relevant to health, such as education, employment, housing, and sport
- Accessibility, defined as access on an equal basis to others to medical facilities, health-related information and communications, health education and counseling facilities and services
- Prevention, treatment, and control of epidemic diseases, including HIV.
- Creation of conditions for all to access medical services and medical attention in the event of sickness.

Source: Convention on the Rights of Persons with Disabilities, arts. 2, 5, 9, 25.

[22] Committee on Economic, Social and Cultural Rights, General Comment 14 U.N. ESCOR DOC. E/C. 12/2000/4, at ¶¶ 4 and 11 (Aug. 11, 2000).
[23] CRPD, *supra* note 1, art. 9.

The AAAQ Framework Applied to HIV and Disability

Availability: HIV-related facilities, goods, and services, including HIV prevention, treatment, care and support, must be available in adequate numbers through a State, including adequate numbers of health care providers trained to provide disability-specific support and accommodation.

Accessibility: Includes four overlapping dimensions:

- *Non-discrimination*: HIV-related services must be available without discrimination on the basis of disability, HIV status (whether symptomatic or not) or any other prohibited ground. States must take positive measures to ensure equality of access to persons with disabilities, including the provision of reasonable accommodation. States must also ensure that persons with disabilities get the same level of medical care within the same systems as others.
- *Physical accessibility*: Health facilities, goods, and services must be within safe physical reach of persons with disabilities and other vulnerable or marginalized groups, such as ethnic minorities and indigenous populations, women, children, adolescents, older persons, and persons with HIV/AIDS. Accessibility also implies that medical services and underlying determinants of health, such as safe and potable water and adequate sanitation facilities, are accessible, within safe physical reach, including in rural areas. Accessibility further includes adequate access to buildings for persons with disabilities, including HIV testing and treatment centers
- *Economic accessibility*: Health facilities, goods and services, such as medicines and assistive devices, must be economically accessible (affordable) to consumers with disabilities and persons living with HIV. This dimension acknowledges the link between poverty and disability.
- *Information accessibility*: Accessibility includes the right to seek, receive, and impart information and ideas concerning health issues. Information relating to health and other matters, including diagnosis and treatment, must be accessible to persons with disabilities. This entitlement is often denied to persons with disabilities because they are wrongly judged to lack the capacity to make or participate in decisions about their treatment and care. However, accessibility of information should not impair the right to have personal health data treated with confidentiality. Additionally, information must be provided in accessible formats.

Acceptability: Health care facilities, goods, and services provided to persons with disabilities must be culturally acceptable and respectful of medical ethics.

Quality: Health care facilities, goods, and services provided to persons with disabilities must be of good quality and scientifically and medically appropriate. Among other things, this quality requirement mandates skilled medical and other personnel who are provided with disability training, evidence-based interventions, scientifically approved and unexpired drugs, appropriate hospital equipment, safe and potable water, and adequate sanitation.

Source: Committee on Economic, Social and Cultural Rights, General Comment No. 14, The Right to the Highest Attainable Standard of Health, U.N. DOC. E/C.12/2000/4 (Aug. 11, 2000): http://www1.umn.edu/humanrts/gencomm/escgencom14.htm

2.8 Equal Access to HIV Prevention Efforts

Persons with disabilities and persons affected by HIV must be provided with equal access to HIV prevention efforts. This coverage is essential for prevention of infection by persons with disabilities and also to ensure that persons with disabilities who are HIV positive receive appropriate counseling on preventing transmission of the virus.

Both the HIV Guidelines and CRPD underscore the importance of equal access to prevention efforts and ensuring that the principle of equal access is they are grounded in legislation. Reasonable accommodation must be provided in the context of HIV prevention efforts.

2.9 Equal Access to HIV Testing and Counselling

A major element of ensuring equal access to HIV prevention efforts is ensuring the accessibility of voluntary HIV testing and counseling. Sometimes referred to as the "Three C's" of HIV testing, (1) counseling and information about HIV must be provided before and after testing; (2) consent to testing must be informed, specific and voluntary by the individual to be tested; (3) and confidentiality regarding testing and rest results must be respected.

South African Example of Equal Access

The South African Constitutional Court held that it was unreasonable for the South African government to withhold the distribution to pregnant women of a drug that would prevented the transfer of the HIV virus to the new born children during childbirth. The Constitutional Court, based on its findings, ordered the South African government to begin immediate distribution of the drug.

Source: *Minister of Health and Others v. Treatment ActionCampaign and Others* [2002] 10 BCLR 10033 (CC).

These basic principles are set forth in the *International Guidelines on HIV/AIDS and Human Rights*. Additional texture is provided in the CRPD, according to which testing and counseling must be made accessible to persons with disabilities and individual reasonable accommodation must be provided.[24] In addition, Article 12 of the CRPD makes clear that persons with disabilities have their right to equal recognition before the law, meaning that they have legal capacity to give informed consent and, further, supported decision-making measures must be put in place for persons requiring support.[25]

[24] CRPD, *supra* note 9, 25.
[25] CRPD, *supra* note 1 at art. 12.

2.10 Equal Access to Quality Treatment, Care and Support

Persons with disabilities and persons affected by HIV must have equal access to treatment, care and support. This includes equal access to antiretroviral medications. The CRPD protects persons with disability from the discriminatory denial of health care or health services on the basis of disability. Article 25 thus acknowledges that in some instances, assumptions about quality of life may lead to discriminatory practices and denial of treatment.[26] Prioritizing "able-bodied" populations over persons with disabilities in access to treatment is discriminatory and prohibited by the CRPD. Persons with disabilities must likewise have equal access to post exposure prophylaxis. Medical personnel as well as law enforcement should be appropriately trained to understand the heightened risk that persons with disabilities face in relation to sexual violence. Such measures could be addressed either within the context of legislation or in a national AIDS strategy.

Specific Measures to Enhance Access to Treatment, Care and Support

The CRPD makes provision for specific measures to be taken in order to advance access to health care services, goods and facilities. These measures can take a variety of forms and may usefully be set forth in legislation, policies, strategies and programmatic guidelines:

- Funding the provision of sign language interpreters for medical appointments, including HIV voluntary testing and counselling;
- Legislation providing access to long term health insurance for persons with disabilities;
- Training of HIV treatment staff on accessibility measures for persons with intellectual disabilities; and
- Government provides HIV prevention pamphlets, including in large print and Braille, for distribution at disabled people's organizations.

Legislation should guarantee access to health care or health services without discrimination which could be achieved through general anti-discrimination legislation that covers persons with disabilities or in specialized disability or public health legislation.

2.11 Informed Consent to Treatment and Health Research

The protection of human subject participation in research is one of the most fundamental elements of human rights law. Informed consent is required for health research and experimentation, in addition to consent to treatment.[27] In addition, the selection of participants in research, whether HIV-related or connected to another aspect of health or

[26] CRPD, *supra* note1, art. 25.
[27] *Id*. arts. 15 and 31.

disability, must be done without discrimination. Other protections apply, including confidentiality of personal information obtained from research participants, equitable access to information and benefits resulting from research, and access to counselling, health and support services during and after research.[28]

The CRPD's principles and standards emphasize the importance of autonomy, independence, and freedom of choice in questions related to health decisions, including admission to health facilities.[29] Legislation should clarify that disability may not be a ground for justifying a refusal to ensure free and informed consent for medical treatment. In many cases, ensuring free and informed consent for persons with disabilities presents no greater challenge than ensuring the same for persons without disabilities. In some cases, additional support might be necessary to ensure the individual is able to provide his or her free and informed consent. Article 12 of the CRPD provides a framework for supported decision-making in order to ensure that the legal capacity of persons with disabilities is respected and protected.[30]

There may be legal contexts where persons with disabilities, along with other groups, may need protection from exploitation, coercion or undue influence. Such protection may be provided in human rights legislation, disability-specific legislation and/or adult protection statutes.

2.12 Equal Access to Safe Blood Supplies

Evidence discloses that the risk of HIV infection by transfusion of HIV-contaminated blood exceeds 90 percent.[31] Some of the most highly publicized cases have involved HIV infection on account of transfusion for persons with hemophilia. While countries around the world have developed mandatory systems for screening blood, tissue and organ products for HIV, others have to reinforce these efforts. In some instances, countries have adopted specific legislation to address safe blood supplies or have introduced protective measures as a result of court cases.

[28] HIV Guidelines, *supra* note 11, Guideline 5, ¶ 22 (c).
[29] CRPD, *supra* note 1, arts. 3 and 25.
[30] *Id*. art. 12.
[31] Lance Gable, et al., *Legal Aspects of HIV/AIDS: A Guide for Policy and Law Reform*, The World Bank 25 (2007).

Safe Blood Supply

Iran: In what is referred to as the Hemophiliacs Case, the government of Iran was directed by Judge Nasirayee to pay financial and spiritual compensation to persons infected with hepatitis and HIV as the result of contaminated blood products. The ruling was made on the basis of international human rights conventions to which Iran is a State party.

India: The Indian Supreme Court in 1996 directed the government to establish a National Blood Transfusion Council in order to ensure a safe blood supply, require licensing abolish the professional sales of blood, and provide trained inspectors to check on the banks.

Source: A. Saberi, "The International Convention on the Rights of Persons with Disabilities and its Applications in the Iranian Regulatory System" in Advancing the Rights of Persons with Disabilities, Allen Moore and Sarah Kornblet, eds., (Stimson Center, Nov. 2011); *Common Cause v. Union of India and Others*, Writ Petn. (Civil) No. 91 of 1992. (1996).

2.13 Privacy and Confidentiality of Personal Information

International human rights law provides for protection against arbitrary or unlawful interference with an individual's privacy, family, home or correspondence and also against unlawful attacks on one's honour and reputation.[32] Privacy rights encompass the obligation to seek informed consent to HIV testing and privacy of information, and the obligation to protect HIV-related information on individuals, along with other personal and medical data subject to protection.

The CRPD protects the right of persons with disabilities, including persons living with HIV, to privacy and confidentiality.[33] It requires States to comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for privacy.[34] It further requires that States comply with human rights and ethical principles in the collection and use of statistics.[35]

2.14 Equal Access to Education

International human rights law prohibits discrimination in education,[36] a right that applies specifically to persons with disabilities in the CRPD.[37] Education rights encompass several elements that are particularly important in the context of HIV.

[32] ICCPR, *supra* note 15, art. 17.
[33] CRPD, *supra* note1, art. 22.
[34] *Id*. art. 31.
[35] *Id*.
[36] ICESCR, *supra* note 20, art. 13.
[37] CRPD, *supra* note 1, art. 24.

All individuals have the right to receive HIV-related education and States must ensure that persons with disabilities have access to all HIV prevention and sexual and reproductive health education and information. Moreover, reasonable accommodation must be provided in order to ensure that access to education is provided without discrimination.

Protection against discrimination in educational settings, whether formal or informal, is also required. For example, students with actual, perceived, or suspected HIV-infection may not be subjected to additional discipline compared with other students, denied participation in school activities or lessons, segregated or isolated from other students, or deprived of benefits or services available to other students.

The right to education also encompasses the obligation of States to promote understanding, respect, tolerance, and non-discrimination in relation to people living with HIV and persons with disabilities. Measures should be taken to promote awareness and anti-harassment and bullying campaigns could be considered. The right of equality and non-discrimination in education includes the right to reasonable accommodation in order to effectively access education for persons with disabilities, and includes not only persons living with HIV, but also children or others affected by AIDS, such as children who have lost both parents to AIDS.

Protection against Discrimination in Education Based on HIV Status

In the **Philippines**, "[n]o educational institution shall refuse admission or expel, discipline, segregate, deny participation, benefits or services to a student or prospective student on the basis of his/her actual, perceived or suspected HIV status."

In **Cambodia**, "[n]o educational institution shall refuse admission or expel, discipline, isolate or exclude from gaining benefits or receiving services to a student on the basis of the actual, perceived or suspected HIV/AIDS status of that student or his/her family members."

In **Kenya**, "[n]o educational institution shall deny admission or expel, discipline, segregate, deny participation in any event or activity, or deny any benefits or services to a person on the grounds only of the person's actual, perceived or suspected HIV status."

Source: The Philippine AIDS Prevention and Control Act of 1998, H. No. 10510, art. VII Discriminatory Acts and Policies § 36; Cambodia, Law on Prevention and Control of HIV/AIDS, No. NS/RKM/0702/015 Chapter VIII Discrimination Acts and Policies, art. 37; and Kenya, HIV and AIDS Prevention and Control Act, Act No. 14, 2006, Part VIII Discriminatory Acts and Policies, § 32.

Protections against discrimination in education based on HIV status or disability may be covered in comprehensive anti-discrimination legislation, child rights laws, education law, integral disability legislation or in HIV and AIDS laws. However, it is important to reaffirm these protections in education-related legislation to ensure protection against discrimination in education and to ensure consistency in the legal framework.

2.15 Equal Access to Employment

The right to work entails the right of every person to access employment without discrimination or precondition, except based upon the necessary occupational qualifications. Discrimination in the context of employment often presents serious barriers for both persons with disabilities and persons living with HIV. It impacts:

- Recruitment processes such as advertising, interviewing, and other selection processes;
- Employment decisions;
- Terms and conditions of employment, including pay rates, work hours, and leave;
- Promotion, transfer, training or other benefits associated with employment;
- Dismissal or other detriment, such as demotion;
- Workplace victimization and harassment; and
- Safety and health in working conditions.

International human rights law prohibits discrimination in employment based on health status and disability and guarantees the right to work and to just and favorable conditions of work.[38] The CRPD protects against discrimination in relation to disability and HIV and, as part of the non-discrimination duty, also requires the provision of reasonable accommodation in employment.[39]

Protections from discrimination may be covered in comprehensive anti-discrimination legislation, in integral disability legislation or in HIV and AIDS laws. These protections should be affirmed in employment-related legislation to ensure consistency in the recognition of rights and protection

Protection against Discrimination in Employment Based on HIV Status

Bahamas, Employment Act of 2001

> In the Bahamas, "[n]o employer... shall discriminate against an employee or applicant for employment on the basis of ... HIV/AIDS."

Zimbabwe, Labor Relations (HIV and AIDS) Regulations

> In Zimbabwe, "[n]o employer shall terminate the employment of an employee on the grounds of that employee's HIV status alone ... or in any other way, be discriminated against on the grounds of his HIV status alone."

South Africa, Employment Equity Act of 1998

> In South Africa, "[n]o person may unfairly discriminate ... against any employee, in any employment policy or practice [on the grounds of] ... HIV status."

Source: Bahamas, Employment Act of 2001, Part I Preliminary, §6; Zimbabwe, Zimbabwe, Labor Relations (HIV and AIDS) Regulations, Part 6 Job status and training, §§ 1 and 2(d); South Africa, Employment Equity Act, No. 55 of 1998, Chapter 2 Prohibition of unfair discrimination, § 6(1).

[38] ICESCR, *supra* note 20, art. 7.
[39] CRPD, *supra* note 1, art. 27.

from all forms of discrimination on the basis of HIV or disability status in the area of employment.

2.16 Equal Access to an Adequate Standard of Living

Many persons with disabilities face barriers to the enjoyment of even the most basic living standards and social protection. They are disproportionally represented among the poor, resulting in significant need for social protection measures. Health insurance policies frequently discriminate against persons with disabilities, as in the case where persons with disabilities are refused health insurance coverage due to the existence of a disability or where health insurance is made contingent on the exclusion of a particular health condition or disability-related health issue from coverage under the policy. Laws related to health insurance – whether private or public – should ensure that persons with disabilities have a right to access health care, including through health insurance, and that conditions for accessing insurance do not discriminate against persons with disabilities.

Welfare and social protection laws relating specifically to disability or relating more generally to a number of population groups, typically cover entitlement programmes of one or more varieties. The CRPD recognizes in Article 28 the right of persons with disabilities to social protection without discrimination on the basis of disability and requires States to take appropriate steps to safeguard and promote the realization of the right to social protection.[40]

In addition, persons with disabilities and persons affected by HIV must have equal access to benefits, including drug benefits, and private health insurance. In no instance should a person with a disability or person living with or affected by HIV experience discrimination in access to housing. HIV-related laws as well as general anti-discrimination legislation and disability-specific legislation should provide comprehensive protection of the right to an adequate standard of living that protects persons with disabilities and persons affected by HIV.

2.17 Protection of Property Rights

International human rights law prohibits discrimination in the context of property rights.[41] The CRPD provides specific protection for persons living with disabilities, including those living with HIV. The CRPD requires States to ensure that persons with disabilities are not arbitrarily deprived of their property and protects against discrimination in:

- owning or inherit property;
- controlling of one's own financial affairs; and

[40] *Id.* at art. 28.
[41] Universal Declaration of Human Rights, G.A. Res. 217 (III), U.N. Doc. A/810, art.17 (1) (Dec. 12, 1948).

- access to bank loans, mortgages, and other forms of financial credit.[42]

In many countries, statutes and customary laws that prevent women from owning, controlling or inheriting property or controlling their own financial affairs similarly prevent persons with disabilities from doing so. This can seriously impact access to safe shelter and living arrangements, along with access to the basic necessities that help protect human health. Disability-specific legislation as well and HIV-related statutes should include guarantees to protect against discrimination pertaining to property.

Prohibiting Discrimination in Property Matters

Disability-Inclusion in Legislation: In **Tanzania**, the 1999 Land Act and Village Act voids or makes inoperative customary laws or decisions taken under customary law to the extent that it prevents equal access to land ownership, occupation or use for women, children or persons with disabilities.

Source: Tanzania, Village Land Act, No. 5 of 1999, section 20(2) 1999).

2.18 Liberty and Freedom of Movement

International human rights law secures for all persons the right to liberty and freedom of movement,[43] a right which is to be protected for persons living with HIV and persons with disabilities on an equal basis with others. These rights provide protection against practices such as quarantine or isolation in a special hospital ward based on HIV status or detention, segregation, or forced institutionalization of persons with disabilities.

HIV-related restrictions on entry, stay and residence are still maintained in some countries and clearly impact freedom of movement and the right to liberty. Entry restrictions based on HIV status are often based on public health grounds, but are not regarded as having any positive impact on prevention of HIV transmission.[44] Persons with

Examples of Freedom of Movement

Iceland does not restrict the movement of persons living with HIV/AIDS, as it allows them to travel to, and becoming a resident of Iceland without having to submit to an HIV test. Most importantly, there exist no regulations that require the deportation of a person found to have HIV/AIDS.

The **United States**, as of 4 January 2010, has lifted all restrictions preventing the entrance into the country of persons who are infected with HIV. Furthermore, the US has also removed the requirement that persons coming to the US must submit to an HIV test and gain a waiver of processing from the Department of Homeland Security.

Source:http://www.hivtravel.org/Default.aspx?PageId=143&CountryId=86; http://travel.state.gov/visa/laws/telegrams/telegrams_4631.htm

[42] CRPD, *supra* note 1, art. 12 (5).
[43] ICESCR, *supra* note 20, art. 12.
[44] *See* HIV Guidelines, *supra* note 11 at p. 40, ftn. 21.

disabilities can face numerous barriers in relation to their freedom of movement and face discrimination very often in seeking asylum on the basis of their disability. Restrictions on entry by adults or children with disabilities are often predicated on resource-related grounds, even where evidence clearly refutes such concerns. Persons living with HIV may likewise face restrictions on similar grounds. In both cases, such restrictions are discriminatory.

The CRPD requires States to observe the principle of non-discrimination in relation to freedom of movement, a right that applies also to persons facing restrictions based upon HIV status.[45]

In recognizing the rights of persons with disabilities to liberty of movement along with the freedoms relating to choice of residence and to nationality on the basis of equality, the CRPD requires that States take measures to ensure that persons with disabilities, including persons living with HIV:

- Have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability or HIV status;
- Are not deprived, on the basis of disability or HIV status, of their ability to obtain, possess and utilize documentation of their nationality or other documentation of identification;
- Are not deprived, on the basis of disability or HIV status, to utilize relevant processes such as immigration proceedings necessary to facilitate exercise of the right to liberty of movement;
- Are free to leave any country, including their own;
- Are not deprived, arbitrarily or on the basis of disability or HIV status, of the right to enter their country.

The right to liberty and freedom of movement must also be accorded to children, including children with disabilities and children affected by HIV. All children must be registered immediately after birth and have the right to acquire a nationality. In addition, children have the right to know and be cared for by their parents.[46]

2.19 Access to Community-based Solutions and Abolishing Coercive Measures

Isolation, quarantine, and other coercive measures have long been used to contain infectious disease. In addition, isolation and segregation of persons with disabilities and other coercive measures, such as forced treatment, have similarly been used against persons with HIV/AIDS. In both instances, such practices inevitably raise serious human rights concerns. They undoubtedly render those subjected to such practices even more vulnerable to abuse and exploitation which, in turn, compromises health and enhances risk

[45] CRPD, *supra* note 1, art. 18.
[46] *Id*.

for HIV infection. Some countries have opted for an absolute prohibition against the utilization of these practices in relation to HIV, whereas others have severely restricted them.

International standards specific to HIV, as well as disability, promote community-based care, as opposed to segregated or isolated care outside the community. International human rights law provides protections against segregation on the basis of HIV or disability and guarantees a range of rights intended to protect persons from violence, coercion and various forms of abuse.[47] The CRPD reinforces these protections and provides for specific measures to be undertaken to comply with such rules.

The CRPD requires that support services be available to persons with disabilities, including persons with HIV, to enable them to exercise their freedom to live in and be a part of the community.[48] In addition, the CRPD aims to ensure that parents with disabilities and children with disabilities have effective supports to enable them to live with their family in the community. For children who have lost one or both parents to AIDS, living in the community should not be compromised and alternatives to orphanages must be found in order to be consistent with the CRPD. Legislation in this context should address:

- Effective access to in-home supports, residential supports, and community necessary for persons with disabilities to live in and be a part of the community;
- Access to generic community services necessary to live in and be a part of the community; and
- Safeguards to ensure that services are effective in protecting persons with disabilities from isolation and segregation from the community.

2.20 Combatting Sexual Violence

Persons deprived of their freedom, whether in prison, detention facilities, psychiatric hospitals, social care homes, orphanages, or other institutional settings are at high risk of HIV infection on account of the prevalence of sexual violence in such contexts.[49] In addition, persons subjected to traditional practices, such as female genital mutilation, often acquire disability as a result and can remain at higher risk of HIV infection due to injuries. Child sexual abuse and child marriage likewise amplify risk of HIV infection.

Discrimination against persons with disabilities can create risk factors for HIV infection. For example, the myth of "virgin cleansing" to cure HIV infection puts women and girls with disabilities at risk on account of false assumptions about their sexuality and heightened vulnerability.[50]

[47] ICCPR, *supra* note 15, arts. 7 and 18.
[48] CRPD, *supra* note 1, arts. 19 and 25.
[49] *See generally* World Report on Disability, *supra* note 4.
[50] *See* Groce, *supra* note 9.

The State has a duty to combat violence in prison, including prison rape and other kinds of sexual violence that relates to HIV protection and prevention. States must also take measures to combat violence against persons with disabilities and persons living with HIV. In addition, persons held in detention have a right to access HIV-related information, and education as well as voluntary counselling and testing and treatment. For persons with disabilities who are detained in prison or in some other institution such as a psychiatric facility, reasonable accommodation must be provided which would include adjustments to ensure equal access to HIV protection and prevention as well as treatment.

2.21 Combatting Trafficking in Persons

Little is known about the relationship between disability and human trafficking and yet it is increasingly recognized that persons with disabilities, in particular woman and girls with disabilities, may be at higher risk of trafficking.[51] This increases the likelihood of sexual violence and abuse. Coercive migration is thus a major concern and must be understood as an issue for persons with disabilities.

Victims of trafficking must have access to services and they must be made accessible to persons with disabilities. The CRPD protects against all forms of violence and abuse and, importantly, requires States to take measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who are victims of exploitation, violence or abuse. It also requires States Parties to put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that trafficking and other exploitation, violence and abuse against persons with disabilities is identified, investigated and, where appropriate, prosecuted. [52]

2.22 Creating Empowering Legal Frameworks to Protect the Rights of Persons with Disabilities and Persons Living with HIV

UNAIDS underscores the importance of protecting the rights of persons affected by and vulnerable to HIV through national legal frameworks.[53] The three dimensions of creating a supportive legal environment, especially for vulnerable groups, include:

- Empowering communities to have access to justice: Accommodating persons with disabilities and persons living with and affected by HIV in legal aid and

[51] International Organization for Migration (IOM), *Thematic analytical study on violence against women and girls and disability* (undated), www2.ohchr.org/english/issues/women/docs/.../IOM2.doc; IOM *Caring for trafficked persons. Guidance for health-providers (*2009). http://publications.iom.int/bookstore/free/CT_Handbook.pdf
[52] CRPD, *supra* note 1 at art. 16.
[53] UNAIDS, Guidance Note, *Addressing HIV-related Law at the National Level* (Sept. 2008).

legal literacy programs; implementing campaigns against stigma and stereotyping and providing human rights training for key service providers;
- Ensuring respect for human rights in the context of law enforcement: For example, capacity building among law enforcement and judiciary on disability inclusion, for example through providing support to women with disabilities who are victims of sexual violence or ensuring that persons with disabilities are effectively accommodated in the criminal justice system;
- Creating enabling law and policy frameworks: For example, ensuring that non-discrimination applies to persons with disabilities and persons living with or affected by HIV, ensuring that reasonable accommodation is a requirement component of non-discrimination, including DPOs in law and policy development.

The *International Guidelines on HIV/AIDS and Human Rights* provide guidance to national governments in incorporating human rights principles into law and polices pertaining to HIV/AIDS. These Guidelines, used in combination with the human rights principles in the CRPD and other human rights conventions, provide supportive frameworks for translating international standards into national level action.

Laws Pertaining to HIV and Disability: Cross-Cutting	
Constitutional provisions: Provisions that accord protection to persons with disabilities, including in a non-discrimination provision.	**Constitutional provisions:** Provisions that accord protection to persons living with or affected by HIV, including in a non-discrimination provision.
Disability-specific legislation: An integral or comprehensive national law on disability or an inclusive education statute.	**HIV-specific omnibus legislation:** An omnibus HIV law or a specific HIV statute relating to employment.
General anti-discrimination legislation: Including disability-specific protection in a general equality and non-discrimination law.	**General anti-discrimination legislation:** Including HIV-specific protection in a general equality and non-discrimination law
Non-disability specific legislation: Laws that relate to a range of people but include specific reference to persons with disabilities (e.g., discrimination law, social security law, guardianship laws, criminal codes, electoral codes).	**Non-HIV specific legislation:** Laws that relate to a range of people but include specific references to persons living with HIV (e.g., inheritance, land law).

The CRPD and the *International Guidelines on HIV/AIDS and Human Rights* should form the basis of an audit of existing legislation to identify potential areas of reform to ensure that the rights of persons living with HIV and persons with disabilities are protected. This will require a thorough review and the identification of legislation that needs to be adopted, modified, or abolished to bring the domestic legal framework into alignment with international norms and standards. Such an audit or scoping exercise could form the basis of a national disability strategy. A disability strategy can complement a national

HIV/AIDS strategy to help set priorities for law reform and policy development. Such instruments may form part of a broader national human rights action plan or may stand alone. In either case, the governments must consult widely with persons with disabilities, persons living with HIV and other stakeholders.

The role of legislation in implementing the human rights of persons living with HIV and persons with disabilities should be understood as one among many methods of ensuring respect for rights in the context of HIV. Well drafted legislation that is ignored, not implemented, and not enforced will not help advance the rights of persons living with HIV or persons with disabilities. Legislation must be accompanied by the allocation of adequate resources to fund implementation. Monitoring mechanisms must be put into place with adequate human and financial resources to perform this role effectively. Institutional structures as well as national development and humanitarian policies and programmes must adopt inclusive practices. Raising awareness within institutions and the general public is essential. Moreover, stakeholders must have knowledge of and be able to claim and defend their rights.

Part 3: Inclusive National Institutional Arrangements for HIV and AIDS Response

Introduction

An effective response to the HIV epidemic requires more than the implementation of law reform and policy change. The establishment of responsive institutional structures - both within and independent of government - is essential for ensuring the inclusion of persons with disabilities, persons living with HIV, and other vulnerable groups in HIV and AIDS response.

Achieving public health goals associated with HIV responses that are consistent with human rights principles must be approached in a coordinated, cross-sectoral manner. Similarly, addressing the barriers that prevent persons with disabilities from accessing HIV-related services rests on the appreciation that disability is a cross-cutting issue that requires a holistic and comprehensive approach. The institutional arrangements and principles intended to guide both HIV response and disability rights implementation are complementary and should be utilized to inform and strengthen each other.

3.1 National Institutional Arrangements Supporting HIV Response and Disability Rights Protection

Efforts to make maximum use of available resources, improve response to the AIDS epidemic at both the national and international levels, and achieve progress in the realization of the Millennium Development Goals led to the adoption of the "Three Ones" principles.[54] This framework outlines the institutional arrangements required in order to improve national level AIDS response, in coordination with all relevant stakeholders, including national coordinating bodies, ministries, major funding mechanisms, multilateral and bilateral agencies, NGOs and the private sector.

"Three Ones" Principles: Improving National Institutional Arrangements for HIV and AIDS Response

In April 2004, the Consultation on Harmonization of International AIDS Funding—bringing together representatives from governments, donors, international organizations and civil society—endorsed the "Three Ones" principles as follows:

- One AIDS national action framework that provides the basis for coordinating the work of all partners;
- One national AIDS coordinating authority, with a broad-based multi-sectoral mandate; and
- One agreed country-level monitoring and evaluation system.

Source: UNAIDS, 'Three Ones' Key Principles – Coordination of National Response to HIV.AIDS Principles for National Authorities and their partners (2004), http://data.unaids.org/una-docs/three-ones_keyprinciples_en.pdf

National-level institutional arrangements to help monitor and support the implementation of disability rights obligations are required by the CRPD and have features similar to the approach taken with respect to AIDS response at the national level. The CRPD establishes national level monitoring, implementation and coordination mechanisms and requires data collection to facilitate the monitoring and evaluation of disability rights implementation.[55] It likewise prioritizes the participation of persons with disabilities in national level monitoring, along with decision-making processes more generally.[56]

Inclusive, country-led processes are likely to foster the establishment of strong institutional arrangements for both HIV and disability responses. Bodies such as national AIDS councils and national disability commissions should possess HIV- specific and disability-specific capacity and expertise. Such institutions should also be regarded as reinforcing of each other in relation to HIV and AIDS response.

[54] *See* UNAIDS, 'Three Ones' Key Principles – Coordination of National Response to HIV.AIDS Principles for National Authorities and their partners (2004), http://data.unaids.org/una-docs/three-ones_keyprinciples_en.pdf
[55] CRPD, *supra* note 1 at arts. 33 & 31.
[56] *Id.* at art. 33(3).

The National Level Institutional Arrangements for CRPD Implementation

- The designation of one or more focal points within government for matters relating to implementation of the CRPD;
- The establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels;
- One or more independent national human rights institutions;
- Participation of civil society in national monitoring; and
- Data collection to monitor and evaluate CRPD implementation.

Source: Convention on the Rights of Persons with Disabilities, arts. 33 and 31.

Table 2: Cross-Cutting, Integrated Approaches to AIDS and Disability Response

AIDS Response	Disability Response
Coordination of National AIDS Response	Coordination of Disability Policy across government
One National AIDS Action Framework	National Disability Strategies or Plans of Action (optional)
One national coordinating authority	Coordination mechanism within government (optional)
One national monitoring and evaluation system fully integrated into the national AIDS framework & inclusive of indicators	One independent monitoring system
Civil society participation, including broad stakeholder participation in formulation of AIDS framework	Participation by persons with disabilities and their representative organizations in disability policy

3.2 National Action Planning for HIV and AIDS Response

The institutional framework for HIV and AIDS response requires the development of a national AIDS action framework. Key stakeholders must be involved in developing, reviewing, and updating the frameworks. This requires, for example, that persons living with HIV, persons with disabilities, women, migrant workers, men having sex with men, and others must participate in all aspects of the formulation of the framework in order to ensure that their interests are protected and respected.

Specific outreach efforts are clearly required in order to build a meaningfully inclusive process. The establishment of strong linkages between disabled peoples organizations and national AIDS councils and AIDS action groups, local mechanisms and those who deliver AIDS-related services is important in order to ensure broad participation in the development, review and periodic updating of national AIDS action frameworks (i.e., strategic visions or plans). The participation of the disability community in AIDS action frameworks fulfils a dual function in that it enhances linkages between persons with disabilities and national authorities and also between the disability community and bilateral and multilateral donors, international institutions, and civil society.

National AIDS Frameworks: Protecting the Human Rights of Persons with Disabilities and Persons Living with HIV

Malawi National HIV/AIDS Policy

- Guarantees freedom from discrimination based on HIV or AIDS status.

South African Labor Employment Act

- Ensures the elimination of workplace discrimination based on HIV or AIDS status.

Afghanistan National HIV Code of Ethics

- Expounds the need for individuals to receive treatment, diagnosis, and support for their HIV or AIDS devoid of discrimination.

Sources: Office of the President and Cabinet National AIDS Commission, Malawi National HIV/AIDS Policy, 2003; South African Department of Labor Employment Equity Act, Act No. 55 of 1998 (1998); Afghanistan National HIV Code of Ethics, HIV and AIDS Coordinating Program, DG Preventive Medicine and Primary Healthcare (2007).

The development of a national AIDS action framework presents important opportunities to ensure that the needs and rights of persons living with HIV, persons with disabilities and other vulnerable populations have their interests addressed.

3.3 National AIDS Coordinating Authority

Effective HIV and AIDS response requires carefully coordinated, cross-sectoral action. National AIDS authorities are expected to address vertical and horizontal coordination and yet too often they face capacity challenges in meeting country objectives in relation to HIV response and universal access. While many national AIDS authorities lack the capacity they need for planning, resource mobilization, coordination, information management, and monitoring and evaluation, especially in relation to underserved populations such as persons with disabilities, disability advocates, DPOs, national disability councils and disability focal points in government ministries or in national human rights institutions can provide assistance in ensuring inclusive HIV response. Such support can help to achieve broad multi-sectoral participation.

3.4 National Level Action Planning and Institutional Arrangements for Disability Rights Implementation

In the same way that national HIV institutional frameworks should be mobilized for and responsive to disability-related human rights concerns, national level institutional arrangements and national disability action planning must take HIV into account. The CRPD stands out among the core human rights conventions because it devotes specific language to the issue of national level monitoring. CRPD Article 33, National implementation and monitoring, requires States Parties to establish specific mechanisms at the national level with a view to strengthening implementation and monitoring of the rights of women, men, and children with disabilities. The CRPD requires States to:

- Designate a focal point or focal points within government relating to implementation – in other words, a designated office or other entity that has primary responsibility for overseeing implementation of the CRPD;
- Consider the establishment or designation of a co-ordination mechanism within government to facilitate related action in different sectors and at different levels; and
- Establish an independent framework, such as a national human rights institution, to promote, protect and monitor the CRPD.[57]

Article 33 further requires that civil society, in particular persons with disabilities and their representative organizations, be involved and participate fully in all aspects of monitoring. Disabled people's organizations thus have an important role to play in ensuring that they are effectively engaged in monitoring at the national level.

An important tool for national level disability rights monitoring is the national disability action plan.[58] Such plans must take into account and complement national efforts on HIV prevention, treatment, care and support. Other mechanisms of national monitoring are also relevant for effective implementation of the CRPD. For example, national courts and tribunals can ensure legal protection of the rights in the CRPD. A national process that monitors a national human rights action plan is also effective for the advancement of disability rights.

3.5 National Level Monitoring and Evaluation Systems

Monitoring the HIV epidemic and the response is essential in order for national AIDS authorities for sound decision-making on the allocation of limited resources and in order to respond rapidly to emerging trends. The evaluation of HIV-related programmes makes it

[57] CRPD, *supra* note 1 at art. 33.
[58] Eilionoir Flynn, *From Rhetoric to Action Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2011); UNAIDS.

possible for national AIDS authorities to understand whether they are achieving their objectives and, if not, to take appropriate action.

The Three Ones framework endorsed by UNAIDS calls for monitoring and evaluation activities to be arranged under the umbrella of a unified national strategic plan. In other words, every country should develop a single set of standardized monitoring and evaluation indicators endorsed by key stakeholders in the country. In addition, the model requires a strong national information system that ensures information sharing among all the stakeholders at the national, district, and local levels. In this context too, persons with disabilities and their representative organizations must participate and contribute to the development and implementation of monitoring and evaluation plans.

Part 4: Ensuring Disability Inclusion in HIV/AIDS Programming

Introduction

The 2011 UN General Assembly Resolution, *Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS*, reaffirms earlier commitments to undertake measures to attain the goal of universal access to comprehensive HIV prevention, treatment, care, and support. It makes clear that universal access cannot be achieved absent a concerted effort to scale up efforts to reach persons with disabilities along with other vulnerable groups. Reaching persons with disabilities is a precondition to effective HIV response and positive public health outcomes.

> The *Political Declaration on HIV and AIDS* expresses "concern that prevention, treatment, care and support programmes have not been adequately targeted or made accessible to persons with disabilities."
>
> Source: *Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS*, G.A. Res. A/65/L.77, U.N. Doc. A/res/65/277, ¶ 31 (July 8 2011).

4.1 Understanding Barriers to Disability Inclusive HIV/AIDS Response

Achieving universal access in relation to HIV/AIDS prevention, treatment, care and support requires ensuring that populations who are marginalized and face discrimination have equal access to quality care and support services. To achieve universal access for persons with disabilities, it is important to recognize barriers that prevent or impede persons with disabilities from fully accessing HIV prevention, treatment, care, and support.

Barriers to Available, Accessible, Acceptable and Quality Disability-Inclusive HIV Prevention, Treatment, Care and Support

Lack of Availability: HIV-related facilities, goods, and services, including HIV prevention, treatment, care and support are often not available to persons with disabilities; health care providers are not qualified in sufficient numbers to provide disability-specific support and accommodation in HIV prevention, treatment, care and support services.

Barriers to Accessibility: Accessibility requires attention to discriminatory, physical, economic and information barriers.

- **Discrimination**: Stigma and discrimination create barriers to HIV prevention, treatment, care and support for persons with disabilities.
- **Physical inaccessibility**: HIV and AIDS prevention, treatment, care and support are often inaccessible to persons with disabilities, including HIV testing and treatment centres, because of physical barriers, poor coordination of health servcies and lack of transport.
- **Economic inaccessibility**: Consumers with disabilities often live in poverty which limits their access to HIV prevention, treatment, care and support; persons with disabilities may not enjoy equal access to health facilities, goods and services, including medicines and assistive devices.
- **Information inaccessibility**: Prevention information, information relating to treatment, care and other matters, are inaccessible to persons with disabilities; and persons with disabilities are often wrongly judged to lack the capacity to make or participate in decisions about their treatment and care.

Unacceptable HIV and AIDS facilities, goods, and services: Persons with disabilities often experience disrespectful treatment in the context of HIV and AIDS; informed consent procedures are not respected for persons with disabilities; confidentiality and privacy of persons with disabilities is often breached.

Poor quality HIV and AIDS facilities, goods, and services: HIV treatment personnel are unfamiliar with disability issues; disability-inclusive practices are absent within evidence-based interventions; equipment and facilities are not adapted or accessible.

In addition to stigma and disability discrimination, numerous barriers impede access to HIV prevention, treatment, care, and support for persons with disabilities. Too often,

prevention and treatment facilities are physically inaccessible for persons with mobility impairments. Essential information is often not accessible to persons with disabilities, for example because written materials cannot be accessed by persons who are blind or radio messaging cannot be accessed by persons who are deaf. Inaccessibility is a serious issue at schools, training venues, and community centres where HIV education is provided. Too often, children with disabilities are a large segment of the out of school population and thus miss out on school-based HIV education. HIV/AIDS and other public health programme implementers have little awareness of disability issues or a history of engagement with disabled people's organizations (DPOs). Individuals who provide technical assistance to implement HIV programmes more often than not possess no disability expertise and therefore leave disability out of their assessments and other work product (e.g. design of household surveys; strategies for outreach). Finally, DPOs are rarely identified as target constituents in drafting national AIDS strategies and plans.

Persons with disabilities–and the organizations they form–can meaningfully and fully engage in HIV/AIDS programming. The forms of engagement include interventions: to educate people about HIV; to provide them with HIV prevention commodities, services, and treatment; to protect them from discrimination and sexual violence, and to empower them to participate in the response. Consultation with persons with disabilities and DPOs is the key to an effective disability inclusive response in HIV programming. It is also a requirement under the CRPD which provides that persons with disabilities must be consulted in decision making on law, policy, and programming. Meaningful participation recognizes the expertise of DPOs and promotes their ownership and sustained engagement.

4.2 Thinking about Disability Inclusion in HIV/AIDS Programming

Poverty, lack of education, poor living conditions, and other human rights issues that impact human health disproportionately affect persons with disabilities. For instance, in many countries, clean water may be publicly available but not accessible to persons with disabilities. Likewise, health care is often not accessible or available to persons with disabilities on an equal basis with others because of factors like inaccessible buildings, lack of communications accommodations in the health care setting, and even denial of treatment based on a disability.

While governments and societies cannot be expected to take responsibility for ensuring that people do not experience any illness or disease, they are responsible for addressing factors in the social, economic, legal, and physical environment that impact health. Therefore, health as a human rights issue is framed in terms of the "highest attainable standard of health." In other words, people have a right to the conditions and resources that promote and facilitate a healthy life. The right to health includes access to vital public

health programming that seeks to prevent HIV/AIDS as well as treat those who are living with HIV/AIDS.

4.3 Reasonable Accommodation and Accessibility in HIV/AIDS Programming

Non-discrimination in the context of HIV/AIDS programming and disability requires the provision of reasonable accommodation. Reasonable accommodations must be provided in relation to HIV prevention, treatment, care and support in order to facilitate equal access to such services by persons with disabilities.

Accessible Practice in HIV/AIDS Programming

Kenya: A health NGO offers special HIV voluntary counselling and testing services for persons who are deaf. The services include confidential HIV counselling and testing at clinics managed by staff who are deaf; mobile VCT activity and community mobilization in urban and rural deaf communities; support to clients who are deaf in need of referral and care; establishment of post-test support groups within deaf communities; and development of communication materials.

Source: UNFPA and WHO, Promoting Sexual and Reproductive Health for Persons with Disabilities (2009), http://whqlibdoc.who.int/publications/2009/9789241598682_eng.pdf

In addition, accessibility is a general principle of the CRPD and is essential to making HIV/AIDS programming inclusive of persons with disabilities.[59] Accessibility in this context aims to eliminate the barriers that stand in the way of full access by all persons with disabilities to HIV/AIDS programmes (and other health programmes). This concerns not only the removal of physical barriers, such as stairs to health care facilities or outreach centres, but also the removal of barriers to information, technologies, transport and communication. The provision of ramps, mobility aids, accessible transport, sufficiently large and unblocked corridors and doors, the availability of HIV/AIDS information in Braille and easy-to-read formats, the use of sign language interpretation and interpreters, and the availability of assistance and support can ensure that persons with disabilities have access to the full spectrum of HIV/AIDS programming.

The failure to respect the principle of accessibility and to provide reasonable accommodations to persons with disabilities in their access to HIV/AIDS programming constitutes a human rights violation.

[59] CRPD, *supra* note 1, art. 9.

4.4 HIV Prevention Programming

Ensuring equal access to HIV prevention programming for persons with disabilities requires specific measures to be undertaken in order to facilitate inclusion. These can take the form of individual reasonable accommodations or other measures that seek to ensure broad accessibility.

Thus, persons who are blind could be accommodated by ensuring that written materials are provided in large print, Braille or electronic format depending on their needs, and that materials held up for viewing in education sessions are passed around for tactile viewing. Condom distribution efforts must include not only community based installation of condom vending machines, but ensure distribution in other areas where persons with disabilities may be, such as rehabilitation community centers or DPO offices. Sign language interpreters must be available for participants who are deaf in education sessions and other accommodations, such as pictorial materials, should be made available for persons who cannot read, such as persons with intellectual disabilities.

Disability Inclusive HIV and AIDS Programming in Zambia

The PEPFAR-funded public-private partnership, Reaching HIV and AIDS Affected People with Integrated Development and Support (RAPIDS), project in Zambia has helped 260,000 children access health care, education, and psychosocial support. RAPIDS trained more than 19,500 volunteer caregivers and provided them with supplies to support 65,790 people living with HIV. Youth prevention activities have reached almost 100,000 youth through trained volunteer peer educators who also teach livelihood skills.

Working in collaboration with the American Institutes for Research (AIR) and BlueLaw International, World Vision placed a disability advocate to provide technical assistance and disability expertise within their mainstream programme. In addition, World Vision staff were trained by BlueLaw and AIR on disability inclusion, as were members of the disability community who took part in HIV outreach efforts. Specialized workshops were also held on international disability rights standards and the Convention on the Rights of Persons with Disabilities. Finally, lessons learned were compiled and disseminated within USAID as a follow-up to the programme in order to educate other PEPFAR implementers on disability inclusion and the barriers that persons with disabilities face in the context of HIV prevention, treatment, care and support.

Source: For more information see Kate Fleming, et al., Vulnerability for Households with Persons with Disabilities and HIV/AIDS in Chongwe, Zambia (Washington, DC: American Institutes of Research, 2009).

Some examples of general measures to help ensure access for all include:

- Undertaking disability audits in HIV programmes to identify barriers and possible solutions;

- Fostering the inclusion of persons with disabilities as personnel in HIV programme implementation;
- Including persons with disabilities on HIV outreach training teams and other relevant training endeavors;
- Improving the capacity of VCT, care and treatment through disability awareness training;
- Designing HIV education and outreach materials to include the voice and image of persons with disabilities and engaging DPOs in such outreach;
- Developing HIV education materials that are accessible and make use of Braille, sign language, and other modes and means of communication and alternative formats;
- Including a disability component in teacher training programmes geared towards HIV response;
- Ensuring that the reform of public health frameworks and the formulation of national AIDS strategies and plans are done in consultation with DPOs and consistent with international standards on disability;
- Recognizing the high risk of sexual violence that persons with disabilities may experience, and providing accessible assistance programmes and training to help eliminate such risk; and
- Conducting research to understand what programmes work for disabled populations and why;
- Conducting research on what specific clinical needs might exist for persons with disabilities vis-à-vis AIDS distinct from those of the general population (e.g., the combination of psychotropic medications taken in conjunction with antiretroviral); and
- Monitoring and evaluating the small number of pilot projects on HIV/AIDS and disability that already exist.

4.5 Integrated Programming

Integrated HIV prevention, treatment, care and support programming across sectors and in relation to development planning, including in poverty eradication, is important for a comprehensive HIV response. The implications for disability inclusion in the context of HIV programming is clear – persons with disabilities and their representative organizations must be meaningfully involved in the formulation and implementation of national development, whether in the health, education, employment, sport, poverty eradication, or other sectors. Their absence is likely to result in missed opportunities for inclusion and, as a result, compromises the goal of universal access.

4.6 Inclusive Budgeting

Inclusive HIV prevention, treatment, care and support programming must take into account budgeting for reasonable accommodations and other specific measures in order to facilitate the participation of persons with disabilities within programming. All too often, programmes do not provide reasonable accommodations for persons with disabilities, thus compromising access to programme materials, activities and facilities. HIV/AIDS programme implementers should include a line item for reasonable accommodations in their programme budgets. The budget note that corresponds with the line item should provide some specific information about how the funding will be allocated towards reasonable accommodations that are necessary and appropriate to ensure equal access for persons with disabilities. For example, budgetary notation could state that reasonable accommodation funding will be used to provide HIV education materials in alternate formats, as well as providing a sign language interpreter for trainings. While there is no set amount to allocate for reasonable accommodations, programme implementers should consider all the possible accommodations necessary for implementation of programme activities and develop their reasonable accommodation budget line consistent with carrying out those activities in an accessible manner. Furthermore, donor organizations should provide budget templates and samples that include line items for reasonable accommodations so that implementing partners understand the need to account for disability inclusion in costing.

Budgeting for Disability Inclusion in HIV and AIDS Programming

Budget analysis is a useful analytical tool that can help to determine:

- Commitment to disability inclusion as a prioritized policy area, and contrasting that commitment to other lower-priority areas;
- Trends in spending in HIV and AIDS programming to ensure that programmes aimed at reaching persons with disabilities receive a growing share of budget over time;
- The cost of policies concerning disability-inclusion in HIV and AIDS programming;
- The impact of budgetary choices on persons with disabilities; and
- The adequacy of HIV and AIDs programming budgets in relation to CRPD obligations.

Source: For more on human rights budgeting in general, see Fundar – Centrode Análisis e Investigación, International Budget Project,International HumanRights Internship Program, Dignity Counts: A guide to using budget work to advance human rights (2004), http://www.iie.org/Programs/IHRIP/Publications

4.7 Inclusive Monitoring and Evaluation

Monitoring the use of resources in the context of HIV and AIDS programming requires the regular assessment of activities to track the progress of programmes. Financial management (monitoring the use of resources) and programme activity monitoring (monitoring progress in implementation of activities) are important dimensions of monitoring for inclusion.

> *"Evaluation is the systemic collection and analysis of information about the characteristics and outcomes of programs and projects as a basis for judgments, to improve effectiveness, and/or inform decisions about current or future programming."*
>
> Source: USAID, USAID Evaluation Policy, January 2011, http://www.usaid.gov/evaluation/USAID_Evaluation_Policy.pdf.

Evaluation in the context of HIV and AIDS programming requires the periodic assessment of accomplishments, achievements and impacts of projects and activities. It should occur during the course of programme implementation and also at conclusion of programming. Evaluation for inclusion should examine the quality of implementation (process), the plausible outcomes (outcome) and overall changes (impact). Quality evaluation can elicit useful information on the effect of a programme in relation to a specific population (i.e. persons with disabilities) and lessons learned which can, in turn, inform approaches to inclusive policy, programmes, and activities.

Very few monitoring and evaluation efforts incorporate a disability lens in development programming. This is problematic as the objective of evaluation is to ensure accountability to stakeholders and to foster learning in order to enhance effectiveness. HIV/AIDS programme implementers cannot determine whether and how a project effectively includes persons with disabilities without incorporating a disability lens in monitoring and evaluation efforts. Additionally, monitoring and evaluation efforts that do not include a disability lens have negative implications on budgeting for disability inclusion. Accordingly, it is essential that monitoring and evaluation efforts integrate a disability lens into the monitoring and evaluation framework to ensure that HIV/AIDS programme implementers effectively budget for disability inclusion during project design and report on their use of funds for disability-related project components.

It is variously argued that disability is difficult to include in monitoring and evaluation efforts. One of the primary reasons for this challenges focuses on the difficulty of tracking the number of persons with disabilities who participate in a project because not everyone has a visible disability and many people with hidden disabilities may not feel comfortable self-reporting. Although this is important information to consider, this is not at all a sound basis for continuing to exclude disability data in monitoring and evaluation and, in fact, runs counter to international standards, including the CRPD.[60] It is essential that HIV/AIDs programme implementers initiate the development of innovative indicators and outputs that have a disability lens but do not require people to self-report on their disability or require programme staff to try to determine if someone has a "hidden" disability. Such an initiative would bring HIV/AIDS programme implementers into alignment with international standards on disability data and statistics.

[60] CRPD, *supra* note 9, at art. 31.

The following indicators serve as useful examples for HIV/AIDS programmes:

- Number of mass media behavior change communications (BCC) that are accessible to persons with various disabilities (e.g. accessible behavior change message for persons who are deaf).
- Number of persons with disabilities trained in BCC strategy development.
- Number of persons with disabilities trained as peer educators.
- Number of peer education trainings for DPOs.
- Number of persons with disabilities served by programme.
- Number of pregnant women with disabilities who received HIV counseling and testing.

Programme implementers should also utilize qualitative methods in monitoring and evaluation efforts that include: detailed document review, case studies, focus groups, project site visits and direct observations, and semi-structured key informant interviews.

4.8 HIV Treatment, Care and Support

Comprehensive treatment, care and support, includes the provision of antiretroviral and other medicines; diagnostics and related technologies for the care of HIV and AIDS, related opportunistic infections and other conditions; good nutrition; and social, spiritual and psychological support; and family, community and home-based care. HIV-prevention technologies, such as sterile injection equipment and antiretroviral medicines (e.g. to prevent mother-to-child transmission or as post-exposure prophylaxis) and, once developed, safe and effective microbicides and vaccines must be made accessible to all. States have an immediate obligation to take steps, and to move as quickly and effectively as possible, towards realizing access for all to HIV prevention, treatment, care and support at both the domestic and global levels. This requires, among other things, setting benchmarks and targets for measuring progress.

Part 5: Participatory Exercises

Introduction

The participatory exercises contained in this chapter aim to generate dialogue around key issues pertaining to disability inclusion in HIV and AIDS law, policy, and programming. The purpose of these exercises is to generate dialogue and understanding around key concepts and issues relevant to disability inclusion.[61]

[61] The exercises are drawn from and/or inspired by the comprehensive curriculum on the Convention on the Human Rights of Persons with Disabilities developed by One Billion Strong: Janet E. Lord et al., *Human Rights. YES! Action and advocacy on the rights of persons with disabilities*, second edition 2012.

Exercise I: Myths and Stereotypes about Persons with Disabilities and Persons Living with HIV

Objective:	To identify common myths and stereotypes about persons with disabilities and persons living with HIV that result in discrimination
Time:	45 minutes
Materials:	Optional: Copies of "Myths and Stereotypes associated with HIV/AIDS and Disability" [See below]

1. Introduce:

To introduce the exercise, explain that discrimination is often based on mistaken ideas and stereotypes that one group holds about another. This exercise will examine the impact of these myths and stereotypes on the lives of persons with disabilities and persons living with HIV.

2. Brainstorm/Analyze:

Divide participants into small discussion groups and ask them to develop a list of myths and stereotypes about persons with disabilities and persons living with HIV. Ask each group to discuss these questions:

- What are some underlying reasons for these views (e.g., fears, cultural and religious attitudes, ignorance)?
- How do these views affect the way persons with disabilities and persons living with HIV are regarded and/or treated by their families? By their communities? In public policy and law?

3. Report/Discuss:

Ask a spokesperson from each group to summarize their conclusions and discuss their findings.

- What seem to be the principal underlying reasons for these myths and stereotypes around disability and around HIV?
- What seem to be the most serious effects of these myths and stereotypes on an individual with a disability or a person living with HIV? On society?

4. Identify Links

Identify the links between the myths and stereotypes outlined above and the impact of these ideas on the human rights of persons with disabilities and persons living with HIV. Discuss these or similar questions:

- Which of these views are most prevalent where you live or where you are working?
- How do these views result in discrimination and prevent persons with disabilities from enjoying their human rights? How might these views affect development programs in the health sector? How could this impact

development results? Do you think these views have an impact on HIV/AIDS programmes? If so, how?
- How can these views be confronted?

Conclude the exercise by distributing the handout "Myths and Stereotypes associated with HIV and Disability." Compare this list with that generated by participants and ask questions like these:

- Were your lists similar to this one?
- Were there ideas on this list you did not include? Did this list omit ideas you included on your lists?
- How do you explain any differences between your list and this one?
- Do you disagree with any of the statements on this list?
- Did this list make you aware of new points of view?

Myths and Stereotypes associated with HIV and Disability

Persons with disabilities –

- •are asexual and do not need any sexual or reproductive health care;
- •do not need to be included in HIV/AIDS programming;
- •always need special, separate HIV/AIDS educational programs;
- •are unable to learn;
- •(Persons with intellectual disabilities) cannot be accommodated in HIV prevention;
- •(Deaf persons) must use alternative ways of communicating because they are stupid.

Persons living with HIV –

- •are immoral
- •are responsible for their health status
- •should be physically isolated and restricted in their movement
- •are contagious and can pass along the infection through casual contact
- •are unfit for work and cannot be accommodated in the workplace
- •are unsafe and should not be allowed to participate in recreational activities with others

Note: This list may be utilized by the facilitator to assess participant response and to fill in gaps. Alternatively it could be distributed as a handout.

Exercise 2: Understanding Disability Inclusion in National AIDS Strategies

Objective:	To understand rights and responsibilities associated with the right to the "highest attainable standard of health" in the context of HIV/AIDS programming for persons with disabilities and persons living with HIV
Time:	45 minutes
Materials:	Paper and pen/pencil or chalkboard and chalk

1. Introduce/Brainstorm:

Emphasize that achieving human health involves both rights and responsibilities. As part of the right to health, States are obligated to undertake steps to prevent, treat, and control epidemic diseases such as HIV. Divide participants into small groups and ask each group to choose one health topic related to HIV/AIDS programming from the list below:

Topics for discussion:

- Information about how to access HIV/AIDS services
- Access to Information about HIV/AIDS treatment and prevention
- Access to Treatment
- Access to antiretroviral medications
- HIV/AIDS Counselling
- Other topics of relevance issues in your community?

Explain that each group should:

a) List what people's rights are regarding this HIV/AIDS issue.

b) Decide what the government's responsibilities are regarding this HIV/AIDS issue.

c) Decide what HIV/AIDS programme implementers, whether local or international, must do to support this issues. Consider the role that disabled peoples organizations and AIDS action organizations might play to support this issue.

d) Decide what individuals must do for themselves.

Demonstrate how to structure and record the discussion using a chart like that below.

Topic: Accessible HIV/AIDS Information		
Human right: Persons with disabilities have a right to information that is accessible. All persons must have equal access to information about HIV/AIDS.		
Government Responsibilities	**HIV/AIDS Programme Implementer Responsibilities**	**Individual Responsibilities**
Make accessible information available	Make materials accessible to consumers with disabilities	Request information in accessible formats
Topic: Equal access to antiretroviral therapy		
Human right: Persons living with HIV have the right of equal access to treatment. No one living with HIV should face discrimination in their access to antiretroviral therapy.		
Government Responsibilities	**HIV/AIDS Programme Implementer Responsibilities**	**Individual Responsibilities**
Prohibit discrimination in access to medical treatment by law	Put measures in place to ensure access to treatment; do not deny treatment on the basis of disability	Request reasonable accommodation if needed

2. Report:

Ask a spokesperson from each group to present their findings.

3. Discuss:

- What measures must a government meet its responsibility to implement this human right? Is your government succeeding in implementing this right?
- What must individuals do to meet their responsibility to implement this human right? Do you think most people understand their responsibilities?
- What special measures should governments take to ensure that persons with disabilities enjoy this human right?

Exercise 3: Analyzing Disability Inclusion in National AIDS Strategies

Objective:	To identify opportunities to include disability rights concepts and principles in national AIDS strategies to advance disability inclusion and to identify opportunities to address HIV-related issues within the context of national disability strategies.
Time:	45 minutes
Materials:	Optional: copies of national AIDS strategies

1. Introduce/Analyze:

Emphasize that national level institutional arrangements, such as national AIDS strategies and national disability action plans, should be consistent with and help to advance the rights of persons with disabilities, including persons living with HIV. States are obligated to consult with persons with disabilities and their representative organizations and AIDS action organizations in the development, implementation, and monitoring of institutional arrangements. Divide participants into small groups. Ask each group to analyze a national AIDS strategy and a national disability strategy.

You may find samples at:

World Bank website - national AIDS strategies:

http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTHEALTHNUTRITIONANDPOPULATION/EXTHIVAIDS/0,,contentMDK:21024859~menuPK:4268557~pagePK:210058~piPK:210062~theSitePK:376471,00.html

World Health Organization website, national disability strategies:

http://www.who.int/disabilities/policies/documents/en/index.html

Groups should consider, as part of their analysis:

AIDS action framework

- Are persons with disabilities acknowledged as a vulnerable group in the national AIDS strategy?
- Does the AIDS strategy reference non-discrimination and, as a core element of non-discrimination, the duty to provide reasonable accommodation for persons with disabilities?
- Are specific measures indicated in order to ensure that persons with disabilities have equal access to HIV prevention, treatment, care and support?
- Does the monitoring and evaluation framework disaggregate data on the basis of disability?
- What other aspects of the AIDS action framework either acknowledge or fail to acknowledge a disability dimension?

National disability strategy

- Are persons living with HIV or HIV-related issues referenced in the national disability strategy?
- Are persons living with HIV recognized as persons with disabilities and as stakeholders in the national disability strategy?
- What other aspects of the national disability strategy either acknowledge or fail to acknowledge persons living with HIV?

2. Report:

Ask a spokesperson from each group to present their findings, noting key observations.

3. Discuss:

- How might AIDS action frameworks and national disability strategies be more inclusive of disability and HIV-related matters, respectively?
- What strategies might be used to ensure inclusion in the development of AIDS action frameworks and national disability strategies?
- How might AIDS action organizations and DPOs work together to ensure that national AIDS frameworks, national disability strategies, and all development instruments (such as Poverty Reduction Strategy Papers) are inclusive?

Exercise 4: Identifying Barriers and Designing for Inclusion in HIV/AIDS Programming

Objective:	To identify the barriers that persons with disabilities face in accessing HIV/AIDS programming and generate workable solutions
Time:	45 minutes
Materials:	Copies of Article 25 of the UN Convention on the Rights of Persons with Disabilities

1. Brainstorm:

Ask participants to give examples of barriers that prevent persons with disabilities from accessing HIV/AIDS programmes in the following areas:

- HIV prevention education
- HIV voluntary testing and counselling
- HIV treatment, including access to antiretroviral drugs
- HIV care and support services

Note to Facilitator: Adapt these scenarios to the needs and context of your participants (e.g., use other settings, other disabilities, other issues relating to HIV/AIDS, including those related to sexuality and reproduction-related or other barriers).

2. Introduce:

Observe that even when HIV prevention, treatment, care and support services are available to the general population, persons with disabilities often face barriers in accessing them. Divide the participants into small groups and give each one a specific topic to address relating to inclusive programming.

Give these instructions:

- Read the topic scenarios and discuss:
- What factors are working to prevent equal access and accommodation in the scenario?
- What are the accessibility barriers, or potential barriers, at issue?
- Where can additional information about access be found to better inform programming?
- What specific solutions are needed to provide reasonable accommodation and general accessibility? What resources do these solutions require?
- What kind of training would HIV/AIDS educators and health professionals require to make sure they can provide the best care (e.g., accessibility training, education on the rights of persons with disabilities)?

Topic Scenario 1:

José is a wheelchair user who is paralyzed from the waist down. He has come with his friends to the community center to participate in HIV/AIDS education session. The session is to be held on the second floor and there is no elevator. He overhears one of the HIV educators says that he is unlikely to need such information since he has a physical disability. He leaves the center.

Topic Scenario 2:

Alika is deaf and comes to an HIV/AIDS testing center alone. She is literate and can communicate in writing. She is seeking voluntary testing and she also wants to know where in the community she can find HIV prevention information so that she and her Deaf friends can learn more. She is concerned that much of the information may not be accessible to them.

Topic Scenario 3:

Karen has an intellectual disability. She is 28 and lives with her family. She has an independent social life, a boyfriend and a job selling fruit in the market. Karen's mother has planned to take her to the local HIV counselling center. The local counselling center is planning a strategy to ensure that the human rights of persons with disabilities are respected in the context of their work. They want to ensure that they have planned appropriate disability accommodations for persons with disabilities, including persons with intellectual disabilities.

Topic Scenario 4:

Marco is head of a local disabled people's organization that is cross-disability in its membership, including persons with many different types of disabilities (e.g., physical, sensory, intellectual, psycho-social). He has asked a local HIV prevention project to design and implement an HIV awareness campaign that will reach persons with disabilities across the country.

3. Discuss:

- What can be done to ensure that people with disabilities receive equal access to HIV prevention, treatment, care and support programmes?
- What kind of training do HIV prevention, treatment, care and support personnel need to make sure they can provide the best care to people with disabilities?
- How might disabled peoples organizations (DPOs) be involved?
- How might AIDS action organizations be involved?
- How might DPOs and AIDS action organizations work together to advance inclusion in programming?
- Are there any extra resources required in order to ensure inclusion? People resources? Budget resources?
- What role would monitoring and evaluation play in ensuring disability inclusion in programming?

Optional Exercise:

Design an accessible medical treatment centre. Either draw what the room would look like or simply list the features it should have to be accessible to persons with all types of disabilities.

Conclusion

This Thematic Guide was developed to provide concrete suggestions on how to protect the rights of persons with disabilities and persons living with HIV in the context of HIV prevention, treatment, care and support. It has emphasized the importance of engaging all those affected by HIV in responses consistent with human rights principles. It provides an overview of HIV-related human rights and suggests concrete ways of taking action in their own programmes and through joint efforts with the national AIDS coordinating authority, under the principles of the "Three Ones."

The promotion and protection of the human rights of persons with disabilities are a neglected but much needed component in the global response to AIDS. A concerted effort is required in order to strengthen the political commitment to disability equality in national HIV responses, to translate that into programmatic action in communities and to ensure accountability for results. Governments, together with civil society, national human rights institutions, multilateral partners and others, must all work together, in a coordinated way, to ensure that the response to HIV is rooted in the principles of non-discrimination, participation and inclusion and disability equality.

Annex

Contents of Annex:

Core Resources Related to HIV/AIDS, Disability and Discrimination

CBM, From Exclusion to Part of the Solution, Lessons Learned Along the Way: Making HIV/AIDS Strategies Inclusive of People with Disabilities in Tanzania (July 2012), http://www.cbmus.org/site/DocServer/CBM-LESSON-LEARNED.pdf?docID=981

Convention on the Rights of Persons with Disabilities, G.A. Res 61/106, U.N. DOC A/RES/61/106 (Dec. 13, 2006).

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HEARD, National Responses to Disability and HIV in Eastern and Southern Africa (Feb. 2010).

Human Rights Watch, HIV and Disability (2012), http://www.hrw.org/news/2012/07/20/hiv-conference-include-people-disabilities. (Easy to read version also available at this website).

International Labour Office, *An ILO Code of Practice on HIV/AIDS and the World of Work* (2001).

Lance Gable, et al., *Legal Aspects of HIV/AIDS: A Guide for Policy and Law Reform*, (World Bank, 2007).

Nora Groce, "HIV/AIDS and Disability," 8 *Health and Human Rights*, 215-225 (2005)

Nora Groce and Reshma Trasi, *"Rape of individuals with disability: AIDS and the Folk Belief of Virgin Cleansing,"* 363 LANCET at 1663-1664 (2004).

Nora Groce, et al, *HIV/AIDS and Disability: Capturing Hidden Voices* (New Haven, Connecticut: World Bank Group/Yale School of Public Health, 2004).

Inter-Parliamentary Union, UNAIDS, and UN Development Programme, *Taking action against HIV and AIDS: A Handbook for Parliamentarians* (2007).

Janet E. Lord, et al., *Human Rights Yes!: Action and Advocacy on the Rights of Persons with Disabilities*, University of Minnesota Human Rights Center, (2012).

Netherlands Ministry of Foreign Affairs & VSO's Right to Life Program, A Handbook on Best Practices Regarding HIV and AIDS for People with Disabilities: Services, Policy Advocacy, Programming (Dec. 2009).

Office of the United Nations High Commissioner for Human Rights and UNAIDS, *HIV/AIDS and Human Rights International Guidelines: Revised Guideline 6 Access to prevention, treatment, care and support*, (2002).

Office of the United Nations High Commissioner for Human Rights UNAIDS *International Guidelines on HIV/AIDS and Human Rights* (2006 Consolidated Version).

Radda Barnen (Swedish Save the Children), *A Matter of Social Context – The Sexual Abuse of Children with Disabilities* (Sweden, 1997).

Sharon Peake, HIV, "Disability and Discrimination: Making the Links in International and Domestic Human Rights Law," 12 J Int'l AIDS Society (9 Nov. 2009).

Michael A. Stein, Charlotte McClain-Nhlapo & Janet E. Lord, *Disability Rights, the MDGs and Inclusive Development*, *in* MILLENNIUM DEVELOPMENT GOALS AND HUMAN RIGHTS: PAST, PRESENT AND FUTURE (Malcolm Langford et al.. eds. 2012).

UNAIDS, Non-discrimination in HIV Responses (2010)

UNAIDS, *Protocol for the Identification of Discrimination against People Living with HIV* (UNAIDS, 2000).

UNAIDS, *Reducing HIV Stigma and Discrimination: a critical part of national AIDS programmes* (UNAIDS, 2007).

UNAIDS and Inter-Parliamentary Union, *Handbook for Legislators on HIV/AIDS, Law and Human Rights: Action to Combat HIV/AIDS in View of Its Devastating Human, Economic and Social Impact*, (1999).

UNAIDS, "'Three Ones' Key Principles – Coordination of National Response to HIV.AIDS Principles for National Authorities and their partners" (2004), http://data.unaids.org/una-docs/three-ones_keyprinciples_en.pdf

UNAIDS, World Health Organization and Office of the High Commissioner for Human Rights, *Policy Brief: Disability and HIV* (2009).

UNAIDS and World Health Organization *Guidance on Ethics and Equitable Access to HIV Treatment and Care* (2004).

UN General Assembly*, Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS*, 8 July 2011.

World Bank, "Disability and HIV/AIDS at a Glance – A World Bank Factsheet*"* (Nov. 2004).

World Bank, *Global Survey on HIV/AIDS and Disability* (April 2004).

World Bank and World Health Organization *The World Report on Disability* (2011).

Timeline on Key Developments in Disability Inclusion in Public Health and HIV/AIDS Response

1948: Universal Declaration of Human Rights: Recognizing the right of all human beings to the highest attainable standard of health.

1966: International Covenant on Economic, Social, and Cultural Rights: Recognizing the obligation of a State to promote, protect, and fulfill socio-economic rights such as the right to highest attainable standard of health.

1982: World Programme of Action concerning Disabled Persons adopted by UN General Assembly

1988: World Health Assembly adopts resolution, Avoidance of discrimination in relation to HIV-infected people and people with AIDS

1989: First International Consultation on AIDS and Human Rights is held

1991: UN General Assembly adopts resolution on Prevention and control of acquired immunodeficiency syndrome.

1993: Standard Rules on the Equalization of Opportunities for Persons with Disabilities adopted by UN General Assembly: Detailed non-binding instrument including access to medical care and services for persons with disabilities.

1994: Committee on Economic, Social, and Cultural Rights, General Comment 5 on Persons with Disabilities: Emphasizing the right to health and the duty to provide reasonable accommodation

2004: World Bank & Yale University study on HIV and Disability: Exploring the inter-relationship between HIV/AIDS and disability

2006: HIV/AIDS and Human Rights Guidelines: Recognizing persons with disabilities as vulnerable group in the context of HIV and AIDS.

2006: UN General Assembly adopts the UN Convention on the Rights of Persons with Disabilities: Requires non-discrimination on the basis of disability and reasonable accommodation in public health, including HIV/AIDS services.

2008: Uganda Conference on Disability and HIV

2009: UNAIDS publishes HIV and Disability Policy Brief

2011: UN General Assembly adopts resolution on Realizing the Millennium Development Goals for persons with disabilities towards 2015 and beyond: Calls on governments to ensure that programmes to combat HIV/AIDS are inclusive of and accessible to persons with disabilities

2011: Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS: Emphasizing disability inclusion.

2012: AIDS Conference: Disability appearing on the main agenda for the first time.

Glossary of Key Terms

Acquired Immunodeficiency Syndrome (AIDS): Is the clinical syndrome caused by the human immunodeficiency virus.

Antiretroviral Drugs: Drugs used in combination as a therapeutic treatment to maximally suppresses, contain and prevent the further progression of the **HIV** virus.

Convention on the Rights of Persons with Disabilities (CRPD): An international human rights convention adopted by the UN General Assembly and ratified by more than 120 States that enumerates human rights obligations in the context of the duty to promote, protect, and fulfil the human rights of persons with disabilities.

Human Immunodeficiency Virus (HIV): Is the virus that weakens a person's immune system, eventually leading to AIDS. HIV devastates the body's ability to fight off infection and disease, which in the end can lead to death.

HIV Prevention, Treatment, Care and Support: Internationally agreed upon elements of a comprehensive approach to halt and reverse the HIV epidemic and mitigate its impact.

International Guidelines on HIV/AIDS and Human Rights: A document published by the Office of the UN High Commissioner for Human Rights and the Joint UN Programme on HIV/AIDS which outlines the relationship between human rights and the access to HIV management, prevention, and care.

Informed Consent: Refers to the process by which a person is provided with the information necessary to fully participate in decisions about his or her health care and also the process required in order for medical research and experimentation to be deemed lawful. Based on a patient's right to direct what happens to his or her body and the ethical duty of the physician/researcher to involve the patient in decision-making.

Medical Model of Disability: Understanding of disability as a narrow, medical problem that needs to be "fixed" or an illness that needs to be "cured." This perspective implies that a person with a disability is somehow "broken" or "sick" and requires fixing or healing and has been discredited by **disabled people's organisations (DPOs)** in favour of the social model of disability.

Disabled People's Organizations (DPOs): DPOs are disability non-governmental organizations that are generally established, led, and governed by people with disabilities themselves.

National AIDS Council: National level body responsible for coordinating a broad-based and multisectoral HIV and AIDS mandate to halt and reverse the HIV epidemic and mitigate its impact.

Progressive Realization: Doctrine that recognises that States have different economic capacities, that full enjoyment of human rights cannot occur over night and the implementations of economic, social and cultural rights may take time to achieve. The doctrine allows States to take steps to the maximum extent possible with regard to their available resources but it does not mean that immediate steps toward implementation can be delayed.

Reasonable Accommodation: The altering of an environment (i.e. workplaces, voting procedures, public areas, etc.) to make it accessible and usable by a person with a disability on an invidualized basis and not causing an undue burden.

Social Model of Disability: Understanding of disability that focuses on eliminating the barriers created by the social and physical environment that inhibit the ability of persons with disabilities to exercise their human rights. This perspective is the favored understanding of disability by **disabled people's organizations** and is reflected in the CRPD.

Three Ones: Internationally agreed upon institutional framework for an effective national AIDS response, encompassing a national AIDS council, a national AIDS strategy and coordination framework among all partners and a country-level monitoring and evaluation system.

Voluntary Counseling and Testing (VCT): Is a type of testing which provides individuals the ability to find out their HIV status, while also having access to counseling to aid them in dealing with either a positive or negative HIV test result.

World Health Organization (WHO): an intergovernmental organization under the auspices of the United Nations that works to promote health worldwide.

For a more comprehensive glossary of international disability rights terms, see Janet E. Lord, et al., *Human Rights Yes!: Action and Advocacy on the Rights of Persons with Disability*, University of Minnesota Human Rights Center, at 334, 2012. For terms pertaining to HIV, see UNAIDS Terminology Guidelines, Oct. 2011, available at: http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118_terminology-guidelines_en.pdf.