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HIV/AIDS and Disability:

Final Report of the 4th

International Policy Dialogue

International Affairs Directorate, Health Canada

March 11-13, 2009
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Canada 

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1.0 EXECUTIVE SUMMARY

With the entry into force of the UN Convention on the Rights of Persons with Disabilities (CRPD), disability issues have received growing recognition in international policy debates. The field of HIV/AIDS is no exception. In collaboration with the Public Health Agency of Canada and the Joint United Nations Programme on HIV/AIDS (UNAIDS), Health Canada hosted an International Policy Dialogue, March 11-13, 2009, in Ottawa, Canada to provide a forum for stakeholders to discuss the unique interaction between HIV/AIDS and disability, and its relevance to global policy development.

A broad range of perspectives were represented, by participants from Africa, North America, and Latin America, from HIV/AIDS and disability networks, and from both government and non-governmental organizations. Participants represented a range of sectors including education/awareness, service provision, policy and programme development, and research, and included both persons with disabilities (PWDs) and persons living with HIV/AIDS (PHAs) as representatives of various networks/organizations.

Through panel presentations, plenary discussion and break-out sessions, participants discussed emerging issues on the intersectionality of HIV/AIDS and disability, and charted a way forward in terms of policy and programme development.

THE CRPD AS A TOOL FOR CHANGE

The CRPD was a foundational theme of the Dialogue. Key concepts included:

- Recognizing that HIV/AIDS is implicitly included in the CRPD through Article 25a, which calls for the provision of accessible sexual and reproductive health and population-based public health programmes;
- Calling on the CRPD Committee of Experts to include HIV/AIDS in guidelines for implementation, monitoring and reporting;
- Developing a campaign to raise awareness among the full range of stakeholders on the CRPD and its potential for advancing the rights of PWDs and PHAs; and
- Advocating for the implementation of the CRPD and the Optional Protocol.

DEFINING/UN-DEFINING DISABILITY

The General Principles of the CRPD may also provide a useful guide to defining disability in the context of HIV/AIDS. These principles focus on removing obstacles (social, environmental, institutional, legal) that limit full and active participation of all persons, regardless of ability, in society.

THE INTERSECTIONALITY OF HIV/AIDS AND DISABILITY

Discussions on the intersectionality of HIV/AIDS and disability were rooted in the experience of PWDs and PHAs.

- PWDs experience all of the risk factors associated with HIV infection, and are often at increased risk because of poverty, severely limited access to education and health care, lack of information and resources to facilitate 'safer sex,' lack of legal protection, increased risk of violence and rape, vulnerability to substance abuse, and stigma; and
- PHAs often develop disabilities as a result of HIV, either as a result of the disease progression or as side effects of antiretroviral treatment. Health care providers and rehabilitation professionals are often unaware of how to properly deal with or mediate the disabling effects of HIV/AIDS and its treatment regimens.

EMERGING ISSUES IN HIV/AIDS AND DISABILITY - GAPS AND CHALLENGES

HIV/AIDS, DISABILITY AND THE LAW

By clearly detailing the human rights obligations of State Parties in the context of disability, the CRPD offers the prospect of a binding treaty and viable legal instrument that could be used to protect and promote equal rights of PWDs and PHAs, complementing (not replacing) other human rights instruments. However, its usefulness as a legal instrument is dependent upon ratification and effective implementation at the country level.

HIV/AIDS, DISABILITY AND SOCIAL/DISABILITY SUPPORT PROGRAMMES

In countries where social/disability support programmes are available, the level of support is often inadequate, resulting in PWDs living in poverty or exacerbating their impoverishment. Barriers to access exist because supports are delivered in silos through multiple departments, jurisdictions, policies and programmes. PHAs may be excluded from benefits because of the episodic nature of impairment. In resource poor countries supports are minimal or do not exist. There are often barriers to receiving second line anti-retroviral medication; to accessing adequate food for maintaining health; to receiving rehabilitation services and assistive devices; and to accessing social support groups. A multi-sectoral approach is needed that brings poverty to the centre of discussions and solutions.

STIGMA IN HEALTH CARE SETTINGS

PWDs face a multitude of challenges when accessing information about HIV/AIDS prevention and support, voluntary counseling and testing, care and treatment. PWDs living with HIV/AIDS experience a double stigma. There is a common misperception that PWDs are sexually inactive, and are unlikely to use drugs or alcohol. AIDS service organizations have tended to overlook the needs of PWDs in prevention campaigns and service development. Health practitioners often lack the necessary knowledge, skills and resources to provide accessible, appropriate services to PWDs at risk for or living with HIV/AIDS. Disability rights groups have tended to place a low priority on providing sexual health information and support. This lack of response severely limits the ability of PWDs to understand safer sex messages and to negotiate safer sexual behaviors.

MENTAL HEALTH AND HIV/AIDS

A large proportion of PHAs experience depression as a result of the psychosocial aspects of HIV, including stigma, social isolation, difficulties with mobility, and inability to work because of functional impairment. HIV can have a direct impact on the central nervous system, causing

cognitive impairments. Front-line health professionals and AIDS service providers often have limited knowledge and skills related to identifying mental health problems of PHAs and providing appropriate support and referral. The training of health professionals and mental health workers is needed to increase sensitivity and improve care for people with mental health problems living with HIV/AIDS.

DEVELOPMENTAL DISABILITIES AND HIV/AIDS

There is a fear that providing information about sex to persons with developmental disabilities will increase their vulnerability. This fear creates a major barrier to their access to information about sexual health and HIV/AIDS prevention. There is a need for more education and awareness about how to share sexual health information with children, youth and adults with developmental disabilities. There is limited knowledge about the special tools that could facilitate access to information. More research is needed to increase understanding of effective means for sharing sexual health information with these groups.

CASE STUDIES OF NORTH/SOUTH PARTNERSHIPS

North-South partnerships involve a two-way exchange of knowledge and competencies. Donor countries/organizations in the North help to build capacity by providing funds and expertise to partners in the South who are implementing policies and programmes, and, in turn learn from the experience of projects in the South with respect to working with marginalized groups who face barriers to access and inclusion. Challenges relate to sustaining pilot projects; securing funds to develop new initiatives; sharing the results and benefits of HIV/AIDS and disability projects; and limited data to build a case for investment in this area.

UNAIDS/WHO/OHCHR DRAFT BRIEF ON HIV/AIDS AND DISABILITY

A draft joint policy brief on HIV/AIDS and disability was developed by UNAIDS, the World Health Organization, and the Office of the High Commission for Human Rights. PWDs are not identified on the UNAIDS' list of high risk populations. While the policy brief has potential to advance the rights of PWDs and PHAs, impact will be limited without uptake by other UN agencies, bilateral and multilateral donor agencies, national governments, NGOs and civil society organizations.

EMERGING ISSUES IN HIV/AIDS AND DISABILITY - NEXT STEPS

OVER-ARCHING THEMES

- Applying a disability lens to HIV/AIDS policies and programmes to assess the current level of activity and investment, and to identify next steps to improve inclusion of PWDs in HIV/AIDS programming and policies;
- Assessing disability policies and programmes to better meet the needs of PHAs;
- Implementing mechanisms for exchange of research and promising practices; for example, through establishing an information clearinghouse on disability and HIV/AIDS;
- Building coalitions and partnerships to support horizontal and vertical policy advocacy, taking care to clearly define the roles of stakeholders and to build on existing infrastructures;

- Creating opportunities for sustained dialogue between disability and HIV/AIDS networks to increase awareness, build understanding, and build the foundation for effective partnerships. Resources for this purpose could be leveraged through existing funding initiatives; and
- Building the capacity of PWDs and disabled persons' organizations to facilitate meaningful involvement in HIV/AIDS education/awareness, policy development, programming and research.

EDUCATION/AWARENESS

- Collaborating to mount a global campaign to raise awareness of disability and HIV/AIDS issues in the context of the CRPD, involving high profile champions;
- Using a mosaic of strategies and activities at the international, regional, country and grassroots levels to reach diverse stakeholder groups, including:
 - ✓ The general public;
 - ✓ PWDs and disabled persons' networks and organizations, and PHAs and AIDS networks and service organizations (international, national and grassroots);
 - ✓ Medical students, rehabilitation professionals, and other service providers working with persons with disabilities and HIV/AIDS;
 - ✓ Policy-makers and decision-makers working within the UN system, international organizations and national governments;
 - ✓ Donors/funders who provide multilateral or bilateral aid to developing countries or who fund activities in the areas of HIV/AIDS, development or human rights; and
 - ✓ The academic community and research funding bodies.
- Identifying regular events and meetings on the topics of HIV/AIDS, disability and/or human rights where disability and HIV/AIDS issues could be profiled;
- Training international health and development staff on the inclusion of PWDs as a regular population to be served; and
- Focusing awareness messages on equal rights, inclusion and removal of barriers to full participation for PWDs and promoting healthy sexuality (appropriate to context).

PROGRAMMING

- Documenting and sharing promising practices in integrated HIV/AIDS and disability programming;
- Studying the lessons learned through joint programming for HIV and tuberculosis at the international, country and grassroots levels;
- Promoting the inclusion of disability issues in the formal education of medical and other health care providers;
- Advocating for the inclusion of PWDs in all work on sexual and reproductive health; and
- Building capacity of AIDS service organizations and disabled persons' organizations.

POLICY DEVELOPMENT

- Advocating for inclusion of PWDs in national HIV/AIDS strategic plans and inclusion of HIV/AIDS in CRPD guidelines, monitoring and reporting processes;
- Integrating disability and HIV/AIDS into the existing UN structures and mechanisms;
- Using donor influence to encourage ratification of the CRPD;
- Initiating country-level situational assessments to inform policy development;
- Building capacity of the community sector to develop shadow reports to countries' status reports on implementation of the CRPD; and
- Developing a regional joint position paper on HIV/AIDS and Disability to be shared at the 2010 World Congress on HIV/AIDS.

RESEARCH

- Developing a standard process for monitoring and reporting in order to establish baseline data and a consistent evidence base on disability and HIV/AIDS;
- Improving measurement and collection of data on disability and HIV/AIDS, including the establishment of research teams to disaggregate information from existing sources;
- Auditing organizations and government departments to identify existing knowledge on disability and HIV/AIDS;
- Disseminating research findings from North-South case studies; and
- Exploring and promoting opportunities for new research on disability and HIV/AIDS.

CONCLUSION

The intersectionality of HIV/AIDS and disability is emerging as an important area of global policy development. Participants of the International Policy Dialogue valued the opportunity to share knowledge and their experiences, to further build common understanding of the issues, and to explore opportunities for collaboration to advance the rights of PWDs and PHAs. Implementation of next steps will depend on building consistent monitoring, surveillance and reporting, and providing future opportunities for networking, information-sharing and dialogue among disability and HIV/AIDS networks at the international, national and grassroots levels.

2.0 BACKGROUND

With the entry into force of the UN Convention on the Rights of Persons with Disabilities (CRPD), disability issues have received growing recognition in international policy debates. The field of HIV/AIDS is no exception. Health Canada identified the need for an in-depth discussion of the unique interaction between HIV/AIDS and disability, and its relevance to global policy development.

In collaboration with the Public Health Agency of Canada and the Joint United Nations Programme on HIV/AIDS (UNAIDS), Health Canada hosted an International Policy Dialogue on HIV/AIDS and disability in Ottawa, Canada, March 11-13, 2009. The Dialogue provided a forum for key stakeholders to come together to discuss and debate emerging issues in the field of HIV/AIDS and disability, and to chart a way forward in terms of policy and programme development.

An advisory committee developed the meeting agenda and the dialogue process, and identified presenters and participants. The members of the advisory committee are listed in Appendix A.

4TH ANNUAL INTERNATIONAL POLICY DIALOGUE ON HIV/AIDS

Approximately 50 key stakeholders participated in the three-day dialogue. A broad range of perspectives were represented, with participants from Africa, North America and Latin America, from HIV/AIDS and disability networks, and from both government and non-governmental organizations. Participants represented a range of sectors, including education/awareness, service provision, policy and programme development, and research. The list of participants is included in Appendix B.

Persons with disabilities (PWDs) and persons living with HIV/AIDS (PHAs) participated as representatives of various networks/organizations. They also shared their personal experiences to enrich the dialogue and to give voice to both the challenges and the abilities of PWDs and PHAs.

A concept paper was prepared and circulated before the meeting, outlining emerging issues related to the intersectionality of HIV/AIDS and disability. These emerging issues formed the basis of the policy dialogue. At its root, the intersectionality of HIV/AIDS and disability relates to the experience of PWDs and PHAs:

- PWDs experience all of the risk factors associated with HIV infection, and are often at increased risk because of poverty, severely limited access to education and health care, lack of information and resources to facilitate 'safer sex,' lack of legal protection, increased risk of violence and rape, vulnerability to substance abuse, and stigma.
- PHAs often develop disabilities as a result of HIV, either as a result of the disease progression or the disabling side effects of antiretroviral treatment. Health care providers and rehabilitation professionals are often unaware of how to properly deal with or mediate the disabling effects of HIV/AIDS and its treatment regimens.

The concept paper also identified the rationale for engaging in dialogue on the intersectionality of HIV/AIDS and disability. PWDs and PHAs share similar experiences of discrimination and exclusion from society. Dialogue can assist in dismantling barriers to participation faced by PWDs, PHAs, and those living with the overlapping, double stigma of both disability and HIV/AIDS.

Dialogue can also support an exchange of knowledge and experience between the HIV/AIDS movement and the disability movement. The HIV/AIDS movement can learn from the disability movement in terms of accepting physical conditions that diverge from the norm, advocating for suitable health care and social services and fighting against exclusion and discrimination. The disability movement can learn from the unprecedented accomplishments of the HIV/AIDS movement on issues around sexuality, advocacy on human rights, workplace discrimination, and medical justice.

3.0 OBJECTIVES OF THE DIALOGUE

The objectives of the three-day dialogue session were to:

- Provide an opportunity to explore the issues and evidence, including shared experiences and challenges, as they relate to HIV amongst PWDs and HIV as a disability;
- Foster knowledge transfer between PWDs, PHAs, subject experts and policy makers, via the sharing of lessons learned and sharing of models for translating these lessons into effective policies and programmes;
- Provide an opportunity to develop relationships that will serve to strengthen both domestic and global responses to the HIV epidemic; and
- Identify gaps and areas where further education, policy development, programming, and research are necessary, including the need for quantitative data.

4.0 OVERVIEW OF THE DIALOGUE PROCESS

The meeting agenda and biographies of presenters are included in Appendices C and D. The dialogue process was designed and facilitated in order to help participants identify common ground in the area of HIV/AIDS and disability, and to support an exchange of experiences and ideas to advance their work. This report presents highlights of the dialogue process, drawing from the following elements:

- A concept paper circulated to all participants outlining emerging issues and relevant policy developments related to the intersectionality of HIV/AIDS and disability;
- An opening key note address by Stephen Lewis focused on opportunities to use the CRPD to further efforts to eliminate discrimination and promote equal rights for PWDs and PHAs;
- A series of panel sessions and presentations, followed by a question/answer period, to provide context and stimulate discussion (see Appendix C – Meeting Agenda); and

- Break-out discussions in small groups focused on emerging issues related to the intersectionality of HIV/AIDS and disability (see Appendix D – Break-Out Session Worksheet).

A summary of the gaps, challenges, opportunities and next steps identified in the break-out sessions provided a launch point for the concluding discussions on next steps in the areas of education/awareness, programmes, policy development and research.

5.0 UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES: A TOOL FOR CHANGE

Use of the UN Convention on the Rights of Persons with Disabilities (CRPD) to protect and promote equal rights of PWDs and PHAs was a foundational theme of the Dialogue. The CRPD can be accessed on-line at www.un.org/disabilities.

SHIFTING TO A RIGHTS-BASED APPROACH

The CRPD can be a catalyst for change by shifting the disability field from charity-based or medical-based approaches to a rights-based approach. This approach views PWDs as active participants in society, ensuring their wellbeing rather than treating them as passive recipients of charitable goodwill.

The CRPD, as a binding international human rights instrument, could be a major advocacy tool to counteract negative perceptions of PWDs. The CRPD describes disability as an outcome of the interaction between the challenged person and the obstacles (social, environmental, institutional, legal) that limit full and active participation in society. This places responsibility on the State for ensuring equal rights by removing these obstacles to the fullest extent possible.

SHIFTING TO SOCIETAL RESPONSIBILITY

The CRPD can be an effective vehicle for making the shift towards a new paradigm of societal responsibility for ending discrimination and ensuring equal rights are extended to every member of society. Racism, sexism, anger and indifference are imposed social norms, often resulting in blaming, isolating, stigmatizing and discriminating against individuals and marginalized groups affected by HIV/AIDS and disability. HIV/AIDS and disability are therefore both human rights and social justice issues meriting attention. The CRPD can help to keep the issue on the agenda and to move public policy forward.

HIV/AIDS EMBEDDED IN THE CRPD

While the CRPD makes no explicit mention of HIV/AIDS, HIV/AIDS is implicitly included in the CRPD under Article 25a, where “State Parties shall provide PWDs with the same range, quality and standard of free and affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population based public health programmes”. Although it will take time, the CRPD could provide a useful platform and set up accountability for moving forward important areas, such as the vulnerability of women, poverty, and equitable access to supports and services for PWDs and PHAs.

Other articles under the CRPD help to open the discourse on the intersectionality of HIV/AIDS and disability, including Article 8 (stigma), Article 9 (accessibility to government programs and

services), Article 31 (appropriate data and statistics on disability), and Article 32 (international cooperation).

While HIV/AIDS is included in principle in the CRPD, it will be important to take steps to ensure that it is considered in the implementation work of the Committee of Experts¹ and the Conference of State Parties.

MONITORING AND ACCOUNTABILITY

To ensure that appropriate action is taken to implement the CRPD, it will be important to develop clear, measurable guidelines and standards for monitoring and accountability². There are clear precedents in place which could guide use of the CRPD to move forward the issue of HIV/AIDS and disability. Monitoring and accountability and the role of the Committee of Experts are more fully discussed in Section 8 under policy development and research.

INVOLVING GOVERNMENTS, ORGANIZATIONS AND CIVIL SOCIETY

Involving the full range of stakeholders in implementation can help the CRPD reach its potential as a tool for change. These stakeholders include international organizations, such as the World Health Organization, UNICEF and UNAIDS, national governments and ministries such as Health Canada and civil society organizations working in the areas of disability and HIV/AIDS. It could also be beneficial to nurture and seek out high profile champions. For example, the new Executive Director of UNAIDS, Michel Sidibé, has taken early opportunities in his new position to speak out against discrimination.

ADVOCATING FOR THE OPTIONAL PROTOCOL

Under the CRPD, State Parties are required to submit reports, establish national focal points, and involve PWDs in developing relevant policies. However, no monitoring mechanism is in place to allow PWDs or their representative organizations to provide an alternative report or to voice their grievances.

The Optional Protocol includes an Individual Communication Procedure, allowing individuals or representative organisations to file a complaint against the state if the state has not fulfilled its obligations under the CRPD (including HIV-related concerns). This is a valuable accountability mechanism warranting a concerted advocacy effort to encourage countries to sign the Optional Protocol.

USING THE ARTICLE ON INTERNATIONAL COOPERATION

Article 32 of the CRPD recognizes the importance of international cooperation and its promotion to ensure that international development programmes are inclusive of, and

¹ The Committee of Experts is responsible for determining how reporting will take place and for developing guidelines for monitoring and data collection. State parties agree to submit reports every four years that demonstrate how they are meeting their obligations under each article of the treaty.

² Stephen Lewis provided examples of the use of guidelines and standards to support monitoring and accountability. For example, the International Labour Organization's guidelines on HIV/AIDS in the workplace are innovative and may inform guidelines and standards under The CRPD. Similarly, the international code for marketing of breast milk substitutes provides a good example of using standards to raise awareness and pressure compliance of manufacturers. The baby-friendly hospital guidelines provide a good example of simple, 10-step guidelines to support monitoring and implementation of best practices.

accessible to, PWDs. Article 32 also outlines that measures to help resource poor countries implement the CRPD should be taken. This effort includes measures to build capacity, to ensure cooperation in research, and to provide technical and economic assistance.

Lobbying all developed countries to ratify the CRPD could provide a useful avenue for influencing development assistance. Using Article 32, stakeholders from developing and developed countries could advocate for channelling part of the Official Development Assistance (ODA) and other forms of international aid towards helping resource poor countries achieve the objectives of the CRPD.

RATIFYING THE CRPD IN CANADA

Canada could take steps to protect and promote the rights of PWDs and PHAs by ratifying the CRPD and the Optional Protocol, and by setting up national focal points for monitoring and implementation. Suggested focal points in Canada included the Canadian Human Rights Commission, provincial human rights commissions, and the Health Portfolio in the federal government. Another approach would be to follow the South African model where the Office of Disabled People and the South African National HIV/AIDS Council were designated to act as focal points.

Canadian AIDS service organizations, disabled persons' organizations and development organizations have shown solidarity and partnership to encourage the Government of Canada to ratify the CRPD. For example, the Canadian Working Group on HIV and Rehabilitation, the Canadian HIV/AIDS Legal Network and the Interagency Coalition on AIDS and Development collaborated to send a letter that was signed by a large number of AIDS service organizations across Canada and that urged the Government to ratify the CRPD.

6.0 EXPLORING THE INTERSECTIONALITY OF HIV/AIDS AND DISABILITY

The intersectionality of HIV/AIDS and disability was discussed in terms of:

- The value of defining or undefining HIV/AIDS as a disability;
- The strategic advantages and disadvantages of the HIV/AIDS and disability movements working together; and
- The integration of disability and HIV/AIDS at the programme level.

THE DOUBLE STIGMA OF DISABILITY AND HIV/AIDS

There is a double stigma experienced by people with both HIV/AIDS and disability. Fear of added discrimination by family, community and society is a barrier to openly sharing HIV/AIDS status or to self-identifying as a PWD. Much effort is required to combat this double stigma, beginning with raising awareness and open communication.

The shared experience of stigma and discrimination of PHAs and PWDs provides a strong foundation for collaboration. PHAs who are just starting to experience disability can learn from those with a pre-existing disability. The HIV/AIDS movement can learn from the disability movement in terms of accepting physical conditions that diverge from the norm,

advocating for suitable health care and social services, and fighting against exclusion and discrimination.

RESISTANCE TO DEFINING HIV/AIDS AS A DISABILITY

There is some resistance to defining HIV/AIDS as a disability, both within the HIV/AIDS movement and within the disability movement:

- Within the HIV/AIDS movement, HIV/AIDS has not historically been widely defined as a disability. Some PHAs have resisted identifying themselves as PWDs, as they do not see any value in being identified as having a disability, but rather see it as an additional stigma. There has been less resistance from within the HIV/AIDS movement in defining HIV/AIDS as a disability where there is a strategic advantage to do so, such as being included in disability support programmes and receiving support benefits.
- Within the disability movement there has been some resistance to defining HIV/AIDS as a disability by those who create false divides, arguing that HIV/AIDS is a “sickness” and having a disability is not..

As early as 1996, UNAIDS had taken the position that HIV/AIDS should be considered a disability, at least in terms of the discrimination factor and the need for legal protection against discrimination.

FOCUS ON INCLUSION AND REMOVING BARRIERS, NOT ON DEFINING DISABILITY

The CRPD does not define disability, but instead describes disability as an outcome of the interaction between the challenged person and the obstacles (social, environmental, institutional, legal) that limit full and active participation in society. Using this approach promotes the inclusion of all persons facing barriers, with a focus on protecting and promoting equal rights, creating enabling environments and advancing universal access in design. PHAs are implicitly included in this definition, and therefore in the CRPD, because they may experience obstacles as a result of impairments arising from the virus or from anti-retroviral treatment.

EPISODIC NATURE OF HIV/AIDS AND ACCESS TO SOCIAL/DISABILITY SUPPORT PROGRAMMES

PHAs experience episodic periods of illness that limit their functional ability and their impairment is not always present or visible. The episodic progress of HIV/AIDS may influence whether PHAs identify as having a disability. Individuals should be supported in self-identifying rather than being labelled by others. In some contexts it may be advantageous for PHAs to identify as PWDs, for the purposes of receiving programme benefits.

SHIFT TO A STRENGTHS-BASED APPROACH TO DISABILITY

The HIV/AIDS movement has recognized that with treatment, HIV/AIDS can become a chronic illness. This new approach opens the door to exploring the common experiences of PHAs and PWDs. It also provides an opportunity to advance a strengths-based approach to disability in the context of HIV/AIDS, focusing on abilities rather than deficits, and on rehabilitation and quality of life rather than medical intervention.

STRATEGIC ADVANTAGES FOR POLICY AND PROGRAMME DEVELOPMENT

There are a number of strategic advantages to recognizing the intersectionality of HIV/AIDS and disability movements. One of the most obvious advantages relates to using the CRPD as a platform to further the rights of PWDs and PHAs at the international and country level, as discussed in Section 5. Other strategic advantages relate to the potential for mutual learning, sharing of expertise and resources, and building a critical mass for advocacy efforts. For example:

- The disability movement has been less effective in advocacy work than the HIV/AIDS movement, despite recent success with establishing the CRPD. The disability movement can learn from the unprecedented accomplishments of the HIV/AIDS movement on issues around sexuality, workplace discrimination and medical justice;
- The extensive global HIV/AIDS movement with its comparatively large resource base could be leveraged to raise awareness and advance the rights of PWDs and PWDs living with HIV/AIDS; and
- Policies and programmes could be strengthened for both PWDs and PHAs by focusing on common barriers to services and supports rather than on defined groups. For example, measures to improve access for people with visual impairment can be put in place regardless of whether the impairment is a result of HIV/AIDS or a pre-existing disability.

FEAR OF HIV/AIDS OVERSHADOWING BROADER DISABILITY RIGHTS ISSUES

Although strong advantages were identified for recognizing the intersectionality of HIV/AIDS and disability, there is a genuine fear that because of the high profile of the HIV/AIDS movement the disability movement could be overshadowed. Furthermore, there is a risk that the nuances and differences among PWDs may be lost. Participants recommended building the capacity of PWDs and disabled persons organizations to ensure their meaningful participation in all aspects of policy, programme development and research.

INTEGRATING HIV/AIDS AND DISABILITY AT THE PROGRAMME LEVEL

There are a number of positive examples of integrating HIV/AIDS and disability programmes to improve services for PWDs and PHAs. Although NGOs carrying out these programmes have limited resources, early results are promising and additional outcomes are expected in the coming years. Examples include:

- Training youth with disabilities to provide HIV/AIDS prevention and treatment information to their peers (South Africa);
- Providing HIV/AIDS screening, information and services to the deaf, by the deaf (Kenya);
- Establishing mental health clinics for PHAs (Uganda); and
- Assessing and improving access of HIV/AIDS programmes to PWDs (Uganda).

These examples are summarized in Appendix E.

7.0 EMERGING ISSUES IN HIV/AIDS AND DISABILITY

Break-out discussions in small groups focused on emerging issues related to the intersectionality of HIV/AIDS and disability.

7.1 HIV/AIDS, DISABILITY AND THE LAW

Until the CRPD was adopted in 2006, there was only one binding international law instrument explicitly referring to the rights of PWDs, the 1989 Convention on the Rights of the Child. There were some ‘soft laws’ in place indicating that PWDs have rights recognized in other international human rights treaties; disability was included within the phrase “other status”.³ This term has been confirmed to also include HIV, ensuring that PHAs are entitled to those same rights without discrimination.

Unlike disability, there is still no binding international law instrument dealing explicitly and directly with HIV and human rights. There are soft law instruments that make reference to implications of international treaties in the HIV context, e.g., the General Comment on the right to health under the International Covenant on Economic, Social and Cultural Rights. There is also international policy guidance on application of international human rights treaties in the context of HIV, such as UNAIDS/Office of the High Commissioner for Human Rights’ *International Guidelines on HIV/AIDS and Human Rights*.

GAPS, CHALLENGES AND OPPORTUNITIES:

- While the CRPD does not create ‘new’ rights for PWDs, it does specify the human rights obligations of State Parties, under international law, in the context of disability. As such, it has the potential to benefit PWDs, including those living with HIV/AIDS;
- In using the CRPD for legal protection, it could be helpful to define the barriers experienced by PHAs rather than the disability itself;
- The CRPD uses a “no-gap” policy approach that cuts across sectors, establishing a minimum threshold for policies and programmes;
- Use of the CRPD could be supported as a human rights instrument by encouraging the Committee of Experts to develop soft laws that explicitly mention HIV/AIDS;
- While people with disabilities are already covered by human rights law, they are often invisible in many structures; HIV/AIDS could be a good entry point for increasing visibility and raising awareness about the larger issue of the rights of PWDs; and
- Some countries have laws in place related to disability and discrimination (e.g. UK, Kenya). It could be useful to share existing legislation, and experiences with their application, to strengthen policies and programmes and to advance the rights of PWDs or PHAs.

³ For example, the Committee on Economic, Social and Cultural Rights issued its General Comment No. 5 in 1994 on “PWDs”, making it clear that discrimination based on “other status” includes discrimination based on disability.

7.2 HIV/AIDS, DISABILITY AND SOCIAL/DISABILITY SUPPORT PROGRAMMES

Social/disability support programmes vary considerably between countries, particularly in the North and South. Countries in the North typically have well-developed supports and government programmes, although there are still gaps and access barriers to be overcome. In contrast, poorer countries in the South may have limited or no income or social supports in place, and the offices administering programmes may not be accessible to PWDs.

GAPS, CHALLENGES AND OPPORTUNITIES -- EXPERIENCE IN CANADA:

- No oversight body of disability income supports is in place in Canada, however, and coordination is limited. PWDs may have problems accessing income and social supports because they are delivered in silos through multiple departments, policies and programmes;
- Each programme may have a different definition of disability, in some cases excluding PHAs from benefits. For this reason it may be beneficial for PHAs to self-identify as disabled in order to qualify;
- For PHAs, there is added complexity in accessing income and social supports because of the episodic nature of their impairment(s). PHAs may not qualify for some programmes that require a person to demonstrate severe and prolonged illness. They may lose benefits if their health improves periodically;
- An additional level of complexity arises from the inter-jurisdictional mix of public and private health insurance, and from separate programmes for employed and unemployed persons;
- In some cases, PWDs lose their health benefits (e.g., to cover medication costs, treatment) or other benefits (e.g. housing) when they return to work. There is a structural disincentive to entering or returning to the workforce;
- The level of support is often inadequate, resulting in PWDs living at or below the poverty level; and
- Those administering social/disability support programmes often have limited knowledge of HIV/AIDS. As a result, individuals applying may be turned away.

GAPS, CHALLENGES AND OPPORTUNITIES -- EXPERIENCE IN DEVELOPING COUNTRIES:

- In many developing countries disability/social support programmes are limited or do not exist;
- There are often barriers to receiving second line anti-retroviral medications, to accessing adequate food for maintaining health, and to receiving rehabilitation services and assistive devices;
- In this context, a multi-sectoral approach is needed that brings poverty to the centre of discussions and solutions. As government income support programmes are often limited or not available, there is a need for other forms of support; and

- In some cases income support is available, but is administered inconsistently. For example, a household survey in India found that some doctors were insisting on supplementary payments in exchange for an accurate assessment of level of impairment, as required to qualify for government support.

In both developed and developing countries, improving disability/social support policies and programmes will depend on raising awareness, educating policy-makers and service providers, and building a strong evidence base. This effort can be supported by developing productive relationships between HIV/AIDS and disability communities.

7.3 STIGMA IN HEALTH CARE SETTINGS

Stigma takes many forms and can be defined as rejecting, isolating, blaming and shaming. This stigma impacts on access to health care services and may lead to discriminatory attitudes of health workers. For example, service providers may ask inappropriate questions and may not respect confidentiality. They may not directly address PWDs seeking care, but instead talk with the accompanying person. Health practitioners can often lack the necessary knowledge, skills and resources to provide accessible, appropriate services to PWDs at risk for, or living with, HIV/AIDS.

PWDs face a multitude of challenges when accessing information about HIV/AIDS prevention and support, voluntary counselling and testing, care and treatment. There is also a common misperception that PWDs are sexually inactive, and are unlikely to use drugs or alcohol, and therefore PWDs have often been left out of prevention campaigns and the development of programmes. These omissions severely limit the ability of PWDs to obtain proper education about safe sex and HIV prevention and to develop capacities to negotiate safer sexual behaviors.

GAPS, CHALLENGES AND OPPORTUNITIES:

- Research findings and case studies from several countries such as Ethiopia, Kenya, South Africa, Mozambique, Rwanda, and Uganda, have shown that many health practitioners lack the necessary skills for adequately responding to the needs of PWDs;
- Health practitioners are often ill-equipped and uncomfortable providing sex education to PWDs, may question the relevance of such education, may not offer HIV testing, or may dismiss a request for HIV testing;
- PWDs may experience physical barriers to accessing health services such as voluntary counselling, care and treatment. For example, poor road conditions may limit travel, offices and clinics may only be accessible by stairs, and written and verbal information may not be provided in an accessible format (e.g. plain language, Braille, through sign language interpretation);
- Women living with HIV/AIDS may face additional barriers in accessing pre-natal care and information on sexual and reproductive health; may be questioned about their decision to have children; may be dissuaded from seeking further care throughout their pregnancy; and may even be dissuaded from being tested;

- AIDS service organizations could improve access to HIV/AIDS information and support services for PWDs, taking into account barriers that may arise from specific disabilities;
- Disabled persons' organizations could help sensitize service providers in AIDS service organizations about how to interact with PWDs, sharing best practices on the use of technology to support HIV/AIDS prevention and support to PWDs;
- To overcome access barriers, mobile voluntary counselling and treatment services could be used. For example, open days for voluntary counseling and treatment could be held in residential areas/shelters where trained personnel teach PWDs about HIV/AIDS;
- At the national policy level, a cross-sectoral approach could be taken to mainstream PWDs into comprehensive HIV/AIDS programmes and activities; and
- In 2006, UNAIDS estimated that up to one in three adults in some southern African countries is living with HIV/AIDS. However, PWDs remain marginalized and excluded from the HIV information, education and communication received by their non-disabled peers, despite an estimated 93 million PWDs living in Africa.

7.4 DEVELOPMENTAL DISABILITIES AND HIV/AIDS

There is a fear that providing persons with developmental disabilities with information about sex will increase their vulnerability. This fear creates a major barrier to their access to information about sexual health and HIV/AIDS prevention.

Channels for accessing health information, including sexual health information, are limited for persons with developmental disabilities. The media is not a useful source of information because health messages are short and there is no follow-up to assist with interpretation. Peers are not a useful source of information because the information might not be accurate. Parents typically are not comfortable talking about sex with their teenage children and may be overwhelmed by the day-to-day challenges of supporting an adolescent with a developmental disability. Health professionals are usually the primary source for health information for persons with developmental disabilities, including physician, nurses, and life skills workers.

However, research has shown that interactions with physicians can be negative, including lack of respect, minimizing symptoms, ignoring the patient and deferring to a family member, not explaining procedures and options, and in some cases can include sexual abuse. Although the primary source of health information, physicians did not typically provide information about sexual health, including prevention of HIV infection.

GAPS, CHALLENGES AND OPPORTUNITIES:

- There is a need for more education and awareness about how to effectively share sexual health information with children, youth and adults with developmental disabilities;
- There is limited knowledge about the special tools and information that could assist children with developmental disabilities to absorb and use sexual health information;

- Sexual health education should be broadened beyond a focus on preventing pregnancy to include healthy sexuality, recognizing sexual violence and preventing HIV/AIDS and other sexually-transmitted diseases;
- Universities, colleges and professional associations could be engaged in training and sensitizing physicians and other health care providers about providing sexual health information to persons with developmental disabilities;
- HIV/AIDS networks could build on the strong foundation of disabled persons' organizations as a way to reach persons with developmental disabilities. Established community groups could help build credibility and relationships, and could serve as channels for information about HIV/AIDS prevention and support; and
- Best practice models for providing HIV/AIDS prevention and sexual health information to persons with developmental disabilities could be shared and adapted by other organizations.

7.5 MENTAL HEALTH AND HIV/AIDS

Many of the issues that apply to HIV/AIDS and developmental disabilities also apply to HIV/AIDS and mental health. Persons with mental health problems may experience discrimination and unequal treatment, barriers in the health system, and unsatisfactory interactions with health service providers. They may not have the language and power to speak out about their needs.

Some mental health problems, such as severe depression, overlap with some of the risk factors for HIV/AIDS. Depression may lead to risk-taking behavior that can result in HIV transmission, such as unsafe sex or drug use.

Many PHAs develop mental health problems, and a large proportion experience depression as a result of the stigma and social isolation that commonly occur amongst PHAs. In addition, HIV can have a direct impact on the central nervous system, causing impairments such difficulty focusing or concentrating, or loss of memory similar to premature dementia.

GAPS, CHALLENGES AND OPPORTUNITIES:

- HIV/AIDS prevention activities need to take mental health risk factors into account, such as depression and low self-esteem. Special consideration could be given to HIV/AIDS prevention strategies for women, as they experience high rates of depression ;
- Further training of front-line health professionals and providers in AIDS service organizations could improve mental health supports for PHAs. Training areas could include: how to recognize signs of depression, anxiety and cognitive impairment, how to provide support and appropriate referrals, where to find mental health resources, and how to work with street-involved people and those with a dual diagnosis of addiction and mental health problem;
- Training of health professionals and mental health workers is needed to increase sensitivity to the people with mental health problems living with HIV/AIDS, to reduce stigma, and to improve supports; and

- Training resources in the workplace are needed to raise awareness in human resources departments about how to support PHAs with mental health problems. Resources developed by mental health organizations in Canada for this purpose could be shared broadly.

7.6 CASE STUDIES OF NORTH/SOUTH PARTNERSHIPS

North-South partnerships involve a two-way exchange of knowledge and competencies. This provides renewed enthusiasm and energy for work in the area of HIV/AIDS and disability.

Donor countries/organizations in the North help to build capacity by providing funds and expertise to countries in the South who are implementing policies and programmes. Countries in the North learn from the experiences of projects in the South about how to work with marginalized groups who face barriers to access and inclusion, particularly in resource-poor settings.

GAPS, CHALLENGES AND OPPORTUNITIES:

- Challenges relate to sustaining pilot projects, securing funds to develop new initiatives, sharing the results and benefits of HIV/AIDS and disability projects, and educating donor countries, governments and NGOs in the value of investing about this area of programming and research.;
- A significant commitment of resources is needed from partners in the North and South, both in terms of funding, human resources and time. A longer-term funding commitment from donors in the North would help to support sustainability;
- Strategies are needed to influence how donor funds are allocated, including bilateral and multi-lateral funding relationships, and to engage Northern companies and foundations in activities in the South. This is contingent on demonstrating the value of projects and the synergy that can be achieved through integrating HIV/AIDS and disability policies and programmes;
- Dedicated lines could be built into project budgets to support research, evaluation and dissemination, and to support building the capacity of PWDs and disabled persons organizations to be actively involved in research activities; and
- To be effective, education and awareness needs to be bi-directional, with knowledge and information shared both with those doing the work at the grassroots level as well as with researchers, policy-makers and government decision-makers.

7.7 UNAIDS/WHO/OHCHR DRAFT BRIEF ON HIV/AIDS AND DISABILITY

The draft policy brief on HIV/AIDS and disability from UNAIDS, the World Health Organization, and the Office of the High Commission for Human Rights discusses the actions urgently needed to increase the participation of PWDs in the HIV/AIDS response. These actions include ensuring PWDs have access to HIV services which are both tailored to their diverse needs and are equal to the services available to others in the community.

In order to advance disability issues within the UN system, the United Nations established the UN Inter-Agency Support Group (IASG) for the CRPD on the Rights of PWDs in 2007. The IASG supports State Parties within a framework of coordinated planning, and links to activities of other UN bodies such as UNAIDS. The IASG will work to raise awareness of the CRPD and its implications for advancing the rights of disabled persons, implement the CRPD, and providing training and capacity-building for using the CRPD.

GAPS, CHALLENGES AND OPPORTUNITIES:

- Dialogue participants suggested that naming sex and the role of sex in HIV prevention and support for PWDs could be more relevant and specific within the brief;
- UNAIDS could revise its list of high risk population to include PWDs, as a complementary activity to disseminating the policy brief;
- UNAIDS could advocate to bilateral funding organizations to fund programmes that address disability and HIV/AIDS issues;
- The IASG process could be used to require all UN agencies to assess how PWDs are included in HIV/AIDS policies and programmes;
- To influence implementation of the CRPD, it may be useful to extend engagement beyond UNAIDS, the World Health Organization and the Office of the High Commission on Human Rights to other UN agencies that have influence at the grassroots level; and
- New partnerships could be developed with human rights organizations who have not previously worked in the field of disability and HIV/AIDS.

8.0 OPPORTUNITIES AND NEXT STEPS

Opportunities and next steps identified by participants included a number of over-arching, cross-cutting themes. These themes are developed further within the specific areas of education/awareness, programming, policy development, research and partnerships.

8.1 OVERARCHING THEMES

PROMOTE THE USE OF A DISABILITY LENS TO REVIEW CURRENT HIV/AIDS RESEARCH, POLICIES AND PROGRAMMES

An immediate next step could be for organizations and networks to apply a disability lens to their HIV/AIDS work. Organizations/networks could assess the current level of activity and investment, and could identify next steps to improve inclusion of PWDs.

This type of audit exercise could be broadly promoted within the UN system, with donors/funding bodies, with national governments, and at the grassroots level with AIDS service organizations. International funding bodies could be approached to fund a call for proposals for the audit of HIV/AIDS policies and programmes.

CONSIDER HIV/AIDS WITHIN DISABILITY RESEARCH, POLICIES AND PROGRAMMES

Research, policies and programmes for PWDs could be assessed to determine the level of awareness, activities and investment in meeting the needs of PHAs. For example, opportunities could be identified to include PHAs within the soft laws and implementation of the CRPD, within national disability and social support programs and within disabled persons' organizations working at all levels.

INVOLVE PWDs AND PHAs AS AGENTS OF CHANGE AT ALL LEVELS

Meaningful involvement of PWDs and PHAs should be ensured in all aspects of work in the area of disability and HIV/AIDS. The concept of "nothing about us without us" from the disability movement, which was adapted to the GIPA (greater involvement of people living with HIV and AIDS) principle within the AIDS movement, must continue to be championed. This means:

- Valuing the experiences and expertise of PWDs and PHAs in shaping the policies and programmes designed to support them;
- Dedicating resources to engage and involve PWDs and PHAs in research and evaluation, policy and programme development, service delivery, and advocacy;
- Providing PHAs and PWDs opportunities to work in leadership, volunteer and staff positions within organizations/networks active in the area of disability and HIV/AIDS; and
- Ensuring participation at policy tables, within the UN system at the country level.

BUILD CAPACITY OF PWDs AND DISABLED PERSONS' ORGANIZATIONS

The HIV/AIDS movement has been well-resourced in comparison to the disability movement, HIV/AIDS advocates have also had the influence, power and expertise to participate at policy tables. For this reason, steps could be taken to build the capacity of PWDs and disabled persons' organizations to facilitate meaningful involvement in processes at all levels of education, policy development, programming and research.

CREATE OPPORTUNITIES FOR NETWORKING AND DIALOGUE BETWEEN DISABILITY AND HIV/AIDS NETWORKS

Collaboration between HIV/AIDS and disability networks is in its early stage. The Dialogue provided an opportunity for participants to build understanding, exchange ideas and identify possible areas for collaboration. However, most people working in the disability or HIV/AIDS movements continue to have limited understanding of the intersectionality of HIV/AIDS and disability. With few exceptions, they have not yet had the opportunity for dialogue, whether at the international, country or grassroots level.

A logical next step is to identify opportunities for dialogue between HIV/AIDS and disability networks. Existing mechanisms, such as regular meetings and conferences, could be used as opportunities for dialogue. Resources could be leveraged through existing funding initiatives to support dialogue at all levels.

ESTABLISH A CLEARINGHOUSE FOR INFORMATION ON DISABILITY AND HIV/AIDS

There is limited information available on research, policies and programmes related to disability and HIV/AIDS. Information and resources that do exist are not widely accessible.⁴ Networking, collaboration and an exchange of learnings could be facilitated through establishing an on-line clearinghouse on disability and HIV/AIDS.

The clearinghouse could be a hub with access to relevant research, reports, awareness-raising tools, examples of promising practices, and lessons learned about what works to advance policy and practice in the area of disability and HIV/AIDS. It could also include links to researchers, organizations and networks active in the area of disability and HIV/AIDS research, policy development and programming, with an interactive function to allow timely exchange of activities, requests for information and events.

DEVELOP STRONGER PARTNERSHIPS AT THE NATIONAL AND INTERNATIONAL LEVELS

The value of strengthening partnerships at the national and international levels was identified. Building coalitions and partnerships could support horizontal and vertical advocacy to inform policy-making. Partnerships could be strengthened by clearly defining the roles of stakeholders and building on the existing infrastructures already in place at the national and international levels.

8.2 EDUCATION/AWARENESS

Limited awareness exists among key stakeholders on the impact of HIV/AIDS on persons with pre-existing disabilities and the impact of disabilities on PHAs. This limited awareness is a barrier to advancing the rights of persons with disabilities and HIV/AIDS in a number of ways:

- Many PWDs, and the organizations that support them, are not aware of their rights under the CRPD;
- Most decision-makers have excluded the needs of PWDs from HIV/AIDS policy and programme development, and the needs of PHAs from disability policy and programme development;
- Most AIDS service organizations do not have an understanding of how to design and deliver HIV/AIDS information and supports that are appropriate and accessible to all PWDs;
- Most disabled persons organizations are not aware that PWDs are at high risk for contracting HIV/AIDS, or of how to support PWDs living with HIV/AIDS;
- Most researchers and evaluators do not design research questions and data collection tools that identify PWDs or PWDs living with HIV/AIDS in statistics used for health policy and planning;
- Civil society has not been engaged in advocating for the rights of PWDs at risk for or living with HIV/AIDS; and

⁴ Some information on disability and HIV/AIDS is currently posted on the World Bank web site at <http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALPROTECTION/EXTDISABILITY/0,,contentMDK:20208464~pagePK:148956~piPK:216618~theSitePK:282699,00.html>

- Most funders do not allocate funds to research, policy or programme development for disability and HIV/AIDS.

Based on the central role of education and awareness in advancing the rights of persons with disabilities and HIV/AIDS, a number of opportunities and possible next steps were identified to increase the visibility of disability and HIV/AIDS issues and to educate key stakeholders.

COLLABORATE TO DEVELOP A GLOBAL CAMPAIGN ON DISABILITY AND HIV/AIDS

To raise the profile of disability and HIV/AIDS issues, a global campaign could be mounted on HIV/AIDS and disability. Because resources are limited, partners could collaborate to develop and share campaign materials targeted to different stakeholder groups. HIV/AIDS and disability networks could explore joint strategies for disseminating materials and engaging key stakeholders on the issues. Full participation of PWDs and PHAs should be ensured in all aspects of developing and mounting a campaign.

To increase effectiveness, a campaign could involve a mosaic of targeted awareness-raising strategies and activities at all levels: international, regional, country and grassroots. The Africa Campaign on Disability and HIV/AIDS could be used as a potential model.⁵

USE THE CRPD AND EXISTING MECHANISMS/CHANNELS

The CRPD could be an effective vehicle for mounting an awareness campaign on disability and HIV/AIDS. Tools developed to educate stakeholders about the CRPD could specifically identify the link to HIV/AIDS. Specific opportunities could be identified to raise the issues through regular events/meetings on the topics of HIV/AIDS, disability and/or human rights. For example:

- Disability and HIV/AIDS issues could be profiled as part of World AIDS Day and World Disability Day;
- Meetings of the Council of State Parties and the Committee of Experts could include agenda items specific to disability and HIV/AIDS; and
- Dialogue sessions, workshops and other awareness-raising activities could be planned in conjunction with the 2010 World Congress on HIV/AIDS.

IDENTIFY AND INVOLVE HIGH PROFILE CHAMPIONS

Identifying and involving high profile champions (eg. celebrities, well-respected statespersons) could help to raise awareness and to significantly increase the profile of disability and HIV/AIDS issues. This has been a highly effective strategy used by the HIV/AIDS movement. This approach could help mobilize civil society to advocate for change.

⁵ The Africa Campaign has provided a unifying umbrella under which disabled people's organizations, organizations of PHAs, NGOs, AIDS services organizations, researchers, activists, and other citizens work collectively to achieve inclusive national HIV/AIDS policies and programmes and equal access for PWDs in Africa to information and services on HIV/AIDS. For more information, see <http://www.africacampaign.info/>

DEVELOP TARGETED TOOLS FOR RAISING AWARENESS

Tools are needed to raise awareness about the CRPD, as well as broader disability and HIV/AIDS issues. Due to the diversity of stakeholder groups and levels of knowledge on the issues, a variety of targeted tools are needed. Immediate next steps could include developing tools focused on the rights of PWDs under the CRPD and on HIV/AIDS and disabilities issues.

Stakeholder groups identified for receiving these targeted education and awareness materials included:

- The general public;
- PWDs and disabled persons networks and organizations (international, national and grassroots);
- PHAs and AIDS networks and service organizations (international, national and grassroots);
- Medical students, rehabilitation professionals, and other service providers working with persons with disabilities and HIV/AIDS;
- Policy-makers and decision-makers working within the UN system, international organizations and national governments;
- Donors/funders who provide multi-lateral or bilateral aid to developing countries or who fund activities in the areas of HIV/AIDS, development or human rights;
- The academic community and research funding bodies; and
- Private businesses/organizations (about rights in the workplace for both PWDs and PHAs and about corporate social responsibility to support change).

FOCUS AWARENESS MESSAGES ON INCLUSION, DIVERSITY AND HUMAN RIGHTS

Key concepts to guide an awareness campaign on disability and HIV/AIDS include:

- Focus on equal rights, inclusion and removal of barriers for full participation of PWDs;
- Develop messages that promote diversity and inclusion of all people (not exclusively focused on disability and HIV/AIDS);
- Articulate the commonalities and the differences in the experience of stigma/discrimination by PWDs and PHAs; and
- Promote healthy sexuality (appropriate to context).

8.3 PROGRAMMES

In most cases, service provision and related programmes do not integrate HIV/AIDS and disability. HIV/AIDS prevention programmes, voluntary counselling and testing, or support services do not generally include or address the needs of PWDs. Disability services and social support programmes do not generally include or address the needs of PHAs. A number of steps

could be taken to improve the inclusion of PWDs, PHAs, and persons with both HIV/AIDS and disabilities in programming.

DOCUMENT AND SHARE PROMISING PRACTICES IN INTEGRATED HIV/AIDS AND DISABILITY PROGRAMMING

There is a need to demonstrate the positive outcomes and synergies that can be achieved through integrated HIV/AIDS and disability programming. Documenting promising practices and the lessons learned could support other organizations to build on and extend efforts to integrate HIV/AIDS and disability programming. Evaluating these programmes could help to demonstrate the benefits of an integrated approach and to make the case for investment to donors/funders.

There has been some success at the international level with integrated programming for HIV and tuberculosis. Although there has been limited success at the grassroots level, there could be valuable lessons applied to advancing integrated disability and HIV/AIDS programming.

PROMOTE THE INCLUSION OF DISABILITY AND HIV/AIDS ISSUES IN THE FORMAL EDUCATION OF MEDICAL AND HEALTH CARE PROVIDERS

Opportunities could be investigated to better include disability and HIV/AIDS issues in the formal education of medical and health care providers. Training is needed to increase understanding of general issues, to reduce stigma, and to build skills for providing sensitive, appropriate care.

Identified topic areas to include in the curricula of universities, colleges and professional licensing bodies included:

- General knowledge and skills for working with PWDs (range of disabilities and supports required);
- Providing accessible, respectful HIV/AIDS prevention information, testing, counselling and care to PWDs;
- Understanding the sexual health of PWDs and promoting healthy sexuality;
- Understanding the link between risk factors for mental health problems and risk factors for HIV/AIDS; and
- Recognizing and providing supports to PHAs with mental health problems (depression, anxiety and cognitive impairment), including street-involved people, injection drug users, and those with a dual diagnosis of addiction and mental health problems.

ADVOCATE FOR THE INCLUSION OF PWDs IN ALL WORK ON SEXUAL AND REPRODUCTIVE HEALTH

Advocacy is needed to ensure the inclusion of PWDs within all work on sexual and reproductive health, including programme planning and service delivery. Education and awareness are needed at all levels to overcome the common assumption that PWDs are not sexually active, and thereby not at risk for HIV/AIDS. Specific areas that were identified included:

- All general outreach efforts on sexual and reproductive health and sex education for adolescents and young adults;
- All maternal/child health programming; and
- All family planning programming (stressing that PWDs also have the right to decide whether or not to have a family and where, when and how to plan this).

There is an immediate need to develop accessible, appropriate information on HIV/AIDS prevention and supports for PWDs.

BUILD CAPACITY IN AIDS SERVICE ORGANIZATIONS AND DISABLED PERSONS' ORGANIZATIONS

There is a need to build capacity among staff and volunteers working at the grassroots level in AIDS service organizations and disabled persons' organizations. Within both service networks, sensitizing staff and volunteers to issues of disability and HIV/AIDS could help to reduce discrimination and the double stigma that exists.

- Training, capacity-building and financial resources are needed for AIDS service organizations to improve physical accessibility and inclusion of PWDs within programming. This includes the full programming spectrum of HIV/AIDS prevention, voluntary counselling and testing, treatment, support and care;
- For disabled persons' organizations, training and capacity-building are needed to reach out to and support PWDs living with HIV/AIDS. Additional funding is needed to support disabled persons organizations' in doing this work; and
- Networking between disabled persons' organizations and AIDS service organizations could improve service planning, better integrate programmes, and strengthen advocacy efforts.

RECOMMEND CHANGES TO PRIORITIES AND GUIDELINES OF UNAIDS AND WHO

A formal recommendation could be brought to UNAIDS to include PWDs on its list of priority high risk groups. This would be a catalyst for review of HIV/AIDS funding, policies and programmes to ensure they are inclusive of PWDs. The WHO could be encouraged to develop guidelines for HIV prevention for PWDs and inclusion of PWDs in HIV/AIDS programmes. While guidelines are currently under development by the WHO for community-based rehabilitation, additional guidelines could help to advance appropriate disability and HIV/AIDS programming.

8.4 POLICY DEVELOPMENT

In most cases, policies at all levels do not integrate HIV/AIDS and disability. There has been little attention to date to PWDs within the broader HIV/AIDS community, and PHAs are also not included in most disability policies.

WORK TOWARDS INCLUDING DISABILITY IN NATIONAL HIV/AIDS STRATEGIC PLANS

Efforts could be made to advocate for the inclusion of disability within national HIV/AIDS strategic plans, monitoring and surveillance. Integrating disability into the national plans could

help ensure that resources are allocated to policy and programme development inclusive of PWDs at risk for or living with HIV/AIDS. Involvement of representatives from disabled persons' organizations in national policy and planning processes could give voice to the needs of PWDs and could help to ensure relevance of policies and plans.

WORK FOR INCLUSION OF HIV/AIDS IN THE IMPLEMENTATION OF THE CRPD

As noted in Section 5.0, the CRPD could be an effective policy instrument for disability and HIV/AIDS issues, contingent on ratification, effective implementation at the country level, and inclusion of HIV/AIDS in guidelines for implementation, monitoring and reporting. HIV/AIDS and disability networks could influence the implementation process by finding opportunities to engage the members of the Committee of Experts in dialogue on disability and HIV/AIDS.

INTEGRATE DISABILITY INTO THE EXISTING UN STRUCTURES AND MECHANISMS

The rights of persons with disabilities and HIV/AIDS could be further advanced within existing UN structures and mechanisms,. Possible actions include:

- Using the CRPD to integrate PWDs into the Millenium Development Goals and Poverty Reduction papers;
- Using the Inter-Agency Support Group process to require all UN agencies to assess how PWDs are included in HIV/AIDS policies and programmes;
- Integrating disability issues into the Universal Periodic Review of the UN High Commission on Human Rights;
- Requesting that the Human Rights Council focus one of its annual interactive policy dialogues on disability on the intersectionality of HIV/AIDS and disability;
- Profiling HIV/AIDS and disability in regional and international Inter-Agency Support Group conferences, as one of the annual themes of the UN High Commission for Refugees and in the 2011 review of the UN Declaration of Human Rights; and
- Engaging the Special Rapporteur on the Right to Health on the CRPD within the context of HIV/AIDS.

USE DONOR INFLUENCE TO ENCOURAGE RATIFICATION OF THE CRPD

To raise awareness and strengthen policies, donor countries could:

- Encourage recipient countries to ratify the CRPD; and
- Work with country partners to conduct national surveys, collect data and include or strengthen disability programmes within their national health, education and social programmes. .

INITIATE COUNTRY-LEVEL SITUATIONAL ASSESSMENTS TO SUPPORT POLICY DEVELOPMENT

Country-level situational assessment could be carried out to identify gaps in inclusion of PWDs in HIV/AIDS programmes and policies. The analysis of information/data on disability and HIV/AIDS could be shared with all stakeholders to provide the foundation for policy change.

BUILD CAPACITY OF THE COMMUNITY SECTOR TO DEVELOP SHADOW REPORTS

There is an important role for disabled persons' organizations and HIV/AIDS networks in preparing shadow reports to those submitted by national governments under the CRPD. These shadow reports can provide a more complete record of the experience of PWDs and PWDs living with HIV/AIDS in achieving the rights outlined in the CRPD.

To fulfill this role, there is a need to strengthen the capacity of the community sector to engage in and influence the policy development process. Resources and expertise could be secured to increase the capacity of disabled persons' organizations to be meaningfully involved in the policy process, including policy research and development, analysis, implementation, monitoring and evaluation.

DEVELOP A REGIONAL JOINT POSITION PAPER ON HIV/AIDS AND DISABILITY

There may be value in developing a joint position paper on HIV/AIDS and disability. There are varying degrees of readiness in different regions for this approach, however. Brazil may move forward with partners in Latin America to develop a regional manifesto on the intersectionality of HIV/AIDS and disability. The 2010 World AIDS Conference could be used as a high profile forum to launch the manifesto. A dialogue session could be organized to share how the HIV/AIDS and disability networks worked together to develop the manifesto and to discuss the value of this approach in other regions, or internationally.

ADVANCE HIV/AIDS AND DISABILITY ISSUES IN THE CANADIAN CONTEXT

A number of specific actions were suggested during the Dialogue to advance the rights and inclusion of PWDs and PHAs in the Canadian context. These include:

- Organizing provincial fora for HIV/AIDS networks and disability networks to dialogue on the CRPD and the intersection of HIV/AIDS and disability;
- Developing roadmaps on disability, development and HIV/AIDS to guide Canada's foreign assistance programmes; and
- Taking action to encourage ratification of the CRPD and the Optional Protocol by the Government of Canada.

8.5 RESEARCH

There is a dearth of research on the intersectionality of HIV/AIDS, and to date, there is no process in place to bring together researchers to develop consistent indicators for measuring disability or HIV/AIDS and disability.

DEVELOP A MONITORING PROCESS AND BASELINE DATA FOR DISABILITY AND HIV/AIDS

Efforts could be made to organize an international meeting focused on identifying appropriate indicators for HIV/AIDS and disability. This could happen within the context of planned UN meetings, such as the September 2009 meeting of the CRPD Committee of Experts for example. This would provide a focal point for standards of measurement or the establishment of an indicator agreement, laying the foundation for the collection of comparable data to build a consistent evidence base.

The range of indicators could include indicators of individual performance and service quality (eg. health clinic assessments), indicators that measure environments that impact health, as well as indicators measuring national programme and policy implementation.

Baseline data on disability and HIV/AIDS is needed at the country level, and then must be rolled up for a global picture. Minimum requirements for necessary data include:

- The number of PWDs;
- The number of PWDs who contract HIV/AIDS;
- The number of persons with HIV/AIDS who develop a disability and the types of disability/functional impairment they experience; and
- Sex disaggregated data to assess differences in statistics for males and females

Other suggestions for data collection included:

- Large scale epidemiological studies on life-related impacts of living with HIV/AIDS over time, including the experience of disability;
- National prevalence studies to document the number of PHAs with disabilities and the impact of the disability on their functional abilities, quality of life and access to income and social supports;
- Workplace costs to accommodate people with HIV/AIDS, and the costs of not accommodating people with HIV/AIDS;
- Benefits of a cross-disability approach, using a rehabilitation lens to examine the experience of other episodic conditions (eg. people with arthritis, with MS, cancer, diabetes, lupus);
- Documentation of best practices across disabilities that could be adapted for PHAs;
- Level of knowledge and skills, and the attitudes of care providers who work with PHAs;
- Impact of inter-professional care, through evaluation of demonstration projects for new models of care provision;
- Impact of policies on of cost and quality of life; and
- Economic cost-benefit analysis of supporting PHAs with disabilities to remain in the workforce through income, social support and rehabilitation programmes.

IMPROVE MEASUREMENT AND COLLECTION OF DATA ON DISABILITY AND HIV/AIDS

Standard disability questions could be built into pre-existing data collection on HIV/AIDS within health systems. This could involve a review of current survey and reporting tools used within the UN system, at the country level (e.g. national surveys, health statistics, health system databases), and at the organizational level (e.g. intake assessment forms, needs assessment surveys).

New ways of measuring disability are needed that take into account episodic impairment experienced by PHAs. Persons with episodic illness are currently often excluded from disability statistics, underestimating the number of persons with disabilities and HIV/AIDS.

Careful analysis of research data will be needed to ensure valid comparisons can be drawn across diverse groups and settings.

ESTABLISH RESEARCH TEAMS TO DISAGGREGATE INFORMATION ON DISABILITY AND HIV/AIDS FROM EXISTING SOURCES

Educational and research institutions typically house a wealth of information on the health of populations, including statistical databases and data from research studies. However, information on disability and on disability and HIV/AIDS has not typically been disaggregated for analysis. Research teams could be established to negotiate with educational and research institutions about accessing and analyzing existing information sources. Existing mechanisms could be used to conduct systematic reviews of study results.

AUDIT ORGANIZATIONS AND GOVERNMENT DEPARTMENTS TO IDENTIFY KNOWLEDGE ON DISABILITY AND HIV/AIDS

An audit process at the country level could be conducted to identify existing knowledge on disability and HIV/AIDS. This would include a review of current surveys for questions on disability and/or HIV/AIDS and the identification of research studies, reports, policies and plans related to disability and HIV/AIDS. This information could be documented and shared within research networks, HIV/AIDS and disability networks to inform policy development, programming and advocacy.

DISSEMINATE RESEARCH FINDINGS FROM NORTH-SOUTH CASE STUDIES

Findings from North-South case studies could be disseminated broadly to help build awareness and engagement, and to make a case for investment in disability and HIV/AIDS initiatives. Methods of dissemination could include writing articles for peer-reviewed journals, submitting abstracts to present at conferences and posting on web sites. Efforts could be made to foster a two-way exchange of learnings between the North and South, and to identify more opportunities for collaborative research in this area.

EXPLORE AND PROMOTE OPPORTUNITIES FOR RESEARCH ON DISABILITY AND HIV/AIDS

There are a limited number of researchers building knowledge about disability and HIV/AIDS. Efforts are needed to engage universities in conducting additional research and to educate research funding bodies about the value of research in this area. Successful engagement could build a new generation of academics and researchers who are sensitized to HIV/AIDS and disability issues. Possible avenues to promote research include:

- Approaching specific researchers to add a disability component to their research;
- Engaging academics by sending them research findings (data, results) and requesting that they provide further analysis and/or to highlight trends;
- Encouraging PhD students in universities to focus their research in the area of HIV/AIDS and disability;

- Exploring how HIV/AIDS and disability research could feed into the work of the Global Forum for Health Research; and
- Influencing research funding bodies to organize a dedicated funding call specific to the intersectionality of HIV/AIDS and disability.

INVOLVE PWDs IN RESEARCH AND PROMOTE PARTICIPATORY ACTION RESEARCH

Participatory action research has direct benefits to communities and has the potential to include disability practitioners, PWDs and PHAs in the research process. Participation could be facilitated by building a dedicated funding line into project budgets that supports the involvement of PWDs and PHAs in the research. Disabled persons' organizations could take an active role in identifying research questions and bringing them forward to universities.

Efforts could be made to build the capacity of disabled persons' organizations and PWDs to become researchers. This could facilitate a shift towards active involvement of the persons affected by the research rather than working with them as passive research subjects.

9.0 CONCLUSION

The intersectionality of HIV/AIDS and disability is emerging as an important area of global policy development. Participants of the International Policy Dialogue valued the opportunity to share knowledge and their experiences, to further build common understanding of the issues, and to explore opportunities for collaboration to advance the rights of PWDs and PHAs. Implementation of next steps will depend on building consistent monitoring, surveillance and reporting, and providing future opportunities for networking, information-sharing and dialogue among disability and HIV/AIDS networks at the international, national and grassroots levels.

Final report prepared by:

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APPENDIX A

MEMBERS OF THE ADVISORY COMMITTEE

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APPENDIX B

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APPENDIX C

MEETING AGENDA

TIME	ITEM
Wednesday, March 11, 2009	
08:00 – 09:00	Registration
09:00 – 09:15	Welcome <ul style="list-style-type: none"> - Karen Dodds (Assistant Deputy Minister, Health Policy Branch, Health Canada)
09:15 – 09:45	Overview of shared experiences of marginalization <ul style="list-style-type: none"> - Chris Bell (Syracuse University)
09:45 – 10:30	Key-note Address <ul style="list-style-type: none"> - Stephen Lewis (AIDS-Free World)
10:30 – 11:00	Break
11:00 – 12:00	Facilitated Discussion on morning presentations
12:00 – 13:30	Lunch
13:30 – 15:00	Panel Discussion: HIV/AIDS advocates and the Disability Rights movement: Finding Common Ground <ul style="list-style-type: none"> - Chris Bell (Syracuse University) - Winstone Zulu (Zambia / Ryerson University) - Penny Parnes (University of Toronto)
15:00 – 15:30	Break
15:30 – 17:00	Plenary: “Defining or Undefining Disability” <ul style="list-style-type: none"> - Steve Estey, Council of Canadians with Disabilities
Thursday, March 12, 2009	
09:00 – 10:30	Plenary “Perspectives on International Policy” <ul style="list-style-type: none"> - Mary Ennis (Disabled Peoples International) - Hendrietta Bogopane-Zulu (South African Parliament) - Rosangela Berman Bieler (IIDJ, New York)
10:30 – 11:00	Break
11:00 – 12:30	Breakout Sessions
	HIV/AIDS, Disability and Law <ul style="list-style-type: none"> - Richard Elliot (Canadian HIV/AIDS Legal Network)
	HIV/AIDS, Disability and social/disability support funds <ul style="list-style-type: none"> - Elisse Zack (Canadian Working Group on HIV/AIDS and Rehabilitation)
	HIV/AIDS, Disability and Stigma in health care settings <ul style="list-style-type: none"> - Elly Macha (African Union of the Blind, Kenya)
12:30 – 13:30	Lunch

13:00 – 13:20	Lunch Talk: “Sexuality and Disability: The Underlying Issue” - Caroline Earle, CREA
13:30 – 15:00	Plenary “Integrating Disability and HIV/AIDS initiatives: What does this mean?” - Myroslava Tataryn (AIDS-Free World) - Jessica de Ruijter (VSO Netherlands) - Betty Kwagala (TASO, Uganda)
15:00 – 15:30	Break
15:30 – 17:00	Breakout Sessions
	Case Studies of North/South Partnerships on Disability and HIV/AIDS - Penny Parnes (International Centre for Disability and Rehabilitation - University of Toronto) - Barbara Marjeram (Canadian National Institute for the Blind) and Elly Macha (The African Union of the Blind)
	Mental Health and HIV/AIDS - Elisse Zack (Canadian Working Group on HIV/AIDS and Rehabilitation)
	Developmental Disability and HIV/AIDS - Shelley Hourston (British Columbia Coalition of People with Disabilities)
	Analysis of UNAIDS’ Draft HIV/AIDS Policy Brief on HIV/AIDS and Disability - Emelia Timpo (UNAIDS)
Friday, March 13, 2009	
08:30 – 09:15	Plenary: Report back from yesterday’s breakout sessions
09:15 – 10:45	Plenary: “The Convention on the Rights of Persons with Disabilities: A Tool to bring about Change” - Richard Elliot (Canadian HIV/AIDS Legal Network) - Elly Macha (African Union of the Blind, Kenya) - Steve Estey (Disabled Peoples International, Canada)
10:45 – 11:00	Break
11:00 – 11:45	Plenary: “The State of Research” - Myroslava Tataryn (AIDS-Free World) - Charlotte McClain-Nhlapo (World Bank) - Elisse Zack (CWGHR)
11:45 – 12:45	Lunch
12:45 – 13:45	Table and Plenary Discussions: “Where Next?”
13:45 – 14:00	Wrap Up and Next Steps - Health Canada Representative
14:00 – 14:30	Closing Plenary Address - Winstone Zulu (Zambia / Ryerson University)

APPENDIX D

BREAK-OUT SESSION GUIDING QUESTIONS

- 1. What are the shared experiences and challenges of people living with pre-existing disabilities and/or HIV/AIDS within this topic?**
- 2. What gaps are there with regards to:**
 - policy development
 - programming
 - research
 - education/awareness
- 3. What are the opportunities for advancing this topic, including (but not limited to);**
 - strengthening partnerships amongst key stakeholders, and engaging new partners
 - linking with international/national initiatives already underway
 - others?
- 4. What are the next steps in moving this issue forward?**

APPENDIX E

EXAMPLES OF INTEGRATING DISABILITY AND HIV/AIDS PROGRAM

EXAMPLE 1: TRAINING YOUTH WITH DISABILITIES TO PROVIDE HIV/AIDS PREVENTION AND TREATMENT INFORMATION TO PWDs WITH HIV/AIDS

In 2005/06, an intern with Disabled Persons International spent six months in Capetown, South Africa developing an education program specifically for persons with disability and HIV/AIDS. Twenty youth with disabilities were chosen from a township. A trainer from the HIV/AIDS Treatment Action Campaign was contracted to train these youth. Youth gained information, and the trainer benefited and learned from the disabled youth. He became an advocate for making all Treatment Action Campaigns inclusive of PWDs, with great progress underway. This example highlights the importance of having the non-disabled service providers exposed to working with the disabled to develop a better understanding and appreciation of the issues.

EXAMPLE 2: PROVIDING HIV/AIDS SCREENING, INFORMATION AND SERVICES TO PWDs BY PWDs

A mainstream voluntary HIV/AIDS counselling and testing organization based in Liverpool, Kenya established three stand-alone clinics for deaf people to increase access to marginalized groups. All staff are deaf, providing testing to their peers, so no interpretation is required. The clinics have now expanded to serve persons with other disabilities, with interpretation provided. The deaf staff members are part of the larger staff team, serving as resources for advice.

EXAMPLE 3: PROVIDING SERVICES FOR PHAs WITH MENTAL HEALTH PROBLEMS

In Uganda, a grassroots clinic was established to provide HIV counselling and home-based care for persons with HIV/AIDS in the community. Many community members were experiencing mental health problems related to their HIV infection. A separate mental health clinic was set up to provide support, which now serves people with mental health problems who are not HIV positive. The clinic is self-financing, receiving support and recognition from the larger organization.

EXAMPLE 4: MAINSTREAMING DISABILITY AT THE ORGANIZATIONAL, WORKPLACE AND PROGRAMME LEVELS

VSO is working to mainstream disability at organizational, workplace and programme levels, taking a rights-based approach aimed at full inclusion of PWDs. An organizational strategy is in place supported by senior management and a handbook on mainstreaming disability tailored to VSO. Volunteers with disabilities are included in programs in developing countries and inclusive education programs train service providers to be more sensitive to needs of PWDs. Access to microcredit supports disabled persons organizations to participate in poverty reduction strategy papers. VSO also provides accessible sexual health information, encouraging mainstreaming with their HIV/AIDS partners.

EXAMPLE 5: ASSESSING ACCESSIBILITY OF HIV/AIDS PROGRAMMES TO PWDs

TASO in Uganda is integrating services for persons with a disability into AIDS service organizations. The Uganda AIDS Commission is learning more about the rights of disabled persons in relation to HIV/AIDS. Research is underway to find out how involved and how effective current AIDS service organizations are in serving PWDs and making sure their needs are voiced at the national level, in partnership with disabled persons organizations. Awareness-raising activities are aimed at educating PWDs about HIV/AIDS using accessible information and educating providers in AIDS service organizations about providing service to persons with a disability (pre-existing or a result of HIV).