UMBRELLA OF PEOPLE WITH DISABILITIES IN THE FIGHT AGAINST HIV AND AIDS (UPHLS)

REPORT ON THE
FIRST NATIONAL FORUM ON HIV& AIDS AND DISABILITY
(KIGALI, La Palisse Hôtel, 28–29/05/2009)

« A HOLISTIC APPROACH TO ADDRESS HIV AND AIDS AMONG PEOPLE WITH DISABILITIES »
# CONTENTS

<table>
<thead>
<tr>
<th>CONTENTS</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABBREVIATIONS</td>
<td>3</td>
</tr>
<tr>
<td>APPENDICES</td>
<td>4</td>
</tr>
<tr>
<td>AKNOWLEDGMENT</td>
<td>5</td>
</tr>
<tr>
<td>I. CONTEXT</td>
<td>6</td>
</tr>
<tr>
<td>1.1. Disability and HIV&amp;AIDS</td>
<td>6</td>
</tr>
<tr>
<td>1.2. Relevance and Theme of the Forum</td>
<td>7</td>
</tr>
<tr>
<td>1.2.1. Relevance</td>
<td>7</td>
</tr>
<tr>
<td>1.2.2. Theme</td>
<td>7</td>
</tr>
<tr>
<td>1.3. Goal and objectives of the Forum</td>
<td>8</td>
</tr>
<tr>
<td>1.3.1. Goal</td>
<td>8</td>
</tr>
<tr>
<td>1.3.2. Objectives</td>
<td>8</td>
</tr>
<tr>
<td>1.4. Expected results of the Forum</td>
<td>8</td>
</tr>
<tr>
<td>1.5. Venue and period</td>
<td>8</td>
</tr>
<tr>
<td>1.6. Program and methodology</td>
<td>8</td>
</tr>
<tr>
<td>1.7. Logistics and visibility of the Forum</td>
<td>9</td>
</tr>
<tr>
<td>1.7.1. Logistic aspects</td>
<td>14</td>
</tr>
<tr>
<td>1.7.2. Visibility</td>
<td>17</td>
</tr>
<tr>
<td>II. PARTICIPATION IN THE FORUM</td>
<td>10</td>
</tr>
<tr>
<td>2.1 Distribution of the participants according to Disability</td>
<td>10</td>
</tr>
<tr>
<td>2.2 Distribution of the participants by institution</td>
<td>11</td>
</tr>
<tr>
<td>2.3 Distribution of the participants by sex</td>
<td>11</td>
</tr>
<tr>
<td>III. KEY MOMENTS OF THE FORUM</td>
<td>12</td>
</tr>
<tr>
<td>3.1. Introduction on “an inclusive communication”</td>
<td>12</td>
</tr>
<tr>
<td>3.2. Official launching ceremony</td>
<td>14</td>
</tr>
<tr>
<td>3.2.1. Official launching speeches</td>
<td>14</td>
</tr>
<tr>
<td>3.2.2. An opportunity of sensitizing</td>
<td>17</td>
</tr>
<tr>
<td>3.3. Exhibition</td>
<td>18</td>
</tr>
<tr>
<td>3.4. Presentations of the Forum</td>
<td>19</td>
</tr>
<tr>
<td>3.4.1. A common comprehension of the problems</td>
<td>19</td>
</tr>
<tr>
<td>3.4.2. A Forum linked to a global dynamics</td>
<td>21</td>
</tr>
<tr>
<td>3.4.3. HIV&amp;AIDS and Handicap: an environment favorable to Rwanda</td>
<td>22</td>
</tr>
<tr>
<td>3.5. Profitable debates</td>
<td>24</td>
</tr>
<tr>
<td>3.5.1. How to reduce discrimination and stigmatization?</td>
<td>24</td>
</tr>
<tr>
<td>3.5.2. Access to care health today: a choking truth</td>
<td>26</td>
</tr>
<tr>
<td>3.6. Exchanges in thematic groups</td>
<td>27</td>
</tr>
<tr>
<td>3.7. Official closure ceremony</td>
<td>38</td>
</tr>
<tr>
<td>IV. DECLARATION OF THE FIRST NATIONAL FORUM ON HIV&amp;AIDS AND DISABILITY</td>
<td>29</td>
</tr>
<tr>
<td>CONCLUSION</td>
<td>34</td>
</tr>
</tbody>
</table>
**ABBREVIATIONS**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ANFSMR</td>
<td>National association of the Deaf and Mute Women</td>
</tr>
<tr>
<td>ART</td>
<td>Anti-rétroviral treatment</td>
</tr>
<tr>
<td>BNR</td>
<td>National Bank of Rwanda</td>
</tr>
<tr>
<td>BCC</td>
<td>Behavior Change Communication</td>
</tr>
<tr>
<td>CDLS</td>
<td>District AIDS Control Committee</td>
</tr>
<tr>
<td>CNDP</td>
<td>National Human Rights Commission</td>
</tr>
<tr>
<td>NACC</td>
<td>National AIDS Control Commission</td>
</tr>
<tr>
<td>FENAPH</td>
<td>National Federation of People with Disabilities</td>
</tr>
<tr>
<td>HI</td>
<td>Handicap International</td>
</tr>
<tr>
<td>HRSA</td>
<td>Health Resources and Services Administration</td>
</tr>
<tr>
<td>HVP</td>
<td>Home of the Virgin of the Poor</td>
</tr>
<tr>
<td>IEC</td>
<td>Information Education and Communication</td>
</tr>
<tr>
<td>MIFOTRA</td>
<td>Ministry of Public service and Labor</td>
</tr>
<tr>
<td>MINALOC</td>
<td>Ministry of Local government, good Governance, Community Development and</td>
</tr>
<tr>
<td></td>
<td>Social Affairs</td>
</tr>
<tr>
<td>MINEDUC</td>
<td>Ministry of Education</td>
</tr>
<tr>
<td>MININFRA</td>
<td>Ministry of Infrastructures</td>
</tr>
<tr>
<td>MOH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>NGOs</td>
<td>NonGovernmental organizations</td>
</tr>
<tr>
<td>DPO</td>
<td>Disabled People’s Organization</td>
</tr>
<tr>
<td>PEPFAR</td>
<td>The U.S. President’s Emergency Plan for AIDS Relief</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
</tr>
<tr>
<td>PWD</td>
<td>Persons with Disabilities</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired immunodeficiency Syndrome</td>
</tr>
<tr>
<td>TRAC MORE</td>
<td>Center for Treatment and Research on AIDS</td>
</tr>
<tr>
<td>TUBAKUNDE</td>
<td>Collective of Plea for the children with intellectual impairments</td>
</tr>
<tr>
<td>UPHLS</td>
<td>Umbrella of Persons with Disabilities Fighting against the HIV and AIDS</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency Virus</td>
</tr>
</tbody>
</table>
LIST APPENDICES

For appendixes, please see the document in French.
AKNOWLEDGMENT

UPHLS thanks any person or entity having contributed to the realization of the First National Forum on HIV and Disability.

The Forum could not have been held without the financial assistance of HI/HRSA/PEPFAR Project and without the technical support from Handicap International. UPHLS expresses its gratitude here.

The Disability Movement was really involved in the preparation and the realization of the Forum. May Persons with Disabilities find in its engaging results a reward for their efforts.

A particular thought goes to all people who agreed to share their expertise by realizing presentations and by ensuring the facilitation of the debates.

One of the characteristics appreciated during Forum is the great participation of the actors whose handicap was not a priority before. We owe the success of the Forum to the interactions between Persons with Disabilities and HIV other actors. In particular, may the Directors of the Hospitals or their representatives, the Technical Assistants of CDLS, the representatives of NGOs and Government institutions, present to the Forum, find here the expression of our gratitude.

UPHLS also thanks the media and the journalists who ensured the media coverage of the Forum.

More particularly, the firm support from the Rwandan government, through the Ministry of Health and the NACC, is worthy of praise. Thanks to the perspicacity of our leaders, Rwanda has advanced in the field of HIV and Disability before even the emergence of international initiatives relating to it. We hope that the results of the Forum will insufflate the necessary dynamics to continue on the current impetus in integrating Persons with Disabilities in the national response to HIV&AIDS.

May Dr. Agnès BINAGWAHO, Permanent Secretary of the MOH, find here the sincere thanks for the creation and the capacity buildings of UPHLS, in which she played an important role. Her advices were also determining in the articulation of the topic of the Forum and in the development of its program, in particular by supporting a global vision privileging the integration of Disability in all the Community Health System.

To Dr. Anita ASIIMWE, Executive Secretary of the NACC, we say thanks for her contribution to the good unfolding of the Forum and for her commitment to continue prioritize the integration of Persons with Disabilities in the national response to HIV&AIDS.

BAGWENEZA Bernard
Executive secretary of UPHLS
I. CONTEXT

1.1. DISABILITY AND HIV&AIDS

The number of people living with a major or moderate handicap is estimated at 335 million in the world. 70% of them live in developing countries. People with Disabilities (PWDs) were ignored for a long time in the national responses of fight against the HIV and the AIDS. For a few years, initiatives aiming at including them have been developed at the continental, countries and community levels.

Numerical importance of People with Disabilities in Rwanda is evident. According to the national census of the population and Housing of 2002, Persons with Disabilities are estimated at 308,501 and are divided as follows:

<table>
<thead>
<tr>
<th>Category of disability</th>
<th>Urban area</th>
<th>Rural area</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with visual impairments</td>
<td>1,577</td>
<td>11,521</td>
<td>13,098</td>
</tr>
<tr>
<td>People with hearing impairments</td>
<td>2,857</td>
<td>18,761</td>
<td>21,618</td>
</tr>
<tr>
<td>Physically impaired – lower members</td>
<td>12,831</td>
<td>77,724</td>
<td>90,555</td>
</tr>
<tr>
<td>Physically impaired – upper members</td>
<td>10,238</td>
<td>67,521</td>
<td>77,759</td>
</tr>
<tr>
<td>Intellectually challenged</td>
<td>1,869</td>
<td>12,947</td>
<td>14,816</td>
</tr>
<tr>
<td>Traumatized</td>
<td>905</td>
<td>2,591</td>
<td>3,496</td>
</tr>
<tr>
<td>Other disability</td>
<td>9,754</td>
<td>77,405</td>
<td>87,159</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>40,031</strong></td>
<td><strong>268,470</strong></td>
<td><strong>308,501</strong></td>
</tr>
</tbody>
</table>

Specific difficulties of People with Disabilities towards HIV and AIDS persist. An important step was made in Rwanda in the recognition of the vulnerability of People with Disabilities to the impact of the epidemic of AIDS and in the inclusion of their concerns within the fighting priorities. But much remains to be made. People with Disabilities in Rwanda are at equal or greater risk of infection of HIV, compared to those living without deficiency. Stigmatization they face makes that they have less opportunity to marry and exposes them to having several sexual partners in a series of unstable relations.

Adults and children with disabilities are up to three times more exposed to be victims of sexual violence and rape. Other factors like the physical dependence, life in institutions and the lack of access to their rights make them also particularly vulnerable to the infection and to abuses. People with Disabilities in Rwanda have currently a limited access to information and services relating to HIV.

Only a minority of children with disabilities receives education, and thus the majority of children with disabilities pass beside the HIV education program developed and implemented within schools. The low rate of literacy among adults with disabilities and the difficulty of reaching the mass media messages for people with hearing and visual deficiency constitute also real challenges to efforts of information dissemination.

Thus, in each district of RWANDA, approximately 10000 people do not correctly take part in the national fight against HIV and AIDS.
1.2. RELEVANCE AND THEME OF THE FORUM

1.2.1. Relevance

Since the launching of the Africa Campaign on HIV and Disability in 2007, each African country was encouraged to install mechanisms allowing the follow-up of the progress made in the inclusion of Persons with Disabilities in the fight against HIV. Rwanda had already entered into dynamics taking into account Disability before this initiative.

Indeed, the creation of UPHLS in 2006 answered the requirement to have a framework of mobilizing all the stakeholders for the inclusion of PWD in the response to HIV and AIDS.

In March 2009 was set up a working group on HIV and Disability. This working group is composed of HIV actors coming from various horizons, and has as role to advance the disability dimension as a cross-cutting concern in all policies and interventions on HIV.

In order to capitalize the efforts carried out up to now and to share as well the challenges as the good practices in the inclusion of PWD, UPHLS proposed to organize on a regular basis national Forums on HIV and Disability.

The first Forum was organized with the financial and technical support of Handicap International through the project of “Strengthening the communities to integrate Persons with Disabilities in the national response to HIV&AIDS in Rwanda”, funded by PEPFAR within the framework of the New Partners Initiative Round 2.

The organization of the National Forum was carried mainly by UPHLS with the close cooperation and support from NACC, TRAC PLUS and Handicap International.

1.2.2. Theme of the Forum

The central theme assigned to the Forum is “A holistic approach to fight against HIV&AIDS among Persons with Disabilities”.

This theme was defined in dialogue with NACC and MOH, and reflects the current vision of UPHLS role towards Persons with Disabilities. Indeed, without taking into consideration multiple challenges faced by these people to access health services, it would be illusory to make fight against HIV and AIDS as an isolated priority.

Thus, this topic directs the stakeholders towards a prospect aiming at making the integration of PWDs to the whole community health system a priority.
1.3. GOAL AND OBJECTIVES OF THE FORUM

1.3.1. Goal

The National Forum aims at the promotion of a lasting inclusion of Persons with Disabilities, their active participation in the actions to fight against HIV and AIDS and in the promotion of health in Rwanda.

1.3.2. Objectives

The first Forum had three objectives:

1. To identify the factors of vulnerability of PWDs with respect to HIV/AIDS in the Rwandan context and the reasons of their weak participation in the national response;
2. To bring the actors of the field of HIV and health to commit themselves about making inclusion of the PWD to their services a priority;
3. To define actions under a holistic approach in order to promote the inclusion and the participation of People with Disabilities in the fight against HIV and AIDS and the promotion of Community health in Rwanda.

1.4. EXPECTED RESULTS

At the end of the First National Forum on HIV and Disability:

• The actors in the field of HIV&AIDS in Rwanda commit themselves to make their services accessible to PWDs being in their zones of intervention;
• The governmental institutions, NGOs and the agencies of the United Nations, the trainings medical and the local persons in charge for the CDLS begin to make more for the inclusion of the PWD;
• Concrete actions resulting from the Forum are released and incorporated in the triennial action plan 2009-2012 of UPHLS.

1.5. VENUE AND PERIOD

Forum 2009 was held over two days (from May 28th to May 29th, 2009) in Kigali at LA PALISSE Hotel of Nyandungu.

1.6. PROGRAM AND METHODOLOGY

A program of the Forum was elaborate (see appendix 2).

The methodology of the Forum was varied and active, made of presentations, debates in plenary and sessions in small groups. Interpretation in sign language was assured. The official languages of the Forum were kinyarwanda, English and French with possibility of a short translation in kinyarwanda in the case of a speech in a foreign language.

Presenters and facilitators were selected according to their experience and the importance of the subjects in link with the central topic.
1.7. **LOGISTICS AND VISIBILITY**

1.7.1. **Logistic aspects**

UPHLS ensured the whole coordination of the Forum logistics:
- visibility tools and equipment of the Forum
- expenses relating to the hiring of the conference rooms, lunches, coffee break/tea and refreshments
- accommodation of certain participants coming from the remote areas.

1.7.2. **Visibility**

The following tools were made within the framework of the Forum visibility:

*Before the Forum:*

- Forum documents (concept notes + Programme) in French and English
- Invitations of the participants
- 250 tee-shirts
- 250 red ribbons
- 5 banners
- An audio spot diffused on 3 radio stations (CONTACT FM, RADIO RWANDA and RADIO SALUS) during 3 days (26th to the 28th may 2009)
- A TV spot diffused on Rwanda television (from 26th to the 4th june 2009)

*After the Forum:*

- A DVD reporting the key moments of the Forum
- An album photo
- A report/ratio of the Forum

In addition to these tools, media coverage was organized in an optimal way, and several radio stations diffused reports on the Forum. It is necessary also to mention that UPHLS has constituted a documentation of newspapers having covered the First National Forum on HIV and Disability.
II. PARTICIPATION IN THE FORUM

The participants to the Forum were 172 persons out of a total of 200 invited persons, and this represent a participation rate of 86%.

The following table informs about the various categories of people and institutions present at the Forum:

<table>
<thead>
<tr>
<th>CHARACTERISTICS</th>
<th>WITH DISABILITY</th>
<th>WITHOUT DISABILITY</th>
<th>TOTAL</th>
<th>GRAND TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>INSTITUTION</td>
<td>F</td>
<td>M</td>
<td>F</td>
<td>M</td>
</tr>
<tr>
<td>FENAPH/DPOs</td>
<td>14</td>
<td>30</td>
<td>15</td>
<td>13</td>
</tr>
<tr>
<td>CDLS</td>
<td>0</td>
<td>0</td>
<td>11</td>
<td>16</td>
</tr>
<tr>
<td>MEDIA</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>NGOs/UN</td>
<td>1</td>
<td>4</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>HOSPITALS</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>15</td>
</tr>
<tr>
<td>GOVERNMENT</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>15</td>
<td>35</td>
<td>44</td>
<td>78</td>
</tr>
</tbody>
</table>

The above table shows that 172 persons attended the Forum. The participation is as follows in each category:

- 72 members of FENAPH or other Organizations of Persons with Disabilities
- 27 Technical Assistants of the CDLS
- 27 journalists
- 23 representatives of NGOs and UN agencies
- 16 representatives of district hospitals
- 7 people from various governmental institutions

Hereafter we analyze the participation according to three criteria: the situation of disability, the represented institutions and gender.

2.1. DISTRIBUTION OF THE PARTICIPANTS ACCORDING TO THE DISABILITY

50 persons out of the 172 participants (29%) to the Forum live with disabilities. The majority of these people are representatives of FENAPH at the national level and at districts level. The DPOs (Organizations of Persons with Disabilities) were also well represented at the Forum.
2.2. DISTRIBUTION OF THE PARTICIPANTS BY INSTITUTION

![Distribution of Participants by Institution](image)

FENAPH and the Organizations of Persons with Disabilities (DPO) constituted the major part of the participants to the Forum (42%). The CDLS Technical Assistants and the representatives of health facilities constituted 25% of the participants, and the media add up 16%. NGOs (13%) and the governmental institutions follow (4%).

Apart from the fact that the activity was carried out by FENAPH and UPHLS and that the representation of the PWD was significant, this portion was important for two main reasons:

- In the campaign on HIV and Disability, the aim is not to mobilize the HIV actors only. DPOs also should be led to include in their planning the fight against HIV&AIDS and to influence their intervention cycles on this theme.
- The real changes will be carried out at the level of the communities, health facilities and persons in charge for the districts hospitals and the CDLS representatives had been invited to the Forum. It was absolutely necessary for the elected officials of FENAPH, who are the focal points of UPHLS, to participate to the Forum because they will have an important role to play at the local level.

2.3. DISTRIBUTION OF THE PARTICIPANTS BY SEX

![Distribution of Participants by Sex](image)

About gender, 59 out of 172 participants (34%) were female while 113 participants (66%) were male.

For more information, please have a look at appendix (1) the complete list of the participants.
III. KEY MOMENTS OF THE FORUM

3.1. INTRODUCTION ON “AN INCLUSIVE COMMUNICATION”

After the presentation and the validation of the Forum program, two persons living with Disabilities explained the particular requirements of an “inclusive communication”.

Miss Consolatrice NIYIBIZI, member of the Rwandan Union of the Blind and currently student at the National University of Rwanda, clarified certain needs of PWD in an event attended by others living without disabilities. These needs include:
- need to reach the places of meeting (to reach the venue)
- availability of tools supporting the understanding of Persons with Disabilities (interpretation in sign language, writings in Braille,...)

She underlined her regret of the existence of multiples and good policies which are addressed to the general population without considering the contribution of PWDs. And for her, that explains in part the mitigated participation of PWDs in the various programs, such as GACACA, Umuganda (Community work), Ubudehe, Mutuelles de Santé,....

Miss Consolatrice declared that the techniques used in meetings (electronic projection, video messages,...) should envisage other specific ways for people with hearing or visual impairments, and when there are visually challenged, to privilege the Braille writing.

She gave a concrete example drawn from its personal experience, to fustigate the attitude of the Rwandan community which considers in general PWDs as invalids:

“One day we were discussing in groups a subject which had been proposed to us. And when I advanced my idea contradicting that of my colleagues, one of them exclaimed: “Oh, my God, I could not imagine that Consolatrice is too intelligent”. Just imagine how much I felt humiliated”.

The speech of Miss Consolatrice thus sensitized the participants to the Forum on the need of a taking into account the positive value of PWDs in all the programs. For her, educating our community, explaining the needs and the potentialities of PWDs, would help to change its glance on the disability in general and on PWDs in particular.

Mrs Pelagie MUHORAKEYE talked about the communication difficulties often faced by people with hearing impairments.

She provided examples which highlight the complexity of the problems caused by the incapacity of the whole community to communicate with people with hearing impairments.
“On the level of the health facilities, the doctors and/or male nurses do not know the sign language and find themselves in the incapacity to help us without the intervention of a third person. It can prove to be necessary that I practise voluntary tracking and I will need the confidentiality like so many of other people. But owing to the fact that I cannot communicate with the doctor or the councillor, there is risk to communicate my statute serologic with my interpreter. This is not a good thing for me for various reasons.

In the legal services and especially at the stations of police force, the women with hearing impairments do not enjoy their rights. Because those which should render service to them do not include/understand them and their offices drive out them. To misuse a girl or a deaf woman is thus today a crime which remains unpunished in the majority of the cases.”

Mrs Pelagie thanked FENAPH which mobilizes sign language interpreters in various meetings, and encouraged the other stakeholders to envisage the possibility that a person with hearing impairments can take part to their meeting or awareness activity. She suggested the training of sign language in all the services planned for the population because that would show the application of the principle of equity and equalization of the chances.
3.2. OFFICIAL LAUNCHING CEREMONY

3.2.1. Official launching speeches

The topic of the Forum invites us to aim high

In her welcoming speech, the acting President of FENAPH, Mrs Donatilla KANIMBA, underlined the topic of the Forum and presented its objectives.

Mrs Donatilla Kanimba introducing the objectives of the Forum (Photo UPHLS)

« A holistic approach to fight against HIV&AIDS among Persons with Disabilities ” is, for Mrs Kanimba, a topic which invites to integrate Persons with Disabilities in the response of our communities towards HIV&AIDS and other diseases. And it consequently allow to search for a global solution to the problems of Persons with Disabilities in various fields : health, education, socio-economic development and full pleasure of the rights.

Important ambitions and limited means: the secret will be the capacity to interact and collaborate

The Program Director of Handicap International (HI), Mr Marc Vaernewyck, thanked the assembly for their participation in order to bring a concerted response to the difficulties faced by Persons with Disabilities, in their legitimate search of recognition and welfare.

The Program Director of HI reconsidered the fact that the group of Persons with Disabilities constitutes a numerically important group. On many aspects of their everyday life, these people are discriminated, stigmatized, victims of false ideas and prejudices and this situation prevents them from reaching like any citizen school, employment and other community activities. And the fact that these people do not sufficiently reach the various health services poses a problem of national importance.

Worried about this “ obvious discrimination ”, he also spoke about the figures which let think that Persons with Disabilities present a prevalence rate to HIV higher than that of the general population. For the Director of HI, by simple human and social justice, we must take up this challenge.

He took the opportunity to introduce the project “ Strengthening communities to integrate Persons with Disabilities in the national HIV&AIDS response in Rwanda ”. This project, carried by HI and financed by PEPFAR through HRSA, is implemented in Co-piloting strategy with UPHLS and in partnership with 7 other organizations.
For the Program Director of HI, such a project contributes modestly to the enormous stakes on a national scale, but it cannot be well carried out without a support of the local actors, responsible for the CDLS, health workers and local authorities. It is a great project with very modest means, and only an effective collaboration and a joint action will make it possible to guarantee its success.

The support of the Rwandan Government is guaranteed to make inclusion of PWDs a reality in the national fight against HIV&AIDS

After having thanked the organizers and the participants to the Forum, Dr. Anita ASIIMWE, the Executive Secretary of NACC, underlined the relevance of the meeting.

Indeed, Persons with Disabilities are among people infected and affected by HIV, and that explains the motivation of the support of the NACC not only for the Forum itself, but especially for all the dynamics aiming at guaranteeing a full participation of Persons with Disabilities in the national fight against HIV&AIDS. Persons with Disabilities form a vulnerable and at risk group, and the Rwandan Government must support them. But, She said, the vulnerability is not a static state, and the NACC will work with all the actors to eradicate the causes and to mitigate the effects of this vulnerability. She invited Persons with Disabilities to continue to fight for their rights, because nobody else knows better than them their own needs.

The Executive Secretary of the NACC underlined the need for an adaptation of tools, methods and techniques of sensitizing/mobilization (IEC/BCC), by taking account of the specificities of people with various disabilities.
While considering the topic of the Forum, the Executive Secretary of the NACC declared the following:

"In the fight against HIV and AIDS, we should not neglect other diseases like paludism, tuberculosis, various transmissible and non-transmissible diseases, which affect at the same degree, if not hard, Persons with Disabilities. The capacity to adopt a holistic approach will allow UPHLS and all the actors engaged at its sides to kill many birds with one stone and to gain in effectiveness and in speed. For example, I question the capacity of a community health volunteer to help a person with hearing impairments whom a child present signs of disease: how does this volunteer communicate? In each umudugudu, there are 5 community health volunteers. Are they able to help all the categories of the population being in their locality? If not, such a Forum should inform on needed actions to equip these Community actors.

And in each umudugudu, works of Community interest (Umuganda) are organized and many subjects are debated by the population. But how do we manage to reach Persons with Disabilities who do not attend these meetings? All that should be concerns for opinion leaders, starting from the community level. And this precisely explains the need for tackling the problem of HIV with a global approach.”

She concluded with the promise to interest all the actors to include PWDs in their programs/activities and reiterated the commitment of the Rwandan Government which will, through the NACC, support sustainable actions aiming at a real integration of Persons with Disabilities in the fight against HIV&AIDS.

In his speech of official opening, the Honorable Pierre Claver RWAKA, representing Persons with Disabilities at the Rwandan Parliament, thanked the organizers and all the participants to the Forum. For him, the Forum comes at the right moment for sensitizing our community against discriminating Persons with Disabilities, and especially about including them in the fight against HIV&AIDS.

While reconsidering the difficulties related to the communication, He underlined the difficulties which are observed in the education and health systems, and reinforced the idea to teach the sign language and to install mechanisms making possible visually impaired to be able to advance with the rest of the population. He also mentioned the need for the organizations of Persons with Disabilities for remaining the key advocates of their cause.

Honorable Pierre Claver RWAKA showed that Rwanda is in advance in terms of disability friendly policies, compared to many other countries. Indeed, He underlined that Rwanda ratified the International Convention on the Rights of Disabled People, and set up a law carrying protection of People with Disabilities in Rwanda. The Government also supported the process of putting in place FENAPH. Currently, ministerial decrees are under development for the application of the above mentioned law in various sectors (health, education, social protection, infrastructures, employment, information, ...). All this show the “political will to allow Persons with Disabilities to fully enjoy their rights as citizens”.
he finally officially declared opened the First National Forum on HIV and Disability, wishing that it leads to suitable resolutions and recommendations in order to induce a real change. He also expressed the hope that this Forum is followed in the future by other spaces of monitoring progress on HIV and Disability.

3.2.2. An opportunity of sensitizing...

During the official launching ceremony, youth with Disabilities from HVP GATAGARA largely contributed to the objectives of the Forum by sensitizing the audience on:

- need to respect the human rights inherent to any person, in particular for a Person with Disability;
- particular difficulties faced by Persons with Disabilities, and which increase their vulnerability to HIV (sexual abuses, beliefs which support sexual abuses and exploitation, difficulties of communicating with the community, lack of education,…).

The participants to the Forum particularly appreciated:

- SNGOs relating to the rights of Persons with Disabilities;
- The sketch “MPEMUKE NDAMUKE” on the abuses and sexual violence towards Persons with Disabilities;
- The poem “tugere umugozi tugenekereze twizimirize icyago” on HIV.
3.3. EXHIBITION

The DPOs (Organizations of Persons with Disabilities) had been encouraged to bring tools and objects to be exposed, and a space was reserved.

The purpose of this exhibition was to sensitize the participants (their majority operate outwards of the disability cycles) on disability realities and on the potentialities of PWDs. Thus, all the exhibitors brought some products realized by Persons with Disabilities.

The following organizations took part to this exhibition:
- 5 centers members of Collective TUBAKUNDE, dealing with children with intellectual impairments (Izere mubyeyi, Jya mu Bandi Mwana, Amizer, Wikwiheba Mwana and Humura Mwana
- Association BERA BOSE of PWD from Nyamirambo
- Handicap International
- National association of the Deaf and Mute women (ANFSMR)

An exhibitor introduces the exhibition to the Executive Secretary of the NACC

The exhibition was inaugurated by Dr. Anita ASIIMWE, Executive Secretary of the NACC. On the basis of the example of this exhibition which highlights the multiple potentialities of PWD, was suggested an idea to support the participation of PWDs to the annual exhibition (EXPO 2009) organized by the Rwanda Federation of the Private Sector and the Ministry of Commerce.

The Executive Secretary of the NACC inaugurates the exhibition and appreciates exposed products while visiting the various stands (Photo UPHLS)
3.4. PRESENTATIONS OF THE FORUM

Nine (9) presentations took place. They used the projection (PowerPoint presentations).

The presentations allowed the participants of the Forum to progress towards:
- A common understanding on HIV&AIDS and Disability;
- A understanding of the total dynamics carrying HIV and Disability to the agenda of HIV actors and governments;
- An analysis of the current environment favorable to the emergence of initiatives to integrate PWD in Rwanda, and the possibility of orienting this integration in a more holistic approach that considers other health issues.

The presentations were followed with the greatest attention (photo UPHLS)

3.4.1. A common understanding of the problems

• Persons with Disabilities have a specific vulnerability

Presentation on “Communication Barriers and Psyco-social Obstacles: how to better adapt prevention strategies”, realized by Teddy KABERUKA (ICAP-Columbia University), has provided an analysis criticizing standard channels of communication as regards to IEC. It showed that these channels present many challenges when it is about the access of PWD to HIV&AIDS related messages.

In his introduction, he made an important observation:

- Each time we make presentations, we bring a text and we project on PowerPoint. And after, it is easy for us to refer to this presentation because we assume that everyone followed. But how can a visually challenged person get such a presentation?
- In our everyday life, we usually use the writing. But we often forget that certain people are blocked either on the level of capacity to read (illiteracy), or on the level of the capacity to see (visual impairments).
- We use the verbal language. But there are people who have hearing or speaking deficiencies. What envisages the community for these people?
With this observation, the participants noticed that there are many transmission channels of HIV messages, but that today the majority of these messages do not reach Persons with Disabilities.

At the end of the exchanges which followed this presentation, the following ideas were retained:
- It is very necessary to invest in tools of communication;
- It is necessary to work out specific strategies in the mobilization of people with various deficiencies;
- People with hearing impairments require a very detailed attention because they are particularly blocked at the level of the communication.

• Inclusion as means and finality

The presentation on “The bases of the inclusion of the vulnerable people today: From concept to practice” was realized by Dr. KARANGWA Evariste, expert in inclusive education and teacher at KIE. This presentation helped the participants to carry out a consideration on:
- Persons with Disabilities and their specific difficulties
- inclusion in all the fields of the life like means of bringing an effective response to the needs of Persons with Disabilities
- Inclusive education

Following is, drawn from this presentation, an example of the various factors blocking the prevention of PWD.

• We cannot fight effectively against HIV if we forget the rights of PWDs

Presentation on “Disability and HIV: A human Rights Perspective” was realized by Honorable Pierre Claver RWAKA (Representative of PWDs at the Rwandan Parliament). This presentation helped to outline the internationally recognized principles which must guide the search for a real integration/inclusion. This inclusion should be the fruit of a recognition of the rights of PWD as human beings and full citizens, instead of being considered as a favor.
3.4.2. A Forum which falls under a dynamics

HIV and Disability: A worldwide awareness

With this presentation of Mr. Bernard BAGWENEZA, Executive Secretary of UPHLS, it was clearly shown that there is currently an awakening (late but salutary) of the decision makers. This awakening relates to the specific vulnerability of PWDs and to the need for adapting the strategies and tools currently used so that these PWDs are really included in the fight against HIV&AIDS. This awakening was preceded by a formal recognition, late too, of rights of Persons with Disabilities in the international texts.

In April 2009, the UNAIDS published a Brief Policy on HIV&AIDS and Disability. Mr BAGWENEZA stressed that this recent policy of the UNAIDS on HIV and Disability constitutes an instrument of the highest importance to mobilize more will and means in order to reduce the impact of HIV and AIDS on PWDs.

Mr BAGWENEZA also developed the various factors of the exposition of PWD to HIV, among which violence and sexual abuse, especially towards girls and women with hearing, visual or intellectual impairments. He concluded his intervention by an important declaration:

“It is necessary to create a favorable environment for each actor to make sure that its interventions are accessible to PWDs. More important, it is necessary that these interventions include them not in a spirit of giving them a favor, but with the firm conviction that PWDs have right to benefit from these interventions”

Africa Campaign on HIV&AIDS and Disability and Kampala Declaration: to join the dynamics

Mr. Gallican MUGABONAKE (HIV and Disability projects Coordinator within Handicap International) recalled the course of the Campaign and summarized the recommendations of the Kampala Declaration.

Since 2007, the “Africa Campaign on HIV and Disability” was launched. The launching meeting took place in Cape Town (South Africa) in January 2007. In March 2008, a second meeting took place in Kampala (Uganda), thus making it possible to validate the strategic orientations of the Campaign from which resulted Kampala Declaration on HIV and Disability.

Kampala Declaration on HIV&AIDS and Disability, challenges governments, service providers related to HIV&AIDS, the African Union, the representatives of the United Nations and many other actors to act for equal access to the services related to HIV/AIDS prevention and a full participation of Persons with Disabilities in the response to HIV&AIDS in all the countries and to all levels.

The meetings of the Campaign are used as place of exchanges and best practices sharing between the various actors and countries. They allow to highlight the reality of Persons with Disabilities towards HIV and AIDS.
3.4.3. **HIV and Disability: a kindly environment to Rwanda**

**Disability, a specific vulnerability to HIV in Rwanda: National challenges and efforts**

Presented by Miss Florida MUTAMURIZA, in charge of sectors at the NACC, this subject had the merit to inform the participants on all the efforts made by the Rwandan Government for the inclusion of Persons with Disabilities in the national policy on HIV and AIDS.

As it underlined, the first explicit efforts of the Rwandan Government were made at the beginning of the year 2006, before even the structuring of the Africa campaign on HIV and Disability. The achievements made from that period include:

- The addition of the group of PWDs as the 15th vulnerable group within the framework of the National Policy and the National Strategic Plan of on HIV&AIDS 2005-2009;
- The creation of UPHLS and continued support provided this organization;
- The creation of a working group on HIV and Disability;
- The integration of PWDs in the Strategic Action plan 2009-2012 of the NACC and in the recent proposals submitted to the Global Fund.

**Persons with Disabilities in the psychological and socio-economic care**

This presentation from Mr. Jacques SINDAYIGAYA (independent consultant specialized on HIV and Disability), reviewed the mechanisms of care of people living with HIV in Rwanda, and showed that all these mechanisms did not, in the past, consider PWDs infected and affected by HIV.

Based on the last years, the presentation showed that PWDs did not profit from the opportunities of the projects like MAP (Multisector Project on HIV&AIDS), the GLOBAL FUND, and NACC/BAD project. Through these projects, important financial resources supported the socio-economic promotion of a multitude of organizations. And Mr Sindayigaya concluded its intervention by raising the following question:

"Knowing that the train already left and that Persons with Disabilities are not on board, how to improve so that the socio-economic mechanisms integrate them?"

**Access to the health services for PWD: how to do more?**

This presentations of Mr. Egide NDAYISHIMIYE (TRAC PLUS) brought a lighting on the current configuration of the VCT&PMTCT services and on medical care of people living with the HIV&AIDS.

It was demonstrated that the country made important steps on the matter, but that there are obstacles which prevent PWDs from enjoying these opportunities. Among the obstacles raised by the presentations appear:

- Lack of reliable data (resulting from studies) on HIV&AIDS and Disability
- The limited number of health workers having competences on the counseling and the communication with PWDs.
- Physical Inaccessibility of PWDs to VCT/PMTCT/ART services (Infrastructures, IEC/BCC tools,…)

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First National Forum on HIV&AIDS and Disability:
« A holistic approach to fight against HIV and AIDS among People with disabilities »
Since the Government is very receptive about the integration of the PWD in HIV programs, Mr Egide enclosed his intervention asking the participants to propose actions to be undertaken for a better access.

**Integration of Disability in the Community Health System**

The MOH support fully UPHLS. In order to contribute so that the Forum gives relevant recommendations considering the whole health system, the MOH supported a study on the integration of Disability in the Community Health System.

Dr. Gerard TWAHIRWA, who led this study, outlined the broad outline likely to allow the Community Health System as a whole to effectively meet the health concerns of PWD. The merit of this presentation lies especially in the analysis of the Community mechanisms whose exploitation would not involve exorbitant costs, but which would be used as lever for an access to all the devices of health care.

*The quality of the presentations was appreciated by the participants to the Forum (Photo UPHLS)*
3.5. PROFITABLE DEBATES

At the end of the presentations, a debate was engaged and centered on two aspects:

- Discrimination and stigmatization, an obstacle to a successful mobilization
- The access to health care is today difficult for reasons including the attitudes of health and community workers

3.5.1. How to reduce discrimination and stigmatization?

The following is a synthesis of the concerns raised by the participants and the tracks of solutions under consideration during debates:

<table>
<thead>
<tr>
<th>Raised concern/ question</th>
<th>Answer delivered</th>
</tr>
</thead>
</table>
| The Rwandan community usually practices a stigmatization of PWDs by using negative and disparaging terms about them. Is it possible to punish those which this denigration practices? | • It is difficult to punish what does not have a reference in our law (and often these terms were used a long time and people were used to them as the natural ones).  
• In the immediate future, it is necessary to stress sensitizing, to promote near the public the correct terms about PWDs. In a long term vision, it would be envisaged to propose a directive or a law repressing this “nullification” towards PWDs. |
| Even though PWDs are represented in administrative and consultative bodies, various authorities do not consider their problems with the due respect. | It is necessary to continue the advocacy actions and the lobbying, and especially to defer the encountered difficulties to FENAPH so that monitoring can be possible. |
| People with hearing impairments wish sign language interpretation on the national television | A ministerial decree is under development, and Hon. Rwaka will approach the concerned Minister for a progress report. |
| Is it possible that MINEDUC integrates the sign language in the list of languages to be learned in schools and Braille method in the secretariat sections? | Indeed the International Convention on the Rights of PWDs recommends the sign language to be defined everywhere among the official languages. This recommendation will be submitted to MINEDUC. |
| What is planned for the expression of a couples of hearing impaired persons if they go for a civil wedding? (is the Sector able to handle the communication issue?) | Interpreters can intervene without problem as in any other activities. However, it is interesting to get information on the existence of legal provisions, since certain leaders would be less sensitive on the issue. |
| Why in Rwanda AIDS is not considered as a Disability and not as a cause of handicap? | There are some countries which take AIDS as a Disability, such as Sweden, Japan, according to the definition they give to HIV and to disability. Rwanda does not consider HIV/AIDS as a disability, but as a disabling illness (able to involve blindness, paralysis,…) |
| It would be appropriate to think about affirmative action to encourage performing PWDs, as the example of the First Lady of Rwanda about girls’ education. | The idea was retained and will be discussed within the Disability Movement |
| The wish to facilitate PWDS for obtaining scholarships (in the sens of the affirmative action) | Idea to be suggested to the competent authorities |
Are there precise figures and details on the localization of PWDs? If not how can we adjust the interventions?

- The results of the census of 2002 are used as a basis but do not provide all needed information.
- In the strategic plan 2009-2012 of UPHLS, a baseline on PWDs is planned.
- MINALOC seeks a budget of a specific census and out of the necessary amount of 200,000,000 rwf, 30 to 40 million are already available.

What is the relevance of the nutritional support provided by certain NGOs in the care of PLWHIV insofar as this support does not last a long time?

- NGOs do what they can with the means at their disposal and in a duration defined in their action plans. A perennial solution passes by the economic empowerment of people living with HIV.

There is a bill on the reproductive health to be soon adopted by the parliament, but specific realities relating to Disability are not mentioned.

- FENAPH and UPHLS will make the follow-up of this law so that the concerns related to the affective and sexual life of PWDs are taken into account.

« We ask for our ideas to be heard and respected without the community judging them according to the extent of our disability »: an idea often taken up by Persons With Disabilities (Photos UPHLS)

The participants to the Forum stressed that AIDS is a disabling illness: when effectively fighting against HIV&AIDS, we will also be limiting the devastator effects of Disability (Photo UPHLS)

First National Forum on HIV&AIDS and Disability:
« A holistic approach to fight against HIV and AIDS among People with disabilities »
Other interventions underlined:

- The necessity of a government involvement on crucial questions like that relative to expressions disparaging PWDs or the use of the sign language
- The necessity of intensive actions to sensitize the community on the rights of PWDs
- Relevance to approach on a professional plan specific bodies (as the Human Rights Commission and the National Police) in order to pose a comprehensive framework of monitoring respect of the rights of PWDs

3.5.2. The access to the care of health today: a shocking truth

The debates on the access to health services were enriched by testimonies by the participants in the Forum. The following testimony was given by Mrs Sharon TUMUSIME, coordinator of FENAPH in Nyanza district:

One day at Gatagara a child with a disability felt sick. He went to the local health center, and shortly after the child came back to HVP center. During the night, the child died. We approached the person who had treated the child to know which was the disease and which he had received. The person had not kept any record on the drugs given to the child (recording a file had been neglected). And the only answer to us was that “In any cases the child was very disabled. He moved even in a wheelchair...!!!». As if this means that there is no need to look after him!!!

After this testimony, some doctors representing health facilities had the following reaction:

Let us be frank, we are not skilled today to accommodate and suitably treat people living with disabilities. Some of us want even to run and flee when they are faced to certain kinds of deficiencies. But if we react like that, it is not by spite. We need more information and trainings, and we would like to know the best practices that exist on the matter. And this Forum is a great opportunity for us of to change mentalities and attitudes towards People with disabilities.
3.6. EXCHANGES IN THEMATIC GROUPS

On the 2nd day of the Forum, the participants devoted a major part of the morning in thematic debates in small groups in order to release the key recommendations of the Forum.

Hereafter are developed topics and the composition of the groups:

<table>
<thead>
<tr>
<th>Group 1</th>
<th>Members</th>
<th>Topic</th>
</tr>
</thead>
</table>
| Group 1 | National and international NGOs + UN system + 1/5 of the CDLS representatives | Prevention:  
• What should be done so that PWDs (any categories of handicap) can reach information?  
• Use and access of the condom: how to do better for PWDs?  
• Which mechanisms to set up to ensure the communication with people with hearing impairments? |
| Group 2 | NACC  
½ of the representatives of the hospitals + 1/5 of the CDLS representatives | Access to HIV&AIDS care services:  
• How to make our VCT and PMTCT accessible to PWDs as well for the counselling and the testing as for the access to the antiretroviral treatment?  
• What can be done for the Rwandan medical facilities correctly treats PWDs?  
• How to integrate Disability in the M&E of the health system? |
| Group 3 | MINEDUC  
CNDP + 1/5 of the CDLS representatives | Which actions to be set up to support the access to education, employment and economic opportunities for PWDs? |
| Group 4 | HI, TRAC PLUS  
+ 1/5 of the CDLS representatives | Research: What are the priority fields of research for the group of Persons with Disabilities in Rwanda? |
| Group 5 | MOH, WHO, ½ of the representatives of the hospitals + 1/5 of the CDLS representatives | Mainstreaming Disability in the Community Health System: which concrete actions to carry out? |

In the groups, the participants released important recommendations  
(Photo UPHLS)

Back from the groups, the participants validated the resolutions and recommendations synthesized in the declaration of the First National Forum on HIV and Disability.
3.7. THE OFFICIAL CLOSURE CEREMONY

Various personalities took part at the official closure of the First National Forum on HIV&AIDS and Disability, and their interventions expressed the satisfaction on the course and the results of the meeting.

Mr Bernard BAGWENEZA, Executive Secretary of UPHLS, thanked the participants to have expressed ideas highlighting the need for inclusion. For him, it is the combination of the presentations and the participants ideas which led to the consistent recommendations. He also thanked the collaborators of UPHLS in the organization of the Forum.

He exhorted the Directors of District Hospitals, the health workers and the Technical Assistants of CDLS to support and develop action plans and intervention mechanisms that consider PWDs. Because, he hammered, the Disability Movement cannot advance this cause alone.

He concluded by promising at the assembly the optimal contribution from UPHLS within the framework of the mainstreaming of PWDs in the health sector.

Mrs Donatilla KANIMBA, the acting president of FENAPH, called upon the participants to contribute to the reduction of the mortality of PWD caused by their vulnerability, and to fight for their wellbeing. For her, this First Forum on HIV & AIDS and Disability “gives us the hope to hold many others in the future which will enrich the Disability Movement”. She warmly thanked all people and institution represented for their participation, and was delighted owing to the fact that from now there are more voices of people not living with disability who will join those of PWDs. Mrs Donatilla finished her short speech by hoping that next Forums will make it possible to evaluate, on a regular basis, the progress made in the health field.

In the name of the Executive Secretary of the NACC, Mrs. Florida MUTAMURIZA officially enclosed the First National Forum on HIV&AIDS and Disability by asking the participants and all the community to actively work for the inclusion of PWDs. She called each person and each institution to apply the recommendations of this Forum. She reiterated the commitment of the NACC so that “Persons with Disabilities are not left behind an more” in the fight against HIV and AIDS in Rwanda.
IV. THE DECLARATION OF THE FIRST NATIONAL FORUM ON HIV & AIDS AND DISABILITY

From the 28th to the 29th May 2009, was held in Kigali the First National Forum on HIV and Disability. The Forum gathered the delegates from the government institutions, the UN agencies, nongovernmental organizations, hospital authorities, the technical assistants of the district AIDS control, journalists as well as the representatives of the organizations of Persons with Disabilities at national level and at the level of the 30 districts of Rwanda.

The participants to the Forum reviewed the alarming situation of Persons with Disabilities, especially in connection with the access to health care and the HIV&AIDS prevention and care services.

The participants to the Forum recognized and commended the efforts of the Government of Rwanda to put Disability at the agenda of the fight against HIV and AIDS. However, they noticed that until today very few organizations working in the HIV prevention include in their interventions Persons with Disabilities. They also deplored the fact that the health facilities do not fill the standards today guaranteeing to Persons with Disabilities a full access to their services.

The participants to the Forum released the following recommendations:

A. RECOMMENDATIONS ON HIV PREVENTION

In order to ensure an effective and perennial prevention for Persons with Disabilities, the participants recommend to the NACC and all the other stakeholders in prevention to set up effective strategies guaranteeing the access to information for Persons with Disabilities.

Normally, information passes through the written messages (booklets, folders, booklets, comic strips, posters), images, through the audio messages and the audio-visual. It proves that certain messages intended for general public do not reach People with various disabilities for reasons such as :

- mobility difficulties preventing them from being where the message is delivered
- limits to apprehend information according to impairments.

So, the participants recommend, according to each type of handicap, the following actions for a full access of Persons with Disabilities to HIV prevention messages:

For people with physical disabilities

- To support a “proximity sensitization” which reaches people within their communities;
- For those who produce billboards and posters, to lay out the messages in a way that they are accessible even for people who cannot stand up.
For people with intellectual impairments:

- To simplify the existing messages and to conceive short messages (not exceeding 30 mn), privileging the illustrations;
- To develop an expertise in sketches accessible to these people compared to their possibilities from apprehension and data processing;
- To sensitize their parents and picture framers in the centers of care on the emotional and sexual life of the young people with intellectual impairments.

For people with hearing impairments

- To simplify the messages by using images;
- To promote messages combined with the use of an interpretation or a transcription in sign language;
- To train people with hearing impairments on the sign language (a common language in all places);
- To train on the sign language the health professionals and the community health volunteers as well as the personnel of the various services dealing with development and/or the dissemination of IEC/BCC messages.

For people with visual impairments

- To optimize the simplification of the messages and their exploitation by audio;
- To put in Braille the main part of the messages intended for the whole of the population;
- To disseminate the equipment relating to Braille and to ensure trainings on their use;
- To train in Braille all the personnel of the establishments practicing inclusive education.

Concerning the use of the condom, the participants observed difficulties that Persons with Disabilities share with the rest of the community, namely:

- The fact that the condom is not available everywhere, and that it is most often available to the health facilities and shops, though there are obstacles which prevent certain members of the community from getting condoms in these places;
- The fact that much PWDs cannot use the condom correctly. Information on its use requires an adaptation privileging the visual and tactile demonstrations which would make this information accessible for all the PWDs.

The participants to the Forum call upon the availability of the condom through all the country, which would be integrated in a sufficient number into the kit of all the community health volunteers, and call upon for sensitizing all the community health volunteers so that their services do not exclude PWDs.

Within the framework of the prevention, the participants to the Forum also recommend the following actions independently of the type of disability:

- Training on HIV in all centers dealing with PWDs;
- Development of programs of HIV awareness and integrate these programs into the timetables of all the centers for Persons with Disabilities;
- Carrying out awareness campaigns on HIV targeting the immediate environment of PWDs.
B. RECOMMENDATIONS FOR ACCES OF PERSONS WITH DISABILITIES TO VCT AND PMTCT SERVICES

The participants to the Forum observed mentalities and negative attitudes on behalf of the resulting from an approximate knowledge of Disability realities. They encourage the health services to take into account the reality of Disability in particular by:

- Trainings on the sign language targeting at least two counsellors in each health facility (VCT and PMTCT);
- The availability, within the health facilities, of sensitization tools allowing a good understanding for all Persons with Disabilities;
- The installation of the mechanisms allowing the health facilities to collaborate with PWD in order to sensitize their peers;
- The inclusion of a chapter on specificities of people presenting various types of handicap in the training of the health workers;
- The consideration of physical accessibility while the rehabilitating the existing centers or while building new health facilities.

C. RECOMMENDATIONS CONCERNING THE MAINSTREAMING OF DISABILITY IN THE COMMUNITY HEALTH SYSTEM

The participants to the Forum recommend the following actions in order to ensure that the health facilities have an optimal capacity to accommodate and offer quality services to PWDS:

- To sensitize families and communities on the necessity of assisting their members living with disability and or HIV and on the necessity to accompany /guide them to the health facilities;
- To train the personnel of the health facilities on the strategies of communication with people with hearing impairments;
- To train the community health volunteers and the local authorities on the realities of Disability; and to install a mechanism of motivation of the community health volunteers who make an effective follow-up of PWDs;
- To promote community health activities such as vaccination, nutrition, cleanliness and in other fields;
- To adapt the medical infrastructures which, today, do not facilitate for PWD the access to their services;
- To use suitable supports of sensitizing;
- To carry out home visits targeting PWD in order to give them information and community health services to which they have right;
- To organize multidisciplinary meetings (health care providers, teachers, community leaders) for exchanges in care of PWDs;
- To make available within the health facilities special equipment according to the type of disability.

To ensure that the data relating to Disability are integrated in the health facilities monitoring and evaluation system, it is recommended to TRAC PLUS and the MOH to insert a heading relating to Disability in the reporting forms.
D. RECOMMENDATIONS CONCERNING ACCESS TO EDUCATION, EMPLOYMENT AND TO ECONOMIC OPPORTUNITIES

The analysis of the vulnerability of PWDs reveals that this vulnerability has its origin in the discrimination from which they suffer. And this discrimination is noticed in the difficulties for PWD of reaching education, employment and economic opportunities.

Considering that the mitigation of the impact of HIV passes by the capacity of the communities to profit from above mentioned opportunities, the participants to the Forum recommend the following actions:

**Access to the instruction**

- To make available didactic materials and didactic modules relating to the rights of PWDs (MINEDUC) and to sensitize the community on the rights of PWDs (CNDP, Churches, DPOs, MINEDUC and its partners,…);
- To increase needed modules for the education of people from various categories of disabilities (MINEDUC);
- To guarantee a financial support of the government for specialized and inclusive schools;
- To reinforce the teaching staff and during refreshment sessions of the teachers, to sensitize on disabilities (MINEDUC);
- To accelerate the implementation of the ministerial decree relating to education for children with disabilities and to initiate/reinforce the partnership between the various actors in the field of the special and inclusive education.

**Access to employment**

- To accelerate the implementation of the ministerial decree on the employment of PWDs (MINALOC and MIFOTRA);
- To organise monitoring/inspection on the injustice faced by Persons with Disabilities during the processes of recruitment or reduction of the personnel;
- To improve the physical accessibility of the work places in favor of PWDs (MIFOTRA, MININFRA, construction Companies).

**Access to economic opportunities**

- put in place a guarantee funds for PWDs (Rwandan Government);
- Reinforcement of the capacities of PWD to become good entrepreneurs;
- To set up measures against stigmatization faced by PWDs and people living with HIV in the financial institutions and insurance companies (Rwandan Government - BNR);
- To reinforce collaboration between the private sector and PWDs in the activities of fighting against poverty and in employment creation;
- To facilitate DPO for their participation in the various displays/exhibitions in order to promote their achievements and to sensitize the public on realities of Disability.
- Given the imminence of Expo 2009 and the impact the visibility of realities of Disability would have, it is recommended to FENAPH and UPHLS to make possible the participation of DPOs in the event.

Recognizing that the promotion of the rights of Persons with Disabilities is in dissociable with their basic rights, the participants to the Forum recommend to the concerned actors, especially
to the Ministry of Justice, the Ministry of Gender and Family Promotion, the National police and the National Human Rights Commission:

- To ensure a framework of monitoring the respect of the rights of PWD;
- To lay a particular stress on violence that Persons with Disabilities undergo because of their physical, mental or communication limits;
- To install a framework allowing their staff to be able to serve people with hearing impairments.

E. RECOMMENDATIONS ON RESEARCH

Aware that the planning of the interventions suffers from lack of qualitative and quantitative data on the situation of Disability in Rwanda, the participants recommend to TRAC PLUS, higher education institutions and other stakeholders in research:

- To run a CAP study on the sexual and affective life of people with various deficiencies and on the perception of the sexuality of Persons with Disabilities by the Rwandan community;
- To run a study on the use of the condom among Persons with Disabilities;
- To inventory and disseminate the existing tools on HIV accessible to PWDs and on the effectiveness from the tools for sensitizing used at the PWD;
- To run a study on the promotion of the abstinence at the PWD and to adapt the good practices already tested for other groups;
- To run a study on the relationship between begging and the risks of infection with HIV;
- To make a research on HIV as a disabling disease and the impact of the side effects of ARVs which can be factors of disabilities;
- To make an early diagnosis of all the Rwandan children as a prevention means of hearing impairments;
- To evaluate the level of access of VCT, PMTCT and ARVs services by Persons with Disabilities.

The participants to the Forum invite all HIV actors in Rwanda to encourage the development of an expertise on HIV and Disability at the national level, by the reinforcement of the networks of exchanges and experience sharing, and by the participation in various events organized at the community, national and international levels.

The participants to the Forum invite finally all the sharp forces of the nation to combine their efforts on these problems, because not only PWDs are exposed to the HIV, but also because HIV&AIDS, as a disabling disease, increases the number of PWDs.

Considering the relevance of a permanent framework of monitoring progress made on the HIV and Disability aspect, the participants recommend to organize, on an annual basis, the national conferences on HIV&AIDS and Disability.
CONCLUSION

The First National Forum on HIV and Disability, which was held from 28th to 29th May 2009, constituted an important event in the field of HIV in Rwanda. Its work was crowned by success and relevant recommendations were developed.

The participation to the Forum was satisfactory, physically and in terms of ideas contribution. The diversification of the competences of the participants constituted an enriching element.

Though the financial situation and other factors made that UPHLS did not have much time for the preparation of the Forum, its objectives were largely achieved and it is up to the organization (UPHLS) to set up a strategy of monitoring its recommendations. It will be particularly relevant to decline the recommendations of the Forum in concrete activities according to whether they can be programmed for the short, the middle or the long term, and UPHLS already started to integrate some of these activities in its strategic plan 2009-2012.

It is clear that the achievement of the ambitions of this dynamics could not only fall on UPHLS. Indeed, without wasting time, it is necessary to develop suitable strategies and actions which allow the health system and other HIV actors to effectively meet the specific needs of Persons with Disabilities. It is also necessary to develop inclusive approaches that:

- guarantee an access for all with the health services without discrimination;
- contribute to the participation of PWDs at the sides of other actors;
- contribute to avoid a double stigma.

The support of the Government will be determining to make progress on the integration of Persons with Disabilities. We hope that the NACC, TRAC PLUS and other actors in the field of HIV will continue to support the work of the working group on HIV and Disability, which will constitute a technical framework of follow-up of the recommendations of the Forum.

The UN agencies will have to support on various plans these initiatives (children with disabilities and HIV, gender, promotion of the reproductive health,…), and the UNAIDS is positioned as the appropriate actor to help UPHLS in the dissemination of the Brief Policy on HIV and Disability.

The nongovernmental organizations will have to contribute to walk on towards an equal access to information and care services. UPHLS will have to approach the RRP+ in order to organize together the care of HIV positive PWDs.

More important, the anticipated projections will not take place if there is not knowledge management on HIV and Disability, and especially if the service providers (health facilities and actors of the Community Health System) do not change mentalities, attitudes and practices. The MOH, the NACC and TRAC PLUS are naturally the appropriate bodies to coordinate this very important component. These institutions have also to include the disability aspect in their monitoring and evaluation systems, in order to guarantee the sustainability of the desired integration.

Holding regularly national conferences on HIV and Disability was retained as a recommendation likely to advance this cause, and UPHLS invites all the partners to help it in the organization of the upcoming meetings.
The challenges are real, but there is a true political will and an awakening of all the actors. The first Forum made it possible to clear the way, and UPHLS hopes that all the actors will support it in the in-depth and long term work to be undertaken.