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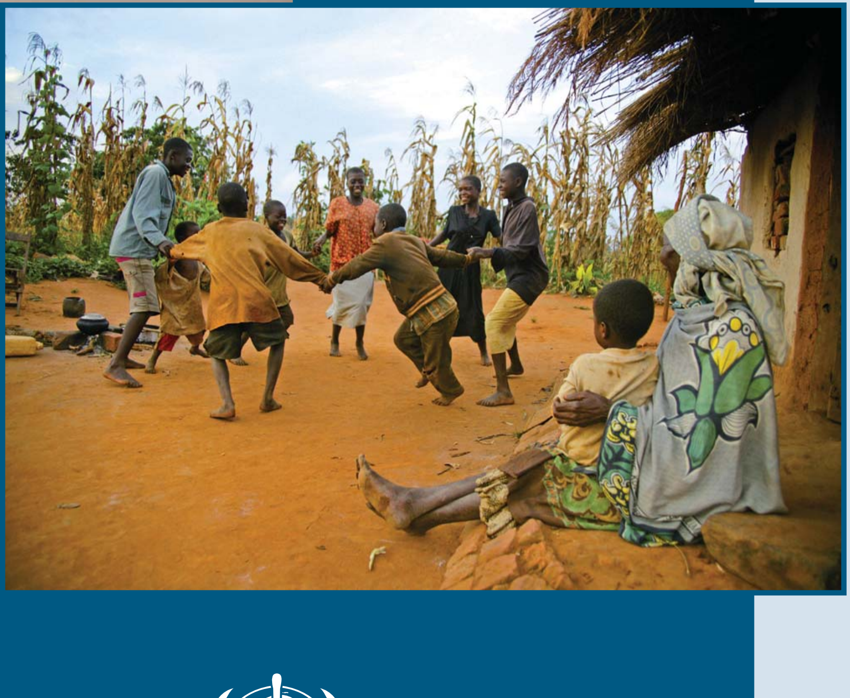
Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV

WHO/UNICEF Global Consultation



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Acronyms

AIDS	acquired immunodeficiency syndrome
ART	antiretroviral treatment
ARV	antiretroviral
FBO	faith based organization
FP	family planning
GYCA	Global Youth Coalition on HIV/AIDS
HIV	human immunodeficiency virus
IAC	international AIDS Conference
IDU	injecting drug use
IEC	information education and communication
IMAI	Integrated Management of Adolescent and Adult Illness
IGO	international governmental organization
IPPF	International Planned Parenthood Federation
IPT	intermittent preventive treatment
NGO	nongovernmental organization
OI	opportunistic infection
ORS	oral rehydration salts
PCP	Pneumocystis carini pneumonia
PEP	post-exposure prophylaxis
PEPFAR	The US President's Emergency Plan for AIDS Relief
PMTCT	prevention of mother-to-child transmission
SRH	sexual and reproductive health
STI	sexually transmitted infection
TB	tuberculosis
UN	United Nations
UNICEF	United Nations Children's Fund
VCT	voluntary counselling and testing
VIPP	Visualization in Participatory Programmes
WHO	World Health Organization
YPLHIV	young people living with HIV

Executive summary

Over 5 million[1] young people are living with HIV, although the vast majority of them do not know that they are infected. With increasing access to HIV testing, more and more young people are likely to discover that they are infected. While some of them will require antiretroviral (ARV) treatment and/or treatment for opportunistic infections (OIs), many will not. Those young people who do not require treatment will, however, require care, support and prevention, and preparation for when they do require treatment. In addition to those adolescents who become infected with HIV during adolescence, with increasing access to ARVs more and more of the children who become infected through vertical transmission will survive into adolescence, and will require ongoing treatment, care, support and prevention during this new and often challenging phase of their lives. The health sector will need to be clear about its role in addressing the specific, complex and diverse needs of adolescents and youth living with HIV.

Recognizing the need to better understand and respond to the health needs of young people living with HIV and AIDS, the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) convened a global consultation on *Strengthening the Health Sector Response to Care, Support, Treatment, and Prevention for Young People living with HIV/AIDS* in Blantyre, Malawi, from 13 to 17 November 2006. The meeting was hosted by UNICEF Malawi, and included more than 45 participants from 18 countries, including young people, a number of them living with HIV; health workers, from a range of professional backgrounds, involved in providing HIV/AIDS treatment, care, support and prevention for young people living with HIV (YPLHIV); and representatives from UN agencies and international and national nongovernmental organizations (NGOs) that are working with young people living with HIV and supporting programmes to meet their needs.

The overarching objective of the consultation was to review and synthesize the experiences of young people living with HIV and health workers responsible for providing services for them, including the identification of gaps and obstacles in the provision and use of services, in order to offer practical recommendations on how to improve the health sector response. Eight priority challenges were identified to which the health sector should respond:

- lack of accurate, relevant, appropriate and non-judgemental information targeting young people;
- lack of services, as a result of multiple barriers to provision, access and use, including scarcity of adolescent-friendly health workers;
- consent and confidentiality;
- lack of psychosocial support;
- problems with adherence;
- difficulties with disclosure;
- stigma, discrimination and isolation; and
- transitions of care (from paediatric to adolescent, and from adolescent to adult).

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[1] The statistics have been updated since the Malawi consultation, and the new updated statistics are presented in this report.

The health sector needs to provide young people living with HIV with a range of services, including developmentally appropriate information about HIV and AIDS; physical and psychosocial care and treatment for HIV and AIDS; mental health and sexual and reproductive health services; and linkages and referral between services in the health sector, and with services provided by other sectors. In addition, it is important to bear in mind the different needs of young people infected with HIV during adolescence, and those young people who were infected during the perinatal period. Based on these priorities, the consultation identified the following issues requiring further development:

- standards for health services for YPLHIV;
- minimum and minimum-plus treatment/care packages for YPLHIV;
- approaches to the provision of psychosocial support for YPLHIV;
- training and orientation of health care workers to provide information and services for YPLHIV;
- training and supporting young people to contribute to health sector activities for YPLHIV; and
- linking with other sectors in order to strengthen the health sector response to care, support, treatment and prevention for YPLHIV.

The consultation highlighted the considerable need for better data on different groups of young people living with HIV, in terms of current and future needs for treatment and care, and for additional research focused on identifying and responding to their specific needs. The meeting concluded with the formulation of action plans relating to the priority challenges facing the health sector, including tasks to be accomplished in the next 6 and 24 months, and responsibilities for achieving them.

1.

Background and rationale

The Declaration of Commitment on HIV/AIDS, endorsed by the UN General Assembly in 2001, "…embraced equitable access to care and treatment as a fundamental component of a comprehensive and effective global HIV response."[1] As a step towards universal access to HIV prevention and treatment for all who need it, WHO launched the "3 by 5" initiative on World AIDS Day in 2003, which aimed to provide treatment for three million people living with HIV in low- and middle-income countries by 2005. At the same time, the advent of the Global Fund to Fight AIDS, Tuberculosis and Malaria and other funding initiatives have greatly increased the level of resources available for treatment in countries. These efforts have galvanized global support to expand access to treatment and have "…demonstrated the feasibility of delivering HIV treatment in even the most resource-limited settings, and confirmed that the extraordinary declines in AIDS-related illness and death seen in high-income countries can be achieved in low- and middle-income countries as well."[2]

As of 2007, more than 30 million people were living with HIV, 5.4 million of whom were young people 15-24 years of age.[3] These young people comprise both those infected during adolescence and those infected through mother-to-child transmission who survive into adolescence. As a result of the life-prolonging effects of antiretroviral therapy, the number of young people living with HIV due to infection during the perinatal period is expected to rise. At the same time, efforts to facilitate people's access to HIV testing are likely to increase the number of young people who know that they are infected as a result of transmission during adolescence.

With the focus on the benefits of ART, it is easy to forget that treatment is only one aspect of comprehensive care for young people living with HIV. The majority of young people who become infected with HIV during adolescence are unlikely to require ARVs because of the delay between infection and the development of symptoms that require treatment. However, during this period they *will* require care, support and prevention, and this is an important time for treatment preparedness.

Many sectors will need to be involved in national responses to meeting the needs and rights of young people living with HIV. However, the health sector will need to play a central role, and in order for it to do this it will be important to understand the specific needs of young people living with HIV, including the needs of different groups of young people defined by characteristics such as age, sex, marital status, parental support, sexual orientation, socioeconomic status and context, and different epidemic scenarios.

As a contribution to improving and expanding the role of the health sector, WHO and UNICEF organized a global consultation on *Strengthening the Health Sector Response to Care, Support, Treatment, and Prevention for Young People Living with HIV/AIDS*. The consultation had several objectives:

- to review and synthesize the needs for care, support, treatment and prevention for adolescents and youth living with HIV, in order to make a compelling case for action;

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[1] See UNAIDS (2006).

[2] Ibid.

[3] The Malawi consultation focused on young people, 10-24 years, although particular attention was paid to adolescents, 10-19 years, with disaggregation by age and sex, when the data were available, and attention to time and mode of infection.

- to define priority elements of care, support, treatment and prevention for YPLHIV;
- to share experiences about interventions for meeting young people's needs, including a focus on increasing access and adherence to treatment and care;
- to review available programme support materials and strategies in order to be clear about what is available, and what needs to be developed; and
- to develop an action plan for the development and implementation of priority interventions.

Before the workshop commenced, several desired outputs were identified:

- peer-review and finalization of the background papers[1] prepared for the consultation;
- a report from the consultation synthesizing the discussions and recommendations; and
- a network of individuals and organizations committed to advocating for and accelerating health sector action to provide care, support, treatment and prevention for YPLHIV.

Despite the growing number of young people living with HIV, their treatment, care, support and prevention needs remain missing from the global agenda. Young people have different needs from small children and adults, and require different approaches to meeting these needs. The Malawi consultation will make a contribution both to understanding the diverse and unique care, support, treatment and prevention concerns of young people living with HIV, and also to achieving recent commitments to universal access, and to existing global goals and targets endorsed during the UN General Assembly Special Sessions on AIDS and Children, New York 2001, and the subsequent high-level meeting held in New York, 2006.

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[1] Two background papers were prepared for the consultation. They explored the issues of care, support, treatment and prevention for young people living with HIV (a) from the perspectives of young people and (b) from the perspectives of health service providers. The final versions of these papers follow the overview report of the meeting (Annexes 2 & 3).

2. Overview of the consultation

Forty-nine participants from 18 countries[1] attended the consultation: young people, including young people living with HIV; service providers from a range of professional backgrounds working with YPLHIV; and representatives from UN agencies and international and national NGOs (see Annex 1: List of Participants).

Participants shared their expectations of the consultation during the initial session of the meeting. Many common themes emerged, which concurred with the overall objectives of the consultation:

- to gain clarity and consensus on the specific needs of YPLHIV;
- to ensure that YPLHIV can participate in making decisions on issues that affect them;
- to share and learn from the experiences of peers and colleagues;
- to understand and outline what can be done to improve care, support, treatment and prevention for YPLHIV;
- to develop partnerships between and among young people and service providers.

Several guiding principles for the workshop were identified and discussed at the beginning of the consultation. Foremost, it was important to remain focused on the specific needs, issues and problems of young people living with HIV, as compared to small children and adults, bearing in mind the diversity of young people living with HIV and the implications that factors such as age, sex, mode of transmission and context may have for the provision and use of services for care, support, treatment and prevention; secondly, to concentrate on practical actions that the health sector can achieve in resource-poor settings; thirdly, not to spend too much time getting caught up in language such as *young people*, *youth*, *adolescents,*[2] *care*, *support*, *treatment and prevention*, but to identify and focus on that group of the population living with HIV who are no longer children and not yet adults, to identify their specific needs and explore approaches to meeting the needs that were identified.

The Malawi Minister of Youth, Sports, and Culture officially opened the consultation after messages from the WHO and UNICEF Country Representatives were shared.[3] The Minister welcomed everyone to Malawi, the warm heart of Africa, and commended UNICEF and WHO for organizing "…this very important meeting". He declared the commitment of the government to provide an enabling and protective environment for young people, and acknowledged the necessity of better understanding the different needs of young people infected during the perinatal period and young people infected during adolescence.

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[1] Bolivia, Botswana, Canada, China, Ethiopia, Indonesia, Kenya, Malawi, Mexico, Namibia, Nigeria, Romania, South Africa, United Republic of Tanzania, Uganda, United Kingdom of Great Britain and Northern Ireland, United States of America, Zimbabwe.

[2] Adolescents 10-19 years, Youth 15-24 years, Young People 10-24 years.

[3] Due to inclement weather, the WHO and UNICEF Country Representatives were unable to attend the workshop. Their opening remarks were read by a WHO and a UNICEF staff person, respectively.

Dr Matshidiso Moeti, the WHO Representative, posed two challenges to the meeting participants: the need to keep a clear focus on the specific needs of young people living with HIV, and on what can realistically be done, particularly in resource-poor settings, to improve the health sector response to the needs of young people living with HIV. The opening remarks of the WHO Representative were echoed by many participants: "do not let this consultation flow into becoming a 101 on care, support, treatment and prevention for HIV in general." Moreover, participants stressed the importance of not just listing the problems facing young people living with HIV, but, more importantly, focusing on practical solutions to address the problems identified.

Following the introductory remarks, there was a presentation that provided feedback from the meeting that the youth participants had held for one day prior to the start of the consultation. This was important to site the meeting in the reality of young people's lives and experiences, and for many people was one of the highlights of the consultation. Nine vignettes of the lives of young people living with HIV were presented. Based on real life experiences, the stories mapped the experiences of young people living with HIV, from how they became infected, through diagnosis to care, treatment and support (or, more often, the lack of it)[1].

A large portion of the consultation was spent in breakout sessions – six in total. At the conclusion of these breakout sessions, the working groups' discussions were synthesized and presented in plenary. Based on the group work from the first two days, which focused on reviewing the background papers and identifying priorities for action from the perspectives of young people and service providers, eight priority issues in relation to care, support, treatment and prevention for young people living with HIV were identified:

- lack of accurate, relevant, appropriate and non-judgemental information targeting young people;
- lack of services, as a result of multiple barriers to provision, access and use;
- lack of psychosocial support;
- consent and confidentiality;
- problems with adherence;
- difficulties with disclosure;
- stigma, discrimination and isolation;
- transitions of care (from paediatric to adolescent, and from adolescent to adult).

These core issues provided the basis for the subsequent group work and discussions. During one of the last breakout sessions, participants outlined key actions that the health sector could implement to address the problems facing young people living with HIV, with a focus on:

- standards for the health sector response to YPLHIV;
- minimum care packages of services for YPLHIV;
- providing psychosocial support to YPLHIV;
- training and orientation of service providers to meet the needs of YPLHIV for care, support, treatment and prevention;

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[1] See Annex 2, which is a revised version of the background paper prepared for the meeting on young people's perspectives to prevention, care, treatment and support for YPLHIV, and includes the vignettes that were developed during the pre-consultation meeting that was organized by the youth participants.

- training and support for YPLHIV to support the provision of care, support treatment and prevention services; and
- linking with other sectors.

The consultation concluded with the identification of five products or activities that the workshop participants would like to achieve by 2008 (by the time of the XVII International AIDS Conference in Mexico), and five products or activities that should be achieved in the next six months. Eleven priority outputs were agreed, with participants committing to one or more of these follow-up activities.

3. Overview of young people living with HIV

As of 2007, more than 5.4 million young people were living with HIV. Increasing access to treatment has decreased the number of AIDS-related deaths and increased the number of people living with HIV, both adults and children.[1] Approximately 5000 young people are infected with HIV each day, and although the majority of them do not know that they are living with HIV, with increasing access to testing, including through provider-initiated testing and counselling, more and more of these young people *will* know their HIV status. Although many adolescents are likely to be at an early phase of their disease and may not require treatment, they will need care and support, information and advice about prevention and preparedness for treatment. At the same time, more and more children living with HIV will transition into adolescence and will require an adolescent-oriented approach from the health workers who are involved with their treatment, care and support.

Sub-Saharan Africa bears the brunt of the pandemic, with 3.2 million young people infected with HIV. Most of these young people have been infected through sexual transmission, and females are disproportionately affected (see Table 1).

TABLE 1: Young people (15-24) living with HIV/AIDS

	Female	Male	Total
East Asia and Pacific	110 000	450 000	570 000
Eastern Europe (CEE/CIS)	100 000	240 000	340 000
North Africa Middle East (incl. Sudan)	47 000	35 000	81 000
Sub-Saharan Africa	2 500 000	780 000	3 200 000
Latin America and Caribbean	140 000	280 000	420 000
South Asia	270 000	440 000	710 000
Totals (Non-Ind. Countries)	3 100 000	2 200 000	5 400 000

Source: UNAIDS, AIDS Epidemic Update, 2007

There are wide differences between countries in the region, in terms of overall prevalence rates. There are also not surprisingly significant differences between sub-Saharan Africa and other regions in terms of modes of transmission, age and sex differentials, and groups of adolescents and youth who are most at risk of acquiring HIV infection. It is clearly important to take such differences into consideration, and to fully understand the dynamics of the epidemic in specific settings, before identifying strategies to strengthen the health sector response to care, support, treatment and prevention for young people living with HIV.

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[1] See Fassinou et al. (2004); Gibb et al. (2003); Kline et al. (2004); Nyandiko et al. (2006); Marazzi et al. (2006); Matida et al. (2004); McConnell et al. (2005); Puthanakit et al. (2007); Severe et al. (2005).

Despite the fact that in generalized epidemics many adolescents are likely to have been infected during adolescence, it is often not the adolescents who have been infected during adolescence that are in contact with health services. In Botswana and Uganda, for example, the vast majority of adolescents being cared for by the health sector have been infected through vertical transmission in the perinatal period. The vast majority of HIV infections in people under the age of 15 years are due to maternal-to-child transmission, and with increasing access to ARVs and, at the same time, poor availability and use of interventions for the prevention of mother-to-child transmission (PMTCT), it is likely that the number of children infected during the neonatal period and surviving into adolescence will continue to rise in the coming years.

BOX 1: What can data tell us?

- What is driving the epidemic?
- Where do we need to target care and prevention efforts in terms of individual (e.g. age, sex), behavioural and environmental characteristics?
- What progress are we making with our prevention efforts?
- What are the most appropriate entry points for attracting young people into care?
- What are the systemic barriers reducing YPLHIV's access to care and treatment: i.e. quality issues?
- What are the resource needs: human, financial, supplies?

While there is growing appreciation of the challenges facing young people living with HIV, there is still a need to be able to quantify the extent of the problem, and in order to do this the data that are collected need to be disaggregated, at a minimum by age and sex.[1] The lack of relevant data makes it very difficult to adequately assess the magnitude and dynamics of the HIV epidemic among young people; to target and prioritize prevention, care and support efforts; to identify the most appropriate entry points for young people to access care; to understand the systemic barriers reducing access to care and treatment for young people, including the quality of the services provided; and to track the allocation and use of resources (human, financial and supplies). There are obvious challenges to collecting data on young people living with HIV that demand innovative research methods, including the involvement of young people themselves. This is a priority area for action, since being able to measure a problem is usually the first step towards doing something about it. See Box 1 and Box 2.

Over 20% of current HIV infections[2] are in young people. A systematic review of the evidence for the effectiveness of interventions to prevent HIV in young people in developing countries, implemented through a range of settings (schools, health services, media, communities and specific interventions for young people most at risk of HIV), has recently been completed.[3] However, interventions to provide care, support, treatment and prevention for young people living with HIV were not included in this review, and they still require development and careful monitoring and evaluation in order to build up an evidence base for this aspect of national responses to HIV and AIDS among young people. Such interventions will need to take into consideration not only individual and contextual differences between young people, including differences in modes of transmission, but also differences in the capacity of health systems to respond.

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[1] Other possible characteristics for disaggregation include domicile (rural/urban), whether the adolescent is living with his/her parents, and educational, marital and socioeconomic status.

[2] With the increasing access to ARVs and the impact that this will have on the longer-term survival of all people living with HIV, the proportion of young people living with HIV as a percentage of total numbers of people living with HIV may decrease, even if the actual numbers increase.

[3] WHO (2006).

BOX 2: Data requirements and issues needing further development

- The number of adolescents and youth needing treatment, care and support, by region: current estimates and projections.
- Data that disaggregate perinatally infected from behaviourally infected adolescents/youth.
- Data disaggregated by gender, mode of transmission, and where possible by factors that increase vulnerability, such as sexual orientation, injecting drug use, homelessness, sex work, and orphans.
- Estimates of the number of young people who are infected but who do not yet need treatment because they are in an early phase of the disease.
- Review of treatment registers in order to provide an age breakdown of people on ARVs.
- Tracking of young people tested for HIV and their links with appropriate services depending on HIV status.
- Indicators and data that monitor numbers of young people retained in care, and numbers lost to follow up.
- Indicators and data that monitor disclosure: how many, how done, to whom?
- Numbers of YPLHIV transitioning from paediatric care to adolescent care, and identification of their special needs.
- Number of YPLHIV transitioning from adolescent care into adult care programmes, including numbers lost to follow up.
- Assessments of entry points for adolescents and youth into care, including monitoring the quality of the care (standards) and identifying opportunities for improvements.
- Indicators to assess the number of facilities that can provide "adolescent/youth-friendly services" (that take the specific needs of young people into consideration), including factors that increase young people's use of services: service providers trained, changes made to health facilities, and demand generation/community support activities implemented.
- Information about where, and how, the majority of young people learn about their HIV status.
- Monitoring of the relative roles of different services/sites accessed by adolescents for counselling and testing, for example sexually transmitted infection (STI) services, family planning services, and prenatal services.
- Monitoring of missed opportunities for testing adolescents and for linking young people who are seropositive with appropriate care.
- Monitoring numbers of young people tested and numbers linked to care (number with recorded CD4, first visit or follow-up care within a year).
- Data about the unique care and support needs of young people that should be met by the health and other sectors.
- An assessment of the obstacles to collecting data about YPLHIV and their needs/responses for treatment, care, support and prevention.
- Current guidance and policies on data collection focusing on YPLHIV and approaches to assessing unmet need.
- Development of clear targets at national level on care, support, treatment and prevention for YPLHIV.
- Development of a modelling methodologies that countries can use to estimate the number of young people needing care, support, prevention and treatment (based on HIV incidence estimates, progression of infection, etc.).
- Clarity about methods for estimating incidence/prevalence in 10-14, 15-19, 20-24 year old girls and boys.
- Clarity about methods for estimating future HIV incidence/prevalence among young people (disaggregated by age and sex).

4. Review of background papers

In the first breakout session, participants formed into two groups: (a) those who wanted to provide comments on the background paper addressing the experiences of young people accessing care, support, treatment and prevention, which had been written from the perspective of young people living with HIV; and (b) those participants who wanted to review the paper focusing on meeting young people's needs for treatment, care, support and prevention that had been written from a health provider perspective. In addition to providing general comments to the authors, the groups were asked to reflect on the following questions:

- Who would this paper be most useful for and how should this influence the structure, focus and content of the next draft?
- What was missing and what required further development?
- What inputs could be provided by participants to the author in the development of the next draft?

When discussing these issues, participants were asked to consider in what ways the needs of young people living with HIV differ from the needs of children and adults; what the key issues are that need to be responded to by the health sector in terms of care, support, treatment and prevention for young people living with HIV; and what are the lessons learned about responding to their needs. Some of the key points from the working group discussions are summarized below.

4.1 I WILL MAKE MY VOICE BE HEARD: PERSPECTIVES AND EXPERIENCES OF YOUNG PEOPLE LIVING WITH HIV ON CARE, SUPPORT, TREATMENT AND PREVENTION SERVICES

This paper provides a synopsis of the needs and experiences of 18 young people living with HIV (8 females and 10 males) in terms of accessing care, support, treatment and prevention, with particular reference to needs that should/could be met by the health sector.[1] It delineates the obstacles limiting access to services and offers suggestions for health care providers on how to tackle these issues, including providing a list of "good practice". The paper concludes by outlining five changes that would enable the health sector to better support young people living with HIV.

1) *Who would this paper be useful for and how should this influence the structure, focus and content of the next draft?*

   Group members defined the target audience for the paper as health care providers, decision-makers, YPLHIV, researchers, youth leaders, teachers and parents.

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[1] The original paper ("Mapping the lives of young people") presented at the meeting provided a synopsis of the experiences of 14 young people. The revised paper is presented in Annex 2.

2) *What is missing and what requires further development?*

It was felt that the paper could be strengthened by addressing in more depth the following subjects:

- fears related to disclosure;
- sexuality, relationships and reproductive health concerns of YPLHIV;
- gender inequalities and young women's vulnerability;
- experiences of adolescents infected perinatally, and of young people who are HIV positive *and* particularly vulnerable or at risk, such as young people who are injecting drug users, homeless, sex workers, trans-gendered, disabled, imprisoned or caregivers;
- a more in-depth analysis of the responses to the questionnaires that had been sent out prior to the consultation, and that had formed the basis for the paper (e.g. why did so few women initially respond?); and
- the voices of young people in rural and hard to reach areas, especially from Africa.

During the plenary discussion, participants agreed that the paper should not claim or aim to be representative of all young people living with HIV, and recommended adding a brief description of the young people who had responded to the questionnaire. The author was asked to reflect more on the African context, to include the experiences of a young person who had become infected as a result of vertical transmission, and to more clearly outline how the needs of young people living with HIV differ from those facing adolescents in general.

Reviewers also noted that programme planners and service providers often forget that young people living with HIV are sexually active, and that young women living with HIV may want to become pregnant. Therefore, access and availability to condoms, family planning and reproductive and sexual health services are essential components of any care and support programme.

3) *In what ways are the needs of young people living with HIV different from the needs of children and adults?*

Some of the ways in which the needs of young people living with HIV differ are as follows:

- Blame is placed on YPLHIV because of their "risky behaviour" which results in stigma and discrimination, whereas small children are treated as "innocents".
- YPLHIV are dealing with their own physical, psychosocial and emotional development, including sexuality.
- Gender inequality reduces the ability of young women (especially those who are married) to negotiate condom use and access services.
- It is more difficult to find and bring young people into care because of the need for parental involvement (this parental involvement may be a very positive factor in providing treatment and care to small children).
- Small children and adolescents are different, and the transition from being a child to an adolescent is difficult: young people can easily "fall through the cracks" (i.e. too old for paediatric care, but too young for the adult services).

Some of the ways in which YPLHIV are different from adults living with HIV follow.

- There are widespread beliefs that YPLHIV are "not supposed" to be having sex.
- Services are less appropriately tailored for young people than they are for adults.

- YPLHIV are more likely to lack the skills to negotiate health services and understand side-effects, treatment options and regimen requirements.
- YPLHIV have a range of future decisions to make, such as having children.
- YPLHIV often depend on their parents (e.g. financially) and therefore cannot make independent decisions.
- The bodies of YPLHIV are still developing, and the long term toxicity of antiretroviral therapy on children and adolescents is not fully understood, particularly in resource-poor settings, including their impact on growth.
- YPLHIV often have less disciplined/structured lives, which makes treatment adherence more difficult.
- YPLHIV face peer pressure, and often want to be the same as their peers even though this may be difficult.
- not all YPLHIV understand or know their legal rights with respect to access to health services that ensure privacy and confidentiality.

4) *What are the key issues that need to be responded to by the health sector in terms of care, support, treatment and prevention for YPLHIV?*

The key issues are:

- availability of pre-test and post-test interventions, including counselling and peer support;
- prevention for/with positives;
- sexual and reproductive health rights and services;
- social and psychological issues;
- food security and nutrition education;
- barriers to treatment;
- livelihoods (to contribute to defraying the burden of health care costs, and to simultaneously developing career opportunities for the future);
- the involvement of young people in the provision of services;
- training of health care providers; and
- addressing the needs of particularly vulnerable young people, including adolescent girls and young men who have sex with men.

4.2 A HEALTH PROVIDER'S PERSPECTIVE ON STRENGTHENING CARE, SUPPORT, TREATMENT AND PREVENTION FOR YOUNG PEOPLE LIVING WITH HIV

This paper provides the perspectives/experiences of people working in the health sector who are responsible for meeting the care, support, treatment and prevention needs of young people living with HIV. It offers an overview of the progression of HIV infection in adolescents and youth; highlights implications for providing services to young people living with HIV; and reviews key issues that need to be considered when providing care, support, treatment and prevention services to young people living with HIV.

1) *What is missing and what requires further development?*

Group members identified several issues in the background paper, which needed to be expanded. These were:

- specific action plan for the health sector response;
- targets and indicators for monitoring health sector interventions;
- differentiating programming approaches for resource rich and resource-poor settings;
- differentiation of programming approaches for adolescents infected vertically and those infected behaviourally; and
- the role of HIV counsellors and other health workers in developing linkages within the health sector and with other sectors.

2) *In what ways are the needs of young people living with HIV different from the needs of children and adults?*

Adolescence is the transition period between childhood and adulthood, and is characterized by major physical, emotional and cognitive changes, as well as significant changes in the relationships between the adolescent and her/his family, caregivers and peers. Young people[1] living with HIV are different from children and adults living with HIV because of the characteristics that define adolescence itself:

- a sense of immortality;
- risk taking "the norm" (developmentally appropriate);
- an emerging sense of identity;
- an emerging sense of autonomy and independence;
- the need to challenge authority figures;
- experimentation with sex and gradual development of sexual identity;
- experimentation with substance use;
- peer pressure; and
- focus on body image.

Additionally, adolescents' health-seeking behaviour is at least quantitatively different for many reasons, including fear related to disclosure, fear of the future (for example jobs, reproductive health), an inadequate safety net, concerns about being judged by health care workers, and inadequate access to services that are able to respond to the specific needs of young people. This may have important implications for adolescents' use of HIV testing and counselling services, and for making contact with the health system for care and treatment.

3) *What are the key issues that need to be responded to by the health sector in terms of care, support, treatment and prevention for YPLWH?*[2]

The key issues identified were:

- transitioning from paediatric care to adolescent care, and from adolescent care to adult care;

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[1] It is important to note that young people have varied capacities to access health and social services. A young person 20 years of age, for example, has more capacity (and in many places more legal rights) to access services than a young person of 16.

[2] Many of these issues will be different for adolescents infected during adolescence, who are just starting care or treatment, and adolescents infected perinatally who are transitioning from paediatric to adolescent treatment/care.

- adherence to treatment and other aspects of care;
- disclosure:[1]
    - to the adolescent;
    - to partner/caregivers/peers/others;
- issues of long term treatment:
    - body image changes, such as lipodystrophy and lipoatrophy;
    - resistance to ARVs;
    - long-term toxicity of ARVs;
- age-appropriate sexual health interventions;
- support for young people's emerging sexuality, sexual orientation and desire for pregnancy;
- psychosocial services, including links to other services, for example life skills, education, parenting;
- age-appropriate mental health services;
- prevention for/with positives: mitigating harm related to sexual and injecting drug use practices;
- adolescent-specific information materials and access to prevention commodities, such as condoms;
- direct involvement of young people in service provision, education and outreach;
- young people's involvement in programme planning (YPLHIV are likely to respond best to providers and services which take into consideration their developmental issues and legal rights).

4) *What are the lessons learned about responding to the needs of YPLWH?*

- Testing must be linked to treatment, care and support services.
- Young people are willing to be tested for HIV, but must be ensured privacy and confidentiality.
- Many different models of providing testing have been implemented (Lesotho, Malawi, South Africa, Swaziland and Uganda), however, they are poorly documented: country specific case studies are needed.
- Community and youth involvement is key to reaching those that are not currently reached by the health care system.
- Health care facilities can use innovative models for making contact with YPLHIV, such as targeting young people with STI or family planning clients.
- Need to learn lessons from, and strengthen linkages with PMTCT programmes.
- HIV tests can be performed by nurses, counsellors and young people, provided that they have adequate training, supervision and support.

Irrespective of the mode of transmission, youth friendly services for young people living with HIV need to be developed, either independent of, or integrated into existing health structures. Three different models were discussed, with their selection being dependent on the epidemic scenario, the existing services and infrastructure, and the availability of resources:

- integration/adaptation of paediatric models;
- integration/adaptation of adult models; and
- adolescent centred/specific care models.

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[1] The issues around disclosure and long-term treatment are likely to differ between those adolescents and youth infected vertically, and those young people whose infection is behaviour related.

5. Identifying priority issues/ problems facing YPLHIV

On the second day of the workshop a nominal group technique was used to prioritize five key issues/ problems facing young people living with HIV to which the health sector could/should respond. Group members were asked to write five key issues on cards, and the list of issues identified by the participants were recorded. Members of the working group then ranked their top five issues that had been identified by the group, and consensus was reached on the five most important issues. During plenary, the five priority issues from each group were presented, and the issues/problems were then clustered into the following categories:

- lack of relevant information (inadequate, inappropriate) targeting young people;
- lack of services (multiple barriers to provision, access and use);
- lack of support, including psychosocial support;
- non-adherence;
- difficulties with disclosure;
- stigma, discrimination and isolation;
- consent and confidentiality; and
- transitions of care (from paediatric to adolescent, and from adolescent to adult).

The synthesis from these discussions was then used as the basis for developing priorities for action by the health sector, and subsequently follow-up action plans. It was recognized that to develop an effective response to meeting the needs of young people living with HIV, the health sector must take into consideration several factors:

- Partnerships should be strengthened between the private and public sectors, and with community based organizations.
- Young people, particularly young people living with HIV, should be key actors in responding to the needs of YPLHIV.
- Families and communities are important gatekeepers and partners for meeting the needs of YPLHIV.
- It is important to be clear about what is desirable *and* what is do-able.
- Many sectors other than the health sector will need to be involved, so linkages and referral are important.
- There is a need for interventions that respond to underlying determinants (e.g. poverty), and the health sector may have an important role in advocating for such interventions.
- The capacity of service providers needs to be strengthened and developed.

After developing consensus about the priority issues for the health sector response, discussion centred on what needs to be done to address these issues, and how appropriate interventions can be provided. Young people living with HIV require:

- developmentally appropriate information on HIV transmission, anatomy and physiology, disease progression, treatment literacy, risk reduction and positive prevention;
- HIV care and treatment, the prophylaxis and treatment of opportunistic infections, ARVs, and nutrition/food;
- mental health and psychological services to respond to adjustment issues, guilt, anger and depression;
- respectful sexual and reproductive health services (including issues of sexuality, sexual orientation, fertility, abstinence, condoms, contraception, emergency contraception, sexually transmitted infections, medical termination of pregnancy, and antenatal and delivery care);
- linkages and referral between services (including linkages between testing and treatment, care, and prevention services).

Throughout the workshop young people shared their experiences, both good and bad, of accessing treatment, care, support and prevention services. It was repeatedly noted that regardless of the type of HIV service, if they are not responsive to the specific needs of young people they will not be used. To increase uptake, therefore, services need to be ‘adolescent friendly’. Health services need to be available, accessible, and appropriate to adolescents in general, and this needs to include adolescents living with HIV. All clinic staff, especially service providers, must be trained to develop the necessary orientation and skills that will enable them to respond more effectively to the needs of adolescents. They should undergo sensitivity training to help them avoid creating stigma and discrimination, as well as training on how to ensure privacy and confidentiality, something that is critical for every aspect of an adolescent accessing health services.

Young people living with HIV need to be involved in the provision of information, support and other interventions for young people living with HIV. A young person who is newly diagnosed with HIV is likely to identify best with another young person living with HIV, and this can facilitate his/her entry into services. However, it is important to be clear about the specific responsibilities that are best suited to young people, what type of training they need to carry out these responsibilities, and to ensure that appropriate compensation and support are in place to help them carry out their tasks effectively. Young people living with HIV, parents and community members need to be informed about the availability of services, in order to generate demand and strengthen community support for adolescent friendly health services.

6. Synthesizing experiences

6.1 LEARNING FROM THE OUTCOMES OF PREVIOUS MEETINGS ON RESPONDING TO THE NEEDS OF PEOPLE LIVING WITH HIV

In order to benefit from the outputs of other relevant meetings, updates were presented from previous regional and global consultations that had recently been organized and that had implications for the care, support, treatment and prevention for young people living with HIV.

Representatives from the International Planned Parenthood Federation (IPPF) provided feedback from a consultative meeting IPPF had organized in South Africa in July 2006 on integrating a focus on young people living with HIV/AIDS into existing sexual and reproductive health programmes and services. The objectives of the meeting were to develop a guide to:

- support IPPF member associations in efforts to ensure meaningful engagement and participation of young people living with HIV and AIDS, at all stages of the response;
- promote access to sexual and reproductive health information and services for YPLHIV;
- ensure reliable access to essential sexual and reproductive health commodities, including male and female condoms;
- ensure access to education, opportunities to develop life-skills, and sexuality education; and
- promote integration of HIV prevention interventions, including voluntary counselling and testing (VCT), into other health services, including sexual and reproductive health (SRH), family planning, maternity and tuberculosis services, and PMTCT.

Participants were provided with a draft of the guidance that was developed during the meeting, and were requested to provide feedback and comments to IPPF.

An overview of the March 2006 Addis Ababa consultation organized by UNFPA, WHO and Engender Health on the sexual and reproductive health needs of people living with HIV[1] was to have been given by one of the participants in the consultation who had attended the Addis meeting. Unfortunately due to delays in travel this was not possible. The objectives of the Addis Ababa consultation were to:

- outline the key challenges and opportunities in policies and programmes to support the sexual and reproductive health needs of YPLHIV;
- review and discuss the content for a proposed guidance document, including principles and programmatic actions; and
- suggest how the proposed guidance document could be made useful to different groups and in different settings.

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[1] The final draft of the meeting report from this consultation is available at http://www.who.int/reproductive-health/hiv/index.html.

It had also been hoped to obtain feedback from a meeting that WHO had organized earlier in the year in Montreux, Switzerland, on positive prevention/prevention with positives. Unfortunately the meeting report had not been finalized and the person who had been invited to make a presentation on the meeting had, at the last minute, been unable to participate in the consultation.[1]

6.2 LEARNING ABOUT PARTICIPANTS' EXPERIENCES OF RESPONDING TO THE NEEDS OF YPLHIV

Day two of the workshops concluded with a marketplace, which gave participants an opportunity to provide an overview of their programmes, including a focus on how aspects of their programmes responded to the key issues/problems that had been identified earlier in the day, and to share their organizations' materials (see Annex 5).

6.3 LEARNING ABOUT WHAT MAKES HEALTH SECTOR PROGRAMMES SUCCESSFUL

The third day of the consultation started with work in groups of participants to identify those factors that facilitate or prevent health sector programmes for young people living with HIV from being successful, based on their own experiences. Group members agreed on the most important characteristics, which they then presented during the plenary. After clustering the responses, nine factors that make health sector programmes for young people living with HIV successful and nine factors that prevent health sector programme from being successful were identified. See Table 2.

TABLE 2: Factors that facilitate or prevent success

What makes health sector programmes successful?	What prevents health sector programmes from being successful?
Appropriate and sufficient personnel	Lack of consistent resources
Adequate resources to make services available and accessible	Stigma and discrimination by clinic staff
Supportive policies and standards	Inappropriate package of services
"One-stop" services	Lack of support services
Effective monitoring and feedback	Inappropriate delivery of services
Creation of support groups and networks	Inadequately trained health workers
Services responsive to the needs of young people	Lack of planning and standards
Involvement of YPLHIV	Lack of attention to YPLHIV
Youth specific information and resources	Lack of linkages and referral

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[1] **Prevention with Positives meeting report reference to be added**

7. Developing core components of the health sector response to YPLHIV

The first three days of the workshop aimed to outline practical guidance for the health sector to better respond to the problems facing young people living with HIV. During the next session, participants were divided into self-selected working groups and asked to identify ways to strengthen the health sector response, using the background papers, the recommendations of previous regional and global consultations, the interventions and materials shared at the Market Place, and the good practice that had been identified from current programmes/projects. Each of the six working groups focused on one of the following questions:

- What standards and targets for the health sector response to YPLHIV could be outlined, for adaptation at national level and for use in quality assurance approaches for programme development and monitoring?
- What is the basic health services package for YPLHIV: minimum and minimum-plus?
- What are the key elements of psychosocial support for YPLHIV: what should be provided, by whom, and with what set of skills?
- What kind of training is needed for service providers in order for them to be able to better respond to the needs of YPLHIV?
- What kind of guidance, training and support is required for YPLHIV to contribute effectively to health services delivery for YPLHIV?
- To which sectors should the health sector link and how should linkages be strengthened?

7.1 STANDARDS AND TARGETS FOR THE HEALTH SECTOR RESPONSE TO YPLHIV

When developing standards for the health sector response to young people living with HIV, the diversity of the target group needs to be considered. Thought should be given to the age, sex and health status of young people living with HIV, the mode of infection (e.g. neonatal, sexual, injecting drug use), the dynamics of the epidemic, the context in which the young people live, and the available resources. Standards should be developed in partnership with government, the private and public sector, community-based organizations, and young people living with HIV.

Standards to consider at policy and facility levels when developing the health sector response to young people living with HIV include the following:

Policy level

1. Policies are in place to protect YPLHIV from stigma and discrimination, and young people receive specific attention in accordance with existing policies dealing with stigma and discrimination of people living with HIV attending health services.
2. Policies are in place that provide YPLHIV with privacy and confidentiality, allowing them to provide informed consent for services based on their evolving capacities and the legislative

framework of the country, and that provide opportunities for YPLHIV to give assent in those situations where it is not possible for them to consent to services.

3. Policies and guidance are in place to support young people in making decisions about disclosure, and to support the decisions that they take in relation to when, to who, and how to disclose their HIV status.
4. Policies and systems are in place that ensure that financial considerations are not a limiting factor in YPLHIV accessing services.
5. Policies are in place that ensure that YPLHIV have access to age, developmentally and educationally appropriate information that is essential for care, treatment, support and prevention.
6. Policies, training, supervision and incentives/remuneration are in place to facilitate the involvement of YPLHIV in providing information and services for YPLHIV, including a focus on how such training can contribute to their personal development and provide them with possibilities for future job opportunities when they are no longer "peers".

Facility level

1. Facilities have mapped available services for YPLHIV in their community/district, in order to strengthen referral, coordination and partnerships to provide effective support to YPLHIV.
2. Facilities are disaggregating all data relating to YPLHIV, from testing to treatment, by age, sex, marital status and whether or not they have parental/caregiver support, and the data that are collected are included in existing management information systems.
3. Facilities have at least one health worker who has received training to respond to the specific needs of YPLHIV (in addition to existing training programmes focusing on treatment and care for people living with HIV in general, and training programmes aimed at ensuring that health services are able to respond to the specific needs of young people in general), and that this person is able to act as a focal point in the facility for YPLHIV.
4. Facilities are providing the basic package of services for YPLHIV, and this is being done in an adolescent/youth-friendly manner.
5. Facilities have procedures and guidance for referral, and tracking systems within the health system, and with other sectors/services providing care and support to YPLHIV.
6. Facilities have established support groups for YPLHIV.
7. Facilities have a coordinating committee that has been briefed on the specific needs of YPLHIV, and there is clear guidance on involving young people in such committees.

7.2 MINIMUM CARE PACKAGE OF SERVICES FOR YPLHIV

While many items in a minimum or minimum-plus package for young people living with HIV are identical to services required for adults, the critical factor is to ensure that services are integrated, that they are age and developmentally appropriate, and that they are responsive to the different needs of adolescents infected vertically and adolescents infected during adolescence (many of whom will require care and support more than treatment). All items in the minimum package should be free of charge. See Table 3.

TABLE 3: Minimum care package for YPLHIV

Minimum	**Minimum Plus** (in addition to the minimum package)
HIV testing and counselling (including pre-test information and informed consent)	
Treatment for: - diarrhoea (ORS) - malaria - de-worming	
Prophylaxis (primary/secondary) for - OIs including PCP and Cryptococcus - Malaria: intermittent presumptive treatment (IPT), and mosquito nets	Prophylaxis (primary/ secondary) - TB - Mycobacterium avium complex
ARV (first and second line), including adherence monitoring	ARV third-line/ experimental
PMTCT and antenatal care	
Complete history and clinical examination: - including weight and height - including a focus on STI signs and symptoms	
Sexual and reproductive health: - condoms (male and female)/contraception/emergency contraception - family planning - pregnancy options and support - pregnancy care (antenatal, childbirth, post-partum) - sex education	Termination of pregnancy
Prevention with/for Positives: - counselling for prevention - positive [healthy] living - family testing - post-exposure prophylaxis (PEP) - condoms - substance abuse counselling - clean needles and syringes for injecting drug users (i.e., access to harm reduction services)	Family/home based VCT
Psychosocial counselling: - mental health screening and referral - adherence counselling - disclosure and ethical partner notification counselling - clinic-based peer support group - bereavement counselling	
Nutrition counselling	Nutrition support
Laboratory: - pregnancy - haemoglobin - syphilis - sputum - CD4	- PAP smear - viral load - resistance testing

TABLE 3: Minimum care package for YPLHIV (continued)

Minimum	**Minimum Plus** (in addition to the minimum package)
IEC materials: - prevention - treatment literacy, including side-effects and possible drug interactions - disease literacy - living positively - existing legal rights [as they apply locally]	
Effective referral system with follow-ups: - linkages with family, community, NGO services - linkages with other youth services - connections with legal institutions	
Immunizations: - tetanus toxoid	Immunizations: - hepatitis B - pneumococcal - human papillomavirus

The group did not reach consensus on (a) whether post-exposure prophylaxis for partners of young people living with HIV and rape victims should be included, and (b) whether it was practical to recommend estimating viral loads. When devising the packages, the group considered what services are feasible in a resource-limited setting. It was also stressed that as many services as possible should be given under one roof, with as few referrals as possible. It will be important to ensure that adolescent/youth-friendly sexual and reproductive health services are available, either in the same facility or through referral.

It needs to be stressed that for many young people recently diagnosed as being infected with HIV and without symptoms, many of the interventions included in this minimum list will not be necessary. However, it will be an on-going challenge for service providers and facilities to ensure that those interventions that will attract and maintain this group of young people into the services are implemented as a priority.

7.3 PROVIDING PSYCHOSOCIAL SUPPORT

Psychosocial support is often a misunderstood concept. In essence, psychosocial support addresses issues that impact on the daily functioning of young people living with HIV, both at a structural and emotional level; it does not include disorders of an organic nature (physiological or psychological). Support for structural issues includes, but is not limited to, assistance in negotiating different systems, for example addressing issues of housing and food security. Emotional functioning encompasses issues such as acceptance of diagnosis, disclosure, isolation, stress, coping mechanisms, and negotiating relationships relative to HIV status. It is important to note that mental illness (such as depression, anxiety and substance use) both enhances young people's vulnerability to HIV and can also emerge in reaction to the diagnosis of HIV. Dealing with mental illness directly or via referral is an important component of care, but is different from, although frequently linked to, the provision of psychosocial support.

The first step in the provision of psychosocial support is to conduct an assessment, in order to measure the level of structural and emotional functioning. An assessment should be conducted during the initial visit and again at follow-up. A number of indicators for structural functioning can be assessed, for example the living situation, disease knowledge, disease progression, school/education status, and family and community support. Emotionally functioning screening encompasses mental health status, the extent of coping and a support network, how long the adolescent has known of his/her status, engagement in any risk behaviours (e.g. substance use), and perceptions of the quality of health care.

Step two is the design of the type of psychosocial intervention to deliver. Internal and external resources then need to be identified which can address the intervention that is being proposed. Internal resources include clinic staff and young people working in the facilities, including young people living with HIV. Once external resources are known, a referral network based on the availability and quality of these services can be created.

Finally, a follow-up plan needs to be designed, in order to ensure that effective support is being provided, either on site or through referral.

It was acknowledged that the development of guidance to address the psychosocial needs of young people living with HIV is long overdue. Once this is developed, it can be adapted at country-level as a training manual in order to create or strengthen staff capacity to provide psychosocial support for young people through HIV care facilities. At a minimum, staff will need to be able to identify the most important psychosocial problems for young people living with HIV in their catchment area, and effective and actionable ways to address these issues. In addition it will be important not only to involve and train service providers, but also caregivers and peers.

7.4 TRAINING OF SERVICE PROVIDERS

The training package for service providers that is currently being rolled out in many countries is the WHO Integrated Management of Adolescent and Adult Illness (IMAI) guidelines and training materials. The guidelines are for people responsible for providing ARV therapy within the context of primary health care, based at first-level health facilities or in district clinics. IMAI provides tools (standardized guidelines and standard packages to train people on using the guidelines) for rapid country adaptation and use in national efforts to achieve the goal of universal access. The modules cover chronic HIV care including ARV therapy, acute care (e.g. the management of opportunistic infections, linking treatment to testing and counselling), palliative care (symptom management at home), and general principles of good chronic care (to support the health system transition from acute to chronic care).[1]

Members of the Working Group on the training of service providers reviewed the existing draft one-day training module on adolescents and HIV that has been developed by WHO to accompany the IMAI training, and provided comments to improve its usefulness.

The training materials are intended to orient health workers to the special characteristics of adolescence, and to identify and practice appropriate ways of addressing important issues for young people living with HIV. They are explicitly for first-level health workers who have been trained in IMAI Basic ART and Chronic Care and who are working with adolescent clients. The training objectives are to:

- inform participants of the phases of adolescent development;
- raise participants' awareness of the specific needs and challenges of adolescence; and

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[1] See WHO (2007).

- strengthen the skills of the participants in providing YPLHIV with appropriate HIV prevention, care, treatment and support in their clinics and communities.

Role plays, VIPP,[1] spot checks, buzz groups and other participatory methodologies are used in the training, which addresses the following topics:

- adolescents and sexuality
- adolescence – a unique phase
- adolescents living with HIV and health care services
- communicating with adolescents
- values clarification through debate
- national situation of HIV and Young People
- clinical aspects of HIV and adolescents
- behavioural aspects of HIV and adolescents
- five As[2] and the adolescent client
- health worker tools for adolescents and HIV.

The group provided a range of comments on the content and process of the module which will be taken into consideration when preparing the next draft for field-testing.

7.5 TRAINING OF YPLHIV

Young people living with HIV can play a unique role in supporting the health sector response to YPLWH. They can input into the provision of services in many ways, for example as counsellors (pre- and post-HIV test), as outreach workers, and by contributing to policy and programme design and oversight. The type and degree of responsibility conferred to a young person must be carefully weighed, as well as the level of training required to carry out specific activities, and the support needed to deal with stress and burn out. Support should include psychosocial services (e.g. debriefing sessions, check-in meetings and supportive supervision), as well as services to address personal growth and development, such as career building, education, family, health and work recognition/incentives.

When recruiting a young service provider, whether for a volunteer or paid position, several factors should guide the process of selection including age, context, gender balance, and ensuring that the young person is representative of the population to which he/she will provide services. Care must be given to avoid tokenism, for example making a symbolic gesture to hire an underrepresented group (e.g. YPLHIV) to deflect criticism and give the appearance of inclusive policies.

The training package will be dictated by the tasks the young person is expected to carry out, but may cover some or all of the following topics:

- advocacy
- public speaking
- leadership skills
- group facilitation skills

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[1] Visualization in Participatory Planning (VIPP) see: http://www.unssc.org/web/images/downloads/VIPP%20UNICEF%20Bangladesh.pdf (accessed 19 Dec. 2007).

[2] Assess, advise, agree, assert, and arrange.

- counselling
- project management, planning, monitoring and evaluation
- resources mobilization
- outreach
- HIV 101
- computer skills
- treatment literacy
- adherence
- sexual and reproductive health
- nutrition
- HIV testing and counselling
- behaviour change.

There is an ongoing need to carefully monitor and evaluate the involvement of young people in programme development and implementation, in order to be able to make a strong case for such involvement by being able to demonstrate that young people's participation makes a significant difference to the outcome of the interventions being developed and delivered.

7.6 LINKING WITH OTHER SECTORS

The following matrix (Table 4) provides an overview of key sectors to which the health sector can link to strengthen the response to young people living with HIV (what the health sector needs other sectors to do in order to strengthen its response, and what the health sector can do to strengthen the response of other sectors), including specific actions that could be undertaken.

TABLE 4: Key sectors in strengthening response to YPLHIV *

Need	Sector	Action
Nutrition	Agricultural, Educational, Business, Community	Initiate feeding programmes to address food security Provide capacity building for child heads of households focusing on livelihoods, for example farming Provide education about the most nutritional uses of available food
Information	Media, Educational, FBOs, Business, Community	Address treatment literacy Promote HIV testing and counselling, and treatment/care services Advocate for SRH needs and rights of YPLHIV Promote behaviour change communication Hold governments accountable to commitments that they have made on YPLHIV Provide information for parents, caregivers, guardians of youth infected and affected by HIV/AIDS Disseminate examples of good practice focusing on integrated programmes for YPLHIV

TABLE 4: Key sectors in strengthening response to YPLHIV * (continued)

Need	Sector	Action
Treatment/ drugs	Business (including Pharma), Political	Donate or subsidize drugs or provide funding for treatment Make drugs affordable (policy implications)
Research	Pharma, Educational (Tertiary)	Increase research projects/data gathering on YPLHIV and related issues
Life skills and livelihoods	Business, Media, Education	Create employment opportunities for YPLHIV (especially by companies supplying the health sector) Develop life skills curricula that are responsive and accessible, and scale them up for young people in and out of school Provide education & higher educational opportunities for YPLHIV
Stigma, discrimination, and disclosure	Media, Education, Political, Legal, FBOs, IGOs, Business, Community	Create awareness to reduce stigma and discrimination against YPLHIV Provide positive role models to assist with disclosure Create and enforce legislation to protect confidentiality & rights of YPLHIV Provide training on how to support disclosure process, including identifying opportunities for young people to disclose Develop school and workplace policies that support and protect disclosure & rights of YPLHIV Link with traditional healers to increase awareness of issues of stigma, discrimination and disclosure
Legal issues	Political/ Parliament, Legal, Criminal Justice, Education	Educate on legal rights of YPLHIV directed to YPLHIV and community members, including treatment legal rights Introduce affordable legal support Advocate for youth-friendly courts and legal system Mainstream youth-specific HIV testing and services, including condoms, for young people in prisons Sensitize the legal system on sexual coercion, criminalization of sexual abuse, age of consent, and confidentiality issues regarding YPLHIV
Advocacy	Political, Education, FBOs, IGOs, Community	Advocate on needs/rights of YPLHIV, based on data from health sector (making it often better positioned to advocate than NGOs/youth) Sensitization of workers in all political sectors
Financing YLWHA Programmes	Political, IGOs, Business	Allocate sustainable funds for programmes Partner with and build capacity of YPLHIV programmes (especially those that are youth-led) Mobilize funding to support training opportunities for YPLHIV, including within the health sector

* NGO involvement is necessary in creating all of these linkages between the health sector and other sectors.

8. Follow-up and evaluation

8.1 FOLLOW-UP ACTIVITIES AND COMMITMENTS

The last exercise of the workshop asked participants to identify five things the participants would like to achieve by 2008 (in time for the XVII International AIDS Conference in Mexico) and five things that should be achieved in the next six months. Many groups took this one step further and offered milestones not only for six months, but also 12, 18 and 24 months.

Priority follow-up activities that were identified included the need to:

- Finalize the meeting report and revise the background papers, for wide dissemination;
- Develop an advocacy publication based on the outcome of the consultation, and identify opportunities to advocate for a strengthened response to the needs of young people living with HIV;
- Hold similar meetings at regional level in order to reflect the specific needs of different regions and share experiences;
- Strengthen and expand existing networks of young people living with HIV, in order to share ideas, experiences and resources and provide support;
- Develop training materials for service providers, in order to orient them to the specific needs of young people living with HIV;
- Identify the information requirements of young people living with HIV, based on the experiences of young people living with HIV, in order to strengthen this component of existing programmes;
- Strengthen the available data on young people living with HIV, including estimates of the current situation and future projections; and
- Synthesize good practice and develop interventions to provide psychosocial support for young people living with HIV, with a focus on adherence, disclosure, dealing with emerging sexuality and discrimination, and preventing high-risk behaviours.

8.2. EVALUATION

The overall evaluation of the workshop was extremely positive, with over 75% of the participants assessing that the meeting objectives and their expectations had been fully met, and nearly 90% considering that the meeting was useful or extremely useful.

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Annex 1

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Annex 2

"I will make my voice be heard..."

Perspectives and experiences of young people living with HIV on care, support, treatment and prevention services

WHO/UNICEF Global Consultation on Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV

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All the young people who are living with HIV – their experiences are a life lesson for everyone working in his area.

The title of this paper "I will make my voice be heard…" uses the words of Jessica, a young woman living with HIV.

Table of contents

Acronyms

ACTS	Access to Care, Treatment and Support (ICW)
AIDS	acquired Immunodeficiency syndrome
ASO	AIDS Service Organization
ART	antiretroviral therapy
ARV	antiretroviral medication
FBO	faith based organization
GCWA	Global Coalition on Women and AIDS
GIPA	Greater Involvement of People Affected
GYCA	Global Youth Coalition on HIV/AIDS
CSO	civil society organization
HBC	home-based care
HCP	health-care provider
HIV	human immunodeficiency virus
IAC	International AIDS Conference
IEC	information, education, communication
IDUs	injecting drug users
ICW	International Community of Women Living with HIV/AIDS
ICT	information and communication technology
NGO	nongovernmental organization
MTCT	mother-to-child transmission
MSM	men who have sex with men
HPV	human papillomavirus
OI	opportunistic infections
OVC	orphans and vulnerable children
PAHO	Pan American Health Organization
PLHIV	people living with HIV
PMTCT	prevention of mother-to-child transmission
STI	sexually transmitted infection
TB	tuberculosis
VCT	voluntary counselling and testing
WHO	World Health Organization
YPLHIV	young people living with HIV
YWCA	Young Women's Christian Association

Executive summary

Voices of young people living with HIV (YPLHIV) are understandable if we listen.[1] The inability to listen to these voices is probably the major obstacle to creating effective programmes for young people.

This paper presents the needs and experiences of 18 youth leaders living with HIV (8 females and 10 males), and the perception of their needs according to 13 NGO health providers and/or youth leaders.

The experiences of young people living with HIV synthesized in this paper showed that health care services were lacking in many ways, especially correct and complete information after testing about HIV status, antiretroviral (ARV) treatment, disclosure strategies and options for healthy living. The attitudes of health care providers were reported as the main barrier explaining why young people have difficulties accessing health services, especially the lack of standards to protect confidentiality of HIV status. The absence of effective referral systems to specialized care centres for young people often meant that young people were not able to access support for their health and psychological needs. Experiences of stigma and discrimination in health care settings are common in the stories of these young people.

The lives of these young people when they were tested for HIV 5–6 years ago were marked by the “good luck” factor of finding a good and well informed health provider, or “the bad luck” of dealing with one who was neither trained nor interested. Many of the experiences collected in this paper reflect unmet needs in relation to social and economic factors affecting vulnerability, in particular lack of means for livelihood and housing.

Although an increasing number of health systems offer some minimum package of ARV treatment, they are limited to certain cocktails. Only a few countries have free access to a range of ARV medications. The problems related to the management of supply and delivery of medications, waiting time for check-up services, opening hours of centres, user fees, distance of services, knowledge and skills of health providers, and stigma and discrimination are currently the main barriers to young people’s access to health services. There are many gaps in the existing services attended by young people.

Only a few “good experiences” in the integration of voluntary counselling and testing (VCT) and care programmes were reported by these young people.

All the young people who have contributed to this report, a number of whom were present at the Malawi consultation, responded to a questionnaire.[2] Almost every young person who responded to the questionnaire demanded greater involvement of young people at all levels of decision-making. It is also important to acknowledge, support and fund the volunteer work they are already doing. Research shows that services designed with the input of young people living with HIV are more effective and have greater coverage.[3]

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[1] Note that in this paper the terms "youth" and "young people" refer to people 10 to 24 years old, as defined by WHO.

[2] The questionnaire was drawn up by the author with the support of the Advisory Committee. For a copy of the questionnaire contact Gracia Violeta Ross at graciavioleta@gmail.com.

[3] Wilson, et al. *Guide on Integrating young people living with HIV/AIDS* in SRH. (draft). See also UNICEF, UNAIDS, WHO, 2002:32-34, Ten Step strategy points 6,7.

These representatives of young people living with HIV suggested five core areas in which they need support from cooperation agencies, youth leaders, NGOs and governments:

1. Involve YPLHIV and strengthen of their role.
2. Provide training and employment for YPLHIV to support the provision of health care.
3. Improve services for YPLHIV.
4. Coordinate efforts that target YPLHIV.
5. Design and implement policies and programmes that address the vulnerability of YPLHIV.

Foreword
One silenced young voice

My name is Violeta Ross. I am from Bolivia and I am 29. I have studied anthropology and completed post graduate studies on gender, sexual and reproductive health. I am also an activist and advocate. I am a woman living with HIV. I was tested HIV-positive at age 23: I survived rape at the age of 20.

When I discovered my HIV positive status, my life was starting, I was finishing my studies in anthropology. However that HIV positive test made me feel that my life was over, just when I had begun the prime years of my life.

I learnt a lot from the first woman in Bolivia to make a public announcement about living with HIV. Though I admired her I did not identify with her, and could not avoid feeling envy.

> *I used to think, "She is 55 and now that she is HIV-positive, she tells me HIV is 'a new life' for her, 'a new beginning'. What can I say about this virus? It just came to steal my life, precisely at the moment that I was starting to think of myself as a complete person."*

I felt that my dreams for the future had been taken away. My desires to have children were described as a "risky situation" in a clinical management manual for women living with HIV. In the midst of loneliness and sadness, I *had to* become an adult. I *had to* learn to live with HIV. All the fun of my adolescence was gone that moment.

After that, I tried to put all these feelings under "the carpet of memories". After all, I was becoming an activist, a leader, and I *had to* be strong, I *had to* perform a role model for other people living with HIV in my country.

When I started collecting experiences of young people living with HIV for this paper, I realized I still feel like them. I realized that my maturity has not taken away my sadness and loneliness, and how much I still need support systems, friends, peers and love. I realized I am still a young woman who desperately needs support.

This perspective underlies this paper. Readers must be aware that the author of this paper is also a young woman living with HIV facing many challenges at the same time, although an activist and educated person.

For me, this paper demonstrates how much we still need to do in order to support those who are most affected by the HIV/AIDS pandemic, and those who are, at the same time, at the forefront of the response. It has also reminded me of the voice of a girl living with HIV, one that I tried to silence as I *had to* become an adult.

As you read this paper, please listen to the voices of positive youth.

1. Why do we need to listen to these voices?

"At least… there must be someone listening." – Amelia, Namibia.

The WHO/UNICEF Global Consultation on *Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV* brought together different stakeholders. The information gathered from NGOs and health providers working with young people clearly indicates that young people have a lot to say about their needs on access to treatment, care, support and prevention. Nevertheless, they are not listened to as they should be.

During the XVI International AIDS Conference in Toronto, the Global Youth Coalition on HIV/AIDS (GYCA) developed a campaign based on suggestions of young people from around the world, in order to sensitize other stakeholders about the priority issues for young people in the context of HIV/AIDS. Under the slogan: "Listen to our youth, they speak the truth",[1] young people from many different backgrounds posted these words and advocacy messages:

LISTEN – ACCESS – SEX – MONEY

It is very interesting to note that these young people selected the need to be listened to as one of the core advocacy messages for other stakeholders working on HIV/AIDS. This particular ability, to listen, is something many of us working on HIV/AIDS need to develop if we want to decrease the impact of the HIV/AIDS epidemic on young people. It is a fact that no-one knows better what young people living with HIV need than YPLHIV themselves.

1.1 SOME EPIDEMIOLOGICAL INFORMATION

This paper wants to challenge the assumption that epidemiology and statistics are the only reasons why we should give more attention to the needs of young people living with HIV. However, in order to provide the context of the HIV/AIDS epidemic among young people, some data are provided here:[2]

- Every day, 5000 young people are infected with HIV.
- Most of them are young women.
- Over half of the 5 million people infected each year are under 25 years old.[3]
- Poverty, unemployment, lack of education, sexual violence and gender inequality increase the vulnerability of young people to HIV infection.

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[1] Nancy Del Col in Children IAC 2006 list-serve, 26 September 2006.

[2] Global Youth AIDS Coalition, Funding Proposal.

[3] Joint United Nations Program on HIV/AIDS (UNAIDS), 2006. For more recent data see UNAIDS/WHO, 07 AIDS epidemic update (http://data.unaids.org/pub/EPISlides/2007/2007_epiupdate_en.pdf pp. 8-14).

- Among young people in Africa, women constitute 77% of new infections.[1]
- Although world leaders made the commitment that by 2005 90% of young people would know how to protect themselves from infection, currently in the hardest hit countries less than 50% of young people can correctly identify modes of HIV transmission.[2]

1.2 YPLHIV ARE DIFFERENT FROM ADULTS AND CHILDREN

During the Global Consultation, a group of 12 youth leaders discussed how young people living with HIV differ from adults and children. These differences mean that the integration of these young people into services designed for children or for adults will not be automatically effective. Young people represent a different group of the population with specific needs for the following reasons.

Young people are different from children because:

- Young people can demand their rights but children cannot.
- Blame is placed on young people because of their "risky behaviour", resulting in stigma and discrimination, whereas children are treated as "innocents".
- Young people are more vulnerable to sexually transmitted infection (STI).
- Young people are dealing with their sexual development which can cause confusion.
- Their lifestyle is generally more risky; and they are more likely to be subjected to sexual violence.
- Outreach is more difficult for young people because they are scattered and it is harder to bring them into care; children are accessible through their parents and caregivers.
- Young people can be lost in the system when in transition from childhood to adolescence, and there is often no follow-up for adolescents when in transition to adult services.

Young people are different from adults because:

- There is a widespread belief that young people are not supposed to be having sex. Since it is taboo, young people hide their sexuality.
- Young people are not involved in policy formation.
- Young people are more likely to lack life skills/professional skills/education/literacy thus it can be more difficult for them to understand important aspects of treatment (e.g. side-effects, treatment regimens, and the importance of adherence).
- Young people have their whole lives ahead of them and have a lot of decisions to make (e.g. whether to have children or get married).
- Young people often depend on their parents (e.g. for money and housing). Thus:
  - they often cannot make independent decisions and must follow their parents' wishes;
  - it may be more difficult for them to disclose their status, access VCT and care services, and adhere to treatment, due to their unsustainable financial situation.
- The system may require parental consent for testing, treatment and services; therefore they may not access services if they do not want their parents to know their status.
- Unemployment and poverty are higher among young people, making it more difficult for them to access services for economic reasons.

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[1] Declaration of Commitment on HIV/AIDS: Five Years Later. Report of the Secretary-General. March 2006, United Nations.

[2] UNAIDS (2006).

- Young people are taken less seriously, and sometimes wait until marriage to disclose their HIV-positive status to avoid being branded as promiscuous.
- Young people can more easily be manipulated/blackmailed by those who know their HIV status into having coerced sex.
- Some treatments affect the ability to have children, and because young people's bodies are still in development some treatments may stunt growth.
- Young people have less disciplined or structured lives, which makes treatment adherence more difficult (because they do not want to wake up at the same time, eat at same time, take pills at same time, etc.).
- Young people face stronger peer pressure and are more dependent on peers for lifestyle guidance, especially if they consider peers as their only family. Adults already have their identity and are more self-reliant/able to adapt.
- Condom use may be more difficult for young people (to prevent infection, re-infection).
- It is more difficult for a younger woman to choose not to have children: there are often social pressures and stigma about being "barren".
- Young people are more likely than adults to be in sero-discordant relationships.
- Young people are more mobile; migration and displacement increases risk of HIV transmission.
- Young people are more often forced into arranged marriages.
- Young people have less stable relationships than do adults.
- It is more acceptable among young people to practice "serial monogamy" and have more partners (although not necessarily concurrent partners) than is the case in older people.
- Young men are more likely to demonstrate "macho" behaviour (including many partners) due to their susceptibility to peer pressure.

On top of dealing with the above disadvantages, young people have to deal with all issues that adults face (gender inequality, homophobia, etc.).

In addition:

- Gender inequality reduces the ability of young women (especially those who married young) to negotiate and access services, including prevention and treatment.
- Young people are less willing to disclose their HIV status because: they do not want to be alone; they want to get married; and they want to avoid violence.
- There are some young people whose parents have forced them into sex work for family income. These young people are vulnerable to being abused and are voiceless.
- There are additional challenges for those who have a disability, have migrated, experienced imprisonment/juvenile detention, or are young men who have sex with men (MSM). Young people who are disabled may feel that they are a burden on their parents and other support systems, and do not want to add the additional burden of HIV. The intersection of poverty and disability results in lack of access to prevention, treatment and other services.
- Young people in prisons are very vulnerable; they do not have access to condoms, VCT, prevention or treatment.

1.3 CONTRIBUTION OF YPLHIV TO THE HIV/AIDS RESPONSE

Despite many challenges, young people living with HIV are contributing to the national responses to HIV in many ways. This paper does not intend to portray the image of these young people as victims and hopeless individuals. We need to understand what they are already doing in order to respond to the HIV pandemic, most often as volunteers and without recognition or recompense for their contribution.

One of the major contributions of young people living with HIV is advocacy in global and international settings, in partnership with civil society organizations (CSOs). This advocacy is primarily for access to treatment for all young people living with HIV. The need to expand the focus of advocacy efforts to include a focus on the need for a more integrated care system was urged by several young people who provided input to this paper. Another priority focus for advocacy messages is the need to have "youth-friendly services", especially in rural areas.

Some young people are serving on a volunteer basis as peer counsellors in public hospitals and clinics, and as peer educators for primary prevention purposes in schools and universities. Others are part of activities implemented through programmes for people living with HIV: the practice of *positive living* by YPLHIV is seen as a major contribution to the AIDS response by creating role models for other young people living with HIV.

However, they recognize that there is a need to involve young people living with HIV at all levels and in a range of issues, for example many of the respondents expressed concern about the issue of orphans and vulnerable children (OVC). Young people are using self-educating strategies in order to become respected advocates; they are looking for empowerment strategies in their older peers. Some young people are on CSO boards of trustees, discussing access to treatment and related issues. Some young people are public speakers; others support the work of the media and involve themselves in research initiatives.

The need to have more voices of young people infected since birth was mentioned as a crucial one, and a current absence in the global forums.

2. How this paper was developed

This document presents to the reader a small collection of the voices of young people living with HIV, from different backgrounds and with different experiences. It is not an exhaustive or representative paper. Nor is it a research report or an update of the statistics for young people.[1] It only aims to provide a platform where the voices of young people living with HIV can be taken seriously.

The areas in which the young people were asked to give input include:

- needs for care, support, treatment and prevention, with particular reference to needs that should/could be met by the health sector;
- young people's experiences when accessing care, support, treatment and prevention from health services; and
- experiences of youth NGOs and other groups currently advocating for or providing care, support, treatment and prevention services for young people living with HIV.

In order to collect inputs from different young people globally, an Advisory Committee with young people living with HIV and people working with them was organized. These committee members provided input to the draft questionnaires that had been prepared, and subsequently reviewed and commented on previous versions of this paper.

This paper was prepared with the input of 18 young people living with HIV[2] (8 females and 10 males) and 13 persons who are currently working with young people living with HIV. The questionnaires were sent out and responded to during the months of September–November 2006.

A public invitation was distributed in different HIV/AIDS electronic list-serves, and individuals who responded expressing their will to participate were sent an initial confirmatory email and then two different questionnaires. The first questionnaire was designed exclusively for young people living with HIV and the second was designed for people working with YPLHIV, and respondents completed the questionnaire that was most relevant to their experiences. The questionnaires were translated into Spanish and also sent to Spanish speaking list-serves.

This was the only methodology possible in the time frame available for this paper.

Almost all the young people who responded are *leaders*, working in youth organizations or AIDS service organizations (ASOs). They are therefore a select group of young people who are informed about the needs of youth in their country or region, have knowledge on youth issues and the political discourse on their needs, work with community-based networks, and can access the internet. The age of those who responded varied from 17 to 29 years.

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[1] For the most up-to-date statistics affecting youth refer to http://data.unaids.org/pub/EPISlides/2007/2007_epiupdate_en.pdf pp. 8-14.

[2] A list of people who contributed questionnaires can be found in Annex 1.

Female respondents had to be found proactively, as they did not respond initially. The fact that less questionnaires were answered by women reflects their relative lack of access to internet. In a regional analysis, fewer questionnaires were received from Africa, the majority being from Latin America or North America.

As no perinatally infected young people responded to the questionnaire, their experiences were explored proactively through interviews with NGOs working with this particular group of YPLHIV.[1] No contributions from health providers working in government or private health facilities were received, only from health providers working in NGOs.

Participants were informed about the purpose of the paper prior to their response to the questionnaires. Participants were given the chance to use their names, change their names or respond anonymously to the questionnaires. Only two young people asked for their names to be changed. This demonstrates that young people living with HIV want to be heard and are ready to reveal their identity in order to do so.

A group of 12 young people living with HIV and/or working for organizations supporting programmes for YPLHIV reviewed the first draft of this paper, in a youth-only session prior to the global consultation on Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV.

During this meeting each young person prepared a vignette/map in response to the question: *What are the needs of YPLHIV in your country?*

These maps were discussed among the young people and presented to the main plenary the next day. Participants at the consultation noted their uniqueness and simplicity and indicated that they were one of the highlights of the meeting. The maps are introduced throughout this paper when they relate to the different needs of YPLHIV.[2] The authors of the maps said the stories on which the maps were based were actual experiences, either of themselves or of people they knew closely. The authors were given the choice of whether or not to put their names on the maps.

In addition to the above, this paper also cites references to literature, such as declarations of youth networks, manuals, discussions in list serves and similar material.

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[1] Body & Soul from the UK specifically developed a piece on perinatally infected youth in order to contribute to this paper.

[2] The maps were photographed and have been included in the paper.

3. Unmet needs of YPLHIV

The young people living with HIV who responded to the questionnaires have mentioned a range of unmet needs. The following is a summary of their needs, and of the inadequacies of the health care system experienced by young people living with HIV.

3.1 DISCLOSURE

The first need of young people after being diagnosed HIV-positive is to have good counselling. An important part of this should be on how to disclose their HIV status, and guidance and support to make choices about disclosure. Generally, the young people were not asked if they wanted to disclose. Most of these young people found their HIV-positive status was disclosed without their permission and consent.

The lack of support and counselling for disclosure usually came together with the experience of not having appropriate pre and post counselling.

Judgmental attitudes from health providers were the first challenge. The lack of standards for post-test counselling sometimes even meant that the results were revealed to a wider audience.

> *"I have been through a critical situation due to lack of confidentiality. In my case, my whole College knew about my test – the health center revealed my status." – Julio, Bolivia.*

Issues of disclosure are particularly complex for young people infected since birth. For perinatally infected children and adolescents the issue is not so much how to tell the family, since everyone around them usually knows. It is how and when to disclose HIV status to the child or adolescent (see section 4.6 which focuses specifically on perinatally infected YPLHIV).

3.2 COUNSELLING ON ART AND ADHERENCE

> *"… when I was about to start ARVs here in Indonesia, the doctor did not explain to me about the drugs or what the side-effects are… when I asked, the doctor explained about something else, so my conclusion is that the doctor do not know how to explain it." – Frika, Indonesia*

Once young people had survived the news of being told that they were HIV positive, some of them had to deal with the issues of getting into medication and being able to adhere to it.

For some of these young people, initiation of antiretroviral therapy (ART) meant a change of lifestyle not always consistent with how they were, or wanted to live their lives. Most respondents remembered the instructions they received as being very difficult to understand.

Elizabeth Franco, a Brazilian researcher, says that the biggest challenges of young people living with HIV are social inclusion and adherence counselling.

> *"We have difficulties with adherence, linked not only to the side-effects but also to the acceptance of the HIV infection, self-esteem and discrimination. There are NGOs and health services working on counselling. But we also look forward to the strengthening of young people in groups (organized in health services and NGOs supported by the country)."*

Franco also mentions that side-effects of ARV treatment, such as lipodistrophy, sometimes undermine the goal of adherence to treatment because of their impact on self esteem and body image of young people.

3.3 PSYCHOSOCIAL, PEER AND FAMILY SUPPORT

Daniel, a young man from England who was perinatally infected with HIV, suggests that HIV/AIDS educational programmes in schools often do not promote peer support for YPLHIV.

> *"The AIDS education programmes out there assume that we are all negative; and that if any of us gets it [HIV] it will only be our fault. So right from the start, it's really hard to tell anyone that you're positive, because then they go oh what have you been up to then, ready to blame us. Why don't they remember that some of us may have had it from birth? And even those of us who did get it through sex or whatever – why do they then just reject us?" – Daniel, United Kingdom.*

> *"I had to wait a week to know the results. Really the time to wait produces a desperate anguish.... At the end when I got the results, it was important to speak with a peer counselor and meet someone who had the virus and looked healthy." – Fernando, Peru*

> *"Well, young people are very scared and confused especially when they have no one to turn to." – Amelia, Namibia*

For most of these young people, it was clear that there was an immediate need for psychosocial support or a network of peers or family support. Some of them were alone in this process, feeling that they were going to die very soon and not knowing what the future held for them. These moments are remembered with a great deal of pain. Most young people appreciated the presence of another person living with HIV in the midst of their anguish.

> *"Immediately after my diagnosis, I faced several needs, ranging from personal acceptance, breaking the silence and the dilemma of family rejection as well*

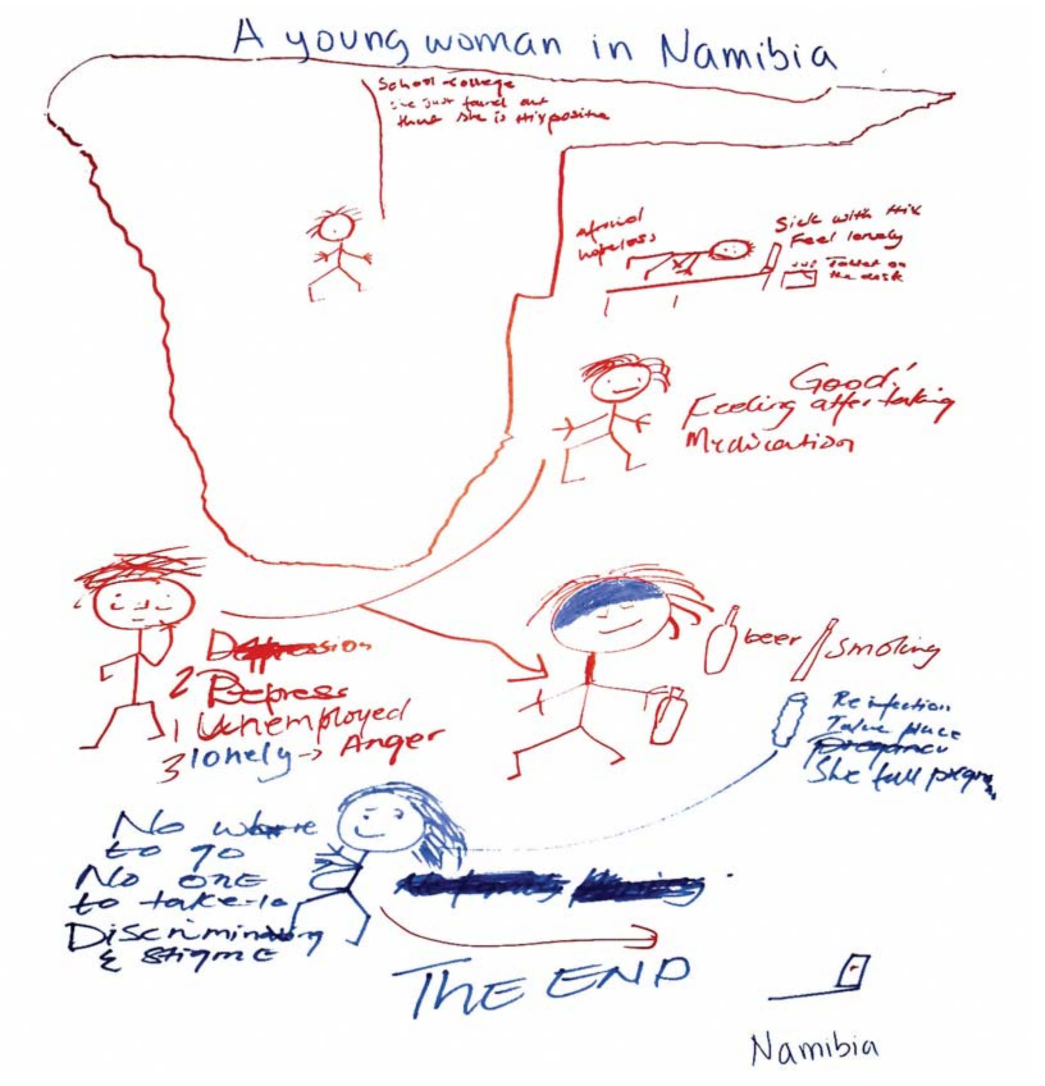
> *as family and community acceptance. Then the need to continue life to its fullest and fulfilment in the era of stigma and discrimination, joblessness and psychosocial trauma.” – Kingsley, Nigeria*

The following map speaks about the importance of ongoing counselling for young people, not only to get them onto the medications they need, but to support them when feelings of anger overtake them and may lead them to do things that are not healthy for them.

This following is the story of a young woman living with HIV in Namibia.

> *“She is still at school when she finds out that she is HIV positive. She falls ill and feels lonely. After getting the medication she feels better, but her anger and loneliness do not go away, so in order to fight this feeling she drinks alcohol, smokes and practices unsafe sex until she gets pregnant.”*

MAP 1: A young woman in Namibia (Author CJ)



3.4 FOOD SECURITY AND NUTRITIONAL SUPPORT

> *"Currently I have a lot of needs. I stopped my ARV for I have no food to eat, and I am very depressed and confused now at this moment. I have a liver problem whereby my urine is orange and I have no appetite. Please help me to see my three year old son go to his first grade and support me in any way that you can – I really want help." – Amelia, Namibia*

When asked if she had any current especial need, Amelia wrote the following:

> *A good home*
>
> *Good food*
>
> *Opportunities to study and upgrade my education*
>
> *A job that will keep me away from funny thinking*
>
> *Healthy living and acceptance*

Currently young people benefit from increasing access to antiretroviral therapy, but for some of them their basic food security needs remain uncovered, let alone nutrition support.

3.5 POVERTY AND ECONOMIC EMPOWERMENT

> *"I would benefit if capital were available so that I could start an income generating project for my family such that they could become self-sustainable. Currently, my family depends on me for financial support, and sometimes it is difficult for me to meet all of our needs." – Makoti, Tanzania*

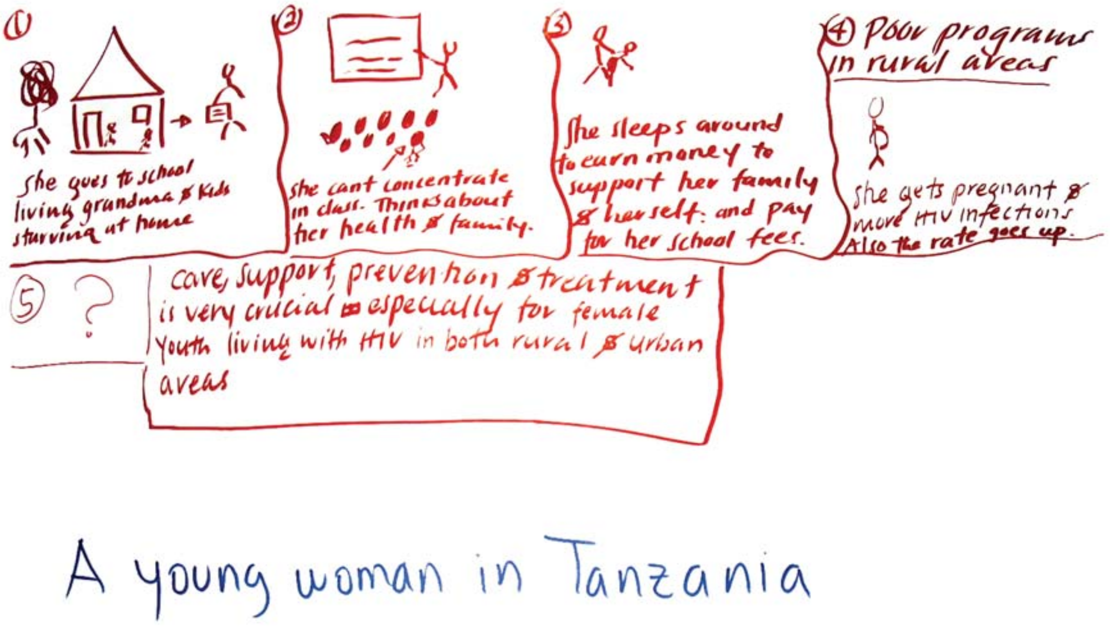
Sometimes the programmes with a strong biomedical perspective do not acknowledge the social and economic issues affecting the health of individuals and communities. The epidemiological approach to the HIV and AIDS epidemic has a strong component of "risk reduction" but often sets aside the issues of vulnerability.

The respondents to the questionnaires stated that young people need job opportunities and means to overcome poverty. In this context one can be cynical about how young people are targeted by many youth programmes for training as peer educators but only on a volunteer basis. Young people need the means to survive and to reduce the conditions of poverty that increase their vulnerability to HIV and other threats. One youth expressed this in the following map telling the story of a young girl in Tanzania:

> *"She goes to school. Leaving 'grandama' and kids starving at home. She can't concentrate in class. Thinks about her health and family. She sleeps around to earn money to support her family and herself and to pay the school fees. [Because the health programmes are] poor in the rural areas, she gets pregnant, there are more HIV infections and the rate goes up. What will happen to*

her? [What is needed:] care and support, prevention and treatment are very crucial, especially for female youth living in the rural areas." – Makoti, Tanzania.

MAP 2: A young girl living with HIV in Tanzania (Author: Makoti Edwin)



The map by Makoti speaks about economic empowerment as a means of avoiding risk and vulnerability for this young woman, her child to be and the entire population. Makoti also put emphasis on the needs for better programmes in the rural areas. These are very important suggestions to be considered in HIV and AIDS programmes, given the fact that today many programmes are concentrated in the urban areas.

3.6 SEXUALITY, REPRODUCTIVE CHOICES, PARENTHOOD AND PREVENTION FOR YPLHIV

"I gave up the desire of having a baby. Prevention does not acknowledge love." – Valeria, Bolivia

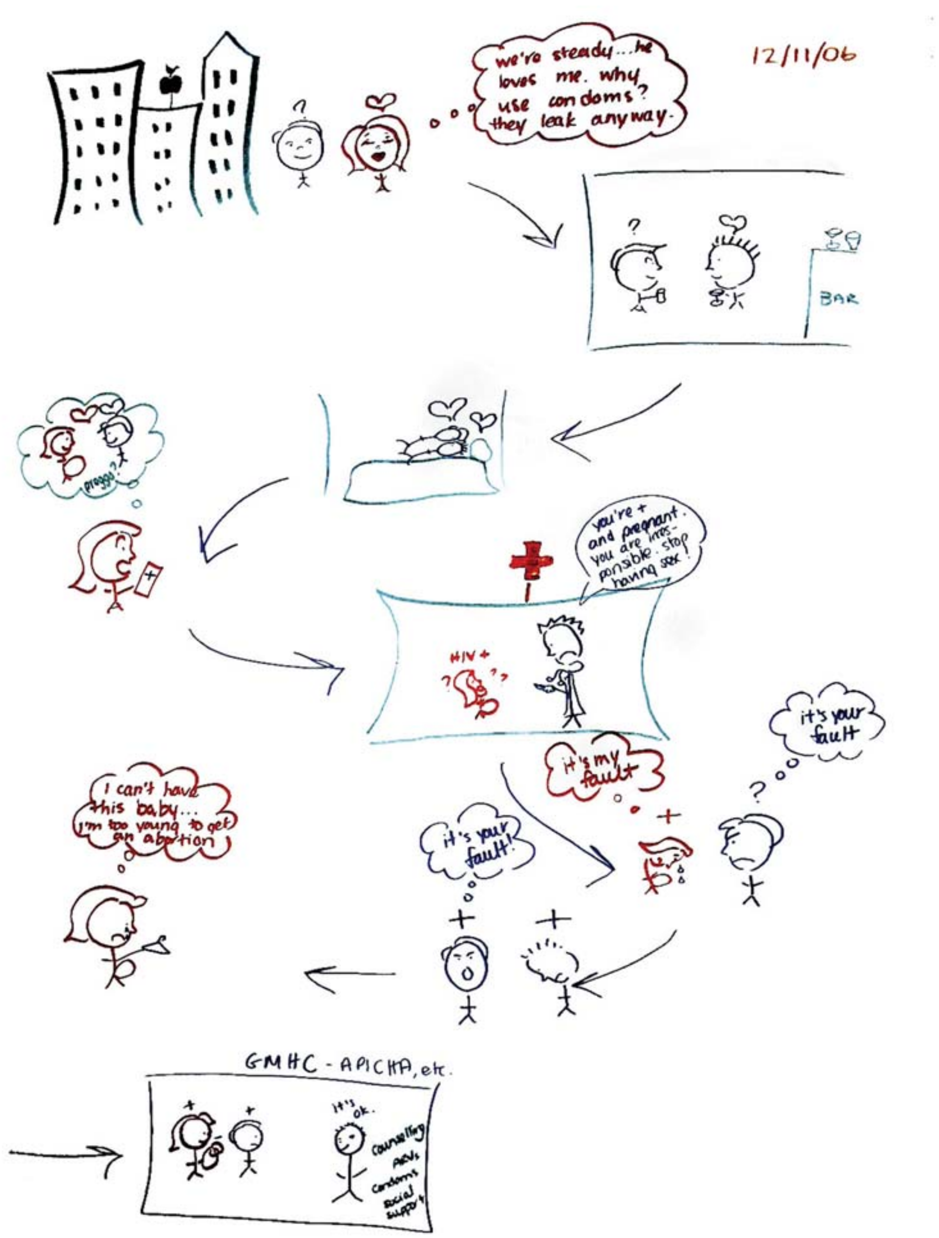
"One of our clients is an HIV-positive young woman (who had been infected at birth). She asked her consultant for advice about having sex with men (before she started doing so) and what was or wasn't safe. The consultant told her that oral sex without a condom was fine and that penetrative sex with a condom was fine and that in neither case was there sufficient risk of

> *transmission for her to feel obliged to tell her partner that she is positive. So, having taken her doctor's advice (which scientifically is correct) she did just those things when she started having sex, without telling her sexual partners. Unfortunately, when she had sex recently with a guy the condom broke – whereupon she immediately told the guy that she is positive and they went together to a health centre. (He went on prophylactic treatment for a month and was eventually tested 3 months later, and tested negative). Luckily the guy was really supportive but their friends and even some of the health staff (they were away from her usual health centre) who weren't HIV specialists … thought the risks were much greater than suggested by her specialist, and so treated her really badly for not having disclosed first … we are, yet again, not just dealing with a health issue, but also dealing with all the myths that surround it and the challenges faced by young people, especially when trying to start out on relationships and dealing with all their fears of rejection." – Youth worker, Britain.*

The quotations above show how much the issues of sexuality and reproductive choices are being neglected in the current counselling services for young people. This is a reason why many young people will resist attending the health services. Many of the respondents experienced this judgemental approach, often denied information when asking about choices for reproduction or sex. Moreover, most of their relationships with health care providers were tarnished with stigma, and, in addition, they risk being shunned by their sexual partner if they disclose their HIV status.

The following map tells the story of a young girl who finds out about her pregnancy and HIV positive status at the same time. When she discovers the news, she is alone. The partner who she thought was in love with her is not there, no-one is with her to provide support. Every place that she turns looking for help she only finds accusations: "It is your fault". Fortunately she finds GMHC (Gay Men Health Crisis) and APICHA (an NGO in New York that targets Asian migrants) and she finds a good counsellor who is able to explain the facts about her pregnancy and her HIV positive status, with the happy ending of having an HIV-negative baby.

MAP 3: A young woman in New York (Author: Joya Banerjee)



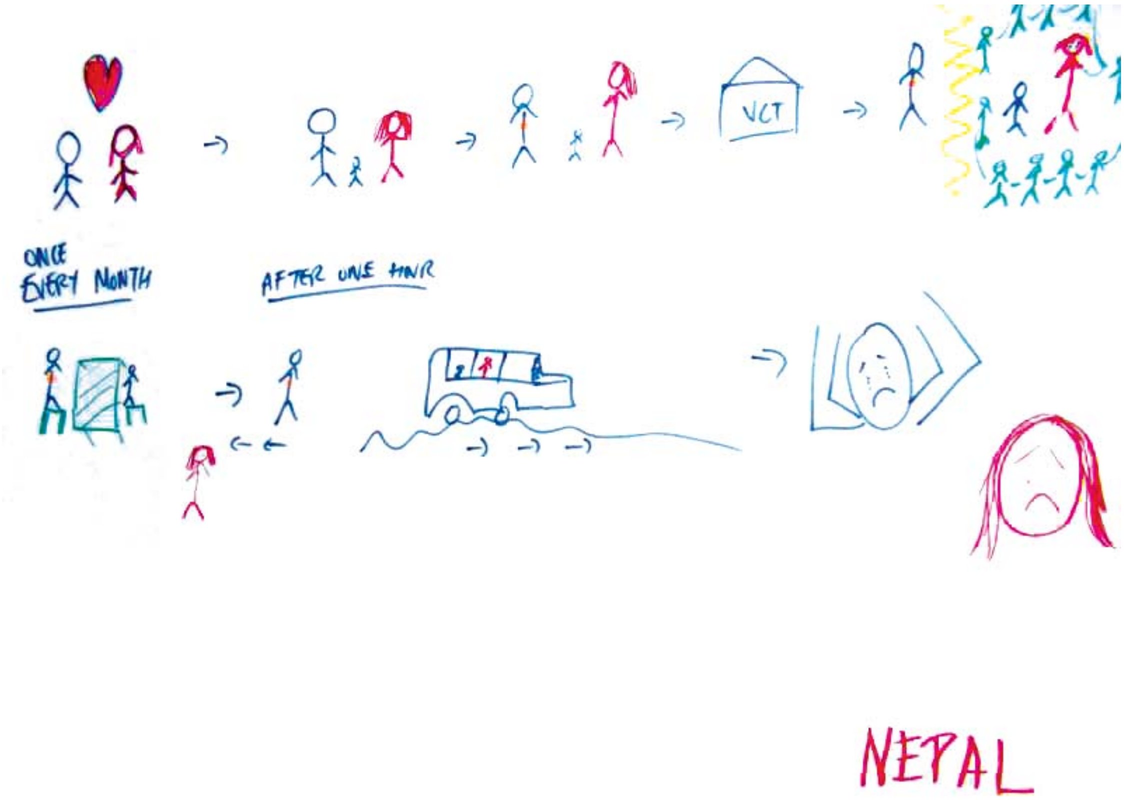
Another issue for young people living with HIV is their potential role as parents, and how this can be undermined if they are HIV-positive.

This map by Tim Shand, tells the story of a couple of parents in Nepal.

> *"A couple falls in love; they decide to go for VCT services; they find out that he is HIV positive but she is not. After learning these results, the family of the woman separates her from her partner and does not let the man see his child. Only once a month is he able to see the child, but there are special*

conditions: the father and the child must be separated by a table; and after 1 hour, the child will be taken away again by the mother's family. This situation is making both parents very sad."

MAP 4: Young parents in Nepal (Author: Tim Shand)



3.7 INTRODUCTION INTO CARE PROGRAMMES

"I was once denied services because I disclosed my HIV status. A nurse did not want to take my blood, nor be in a room with me, because I was HIV positive. I was turned away from the clinic because of my HIV status. I did not walk off freely. I made the other clinic staff aware of why I was denied health services. I confronted the doctor and demanded that the nurse get some training on dealing with patients who are HIV positive, an 'HIV 101', but he rejected my comments, and I had no choice but to seek services from the Legal AIDS clinic in Toronto. In the end it was brought to court and the nurse had her licence suspended and was ordered to access training on 'HIV 101' and ways of transmission." – Marco, Canada

> *"In the hospital where I go to see my doctor, he puts yellow stickers on all my blood sample forms. So where I go to get my blood taken everyone can see (unless I'm careful to hide them) that I have something different. One woman taking my blood put gloves on when she saw the yellow sticker on my papers, then cut the tip of the index finger off her glove off so she could find my vein better! That just makes a mockery of the whole system. Surely, they ought to be treating all of us who they take blood from the same, to protect themselves instead of labelling just some of us as dangerous and others not? Sometimes it makes me feel pretty depressed. But you don't like to say anything in case they take it out on you." – Daniel, United Kingdom.*

When young people start their journey in health care services, the first encounters are often marked by experiences of discrimination. Though youth who were infected perinatally are more used to attending health care services, the transition from child care services to services for adults creates anxiety for them. However, for young people infected perinatally there seems to be less stigma and they are not blamed in the way experienced by young people infected during adolescence. For any of the groups, the transition into the general health services is not easy.

3.8 STRATEGIES TO COPE WITH STIGMA AND DISCRIMINATION

> *"My school teacher keeps on telling us about some AIDS project for young people that she supports in India. But she never thinks that maybe someone in her own class is sitting there feeling miserable … because this is a part of my life too. Everyone just seems to think this is happening to someone else, somewhere else. I get really upset too when other students laugh and joke about 'gays' and 'AIDS'. The prejudice out there about all these things really gets me down. Just because there is treatment here in Britain, it doesn't mean any of the stigma has gone away." – Daniel, United Kingdom.*

It is very important to note that young people living with HIV in all countries, irrespective of their access to ARVs and professional care, feel that there is a lot of stigma and discrimination and little or no support to develop strategies to cope with it.

The experiences of stigma and discrimination give some young people the feeling that they are living a double life. They live one life with their friends and school mates, and another life with peers living with HIV. This poem reflects how much stigma and discrimination can literally tear apart the lives of HIV positive teenagers:

Me, Myself and I (by CN)

Why can't I be happy all the time?

Living a double life was never something I thought of.

Ever since I found out life has always been difficult.

So why can't I be happy all of the time?

I've always been shy when meeting new friends except when I arrived at Teen Spirit.

When I sometimes feel lonely, Teen Spirit has always been there to comfort.

Now I have friends that understand what it feels like to be me.

They understand what I'm going through and still they welcome me, and I like it.

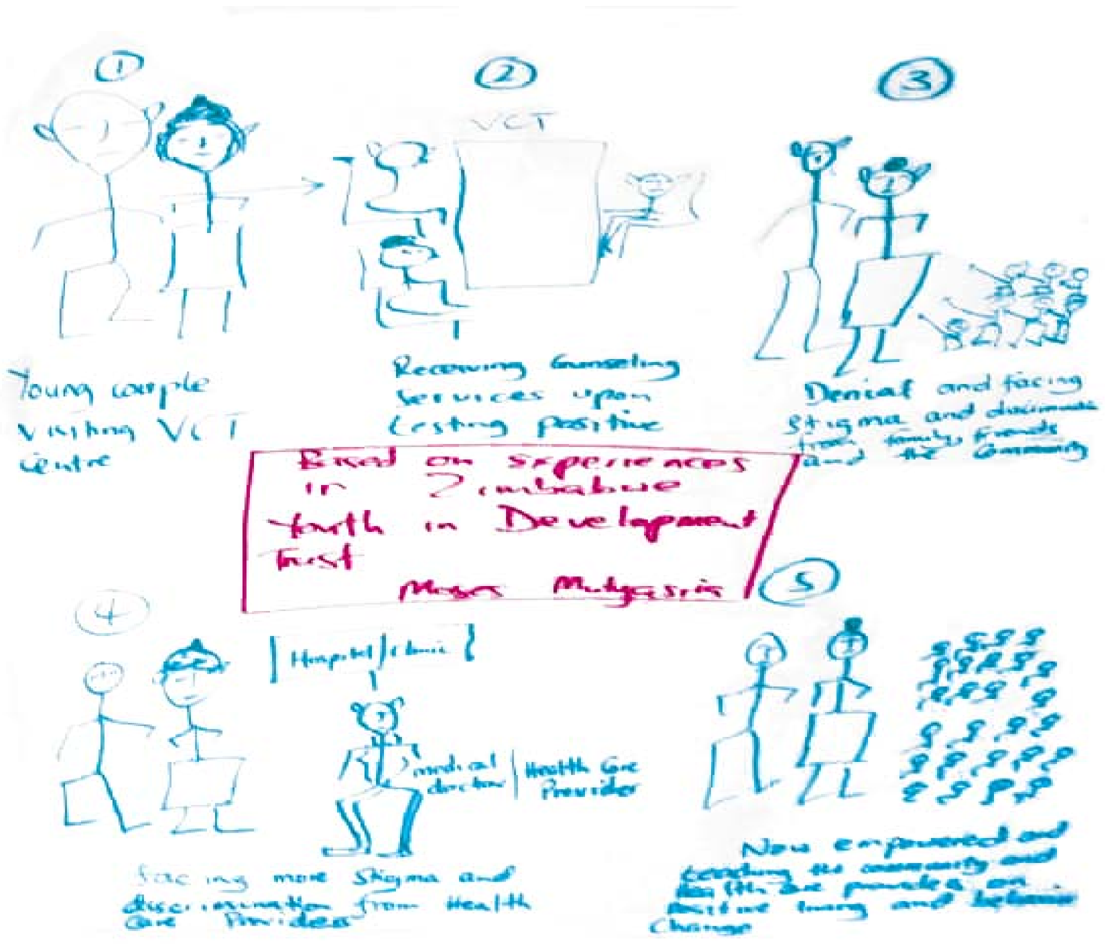
Body&Soul Newsletter, Hope, *2004:4*

The informants mention peer groups or youth groups as being the only effective means of combating and developing skills to challenge stigma and discrimination. One adolescent says:

> *"Like any other teenager, I try to live a normal life. Since I started coming to my second home Teen Spirit, I have made a lot of friends, learn about living positively and get all of the support that I need. I have learnt a lot from Teen Spirit, and every week I just can't wait to meet up with others, knowing that I am not alone, and that I can meet up with other teens living in the same situation as me." – Destiny,* Body &Soul Newsletter, Hope, *2004:7*

The experiences of groups like Youth in Development Trust (YDT) in Zimbabwe are living proof that young people are making efforts to fight stigma and discrimination. This map was made by Moses Mutyasira a youth worker of YDT, and it tells the story of a couple visiting a VCT service. Although confronted with the stigma and discrimination of health providers and the denial of their family and community members, the couple learns about positive living and they are empowered through the knowledge that they receive, to the point that today they are serving the community as agents of change.

MAP 5: A young couple in Zimbabwe (Author Moses Mutyasira)



Another area where young people living with HIV experience discrimination is at the workplace. It can be very difficult for young people to keep a job if their employer discovers their HIV-positive status. Workplaces need to protect young people who disclose their status, otherwise insistence that YPLHIV disclose their status will only isolate them further.

> *"There is treatment and care here but young people hide and are not open to revealing their status. For example, when you try to apply for a job, if they know your status, you will have problems." – Therese, Rwanda.*

3.9 VIOLENCE AND GENDER INEQUALITY

Currently there are many resources highlighting the vulnerability of women and young girls due to gender norms.[1] Two maps at the Blantyre consultation tell about the vulnerability of young women to the epidemic. The first map addresses the issue of vulnerability related to economic means to survive;

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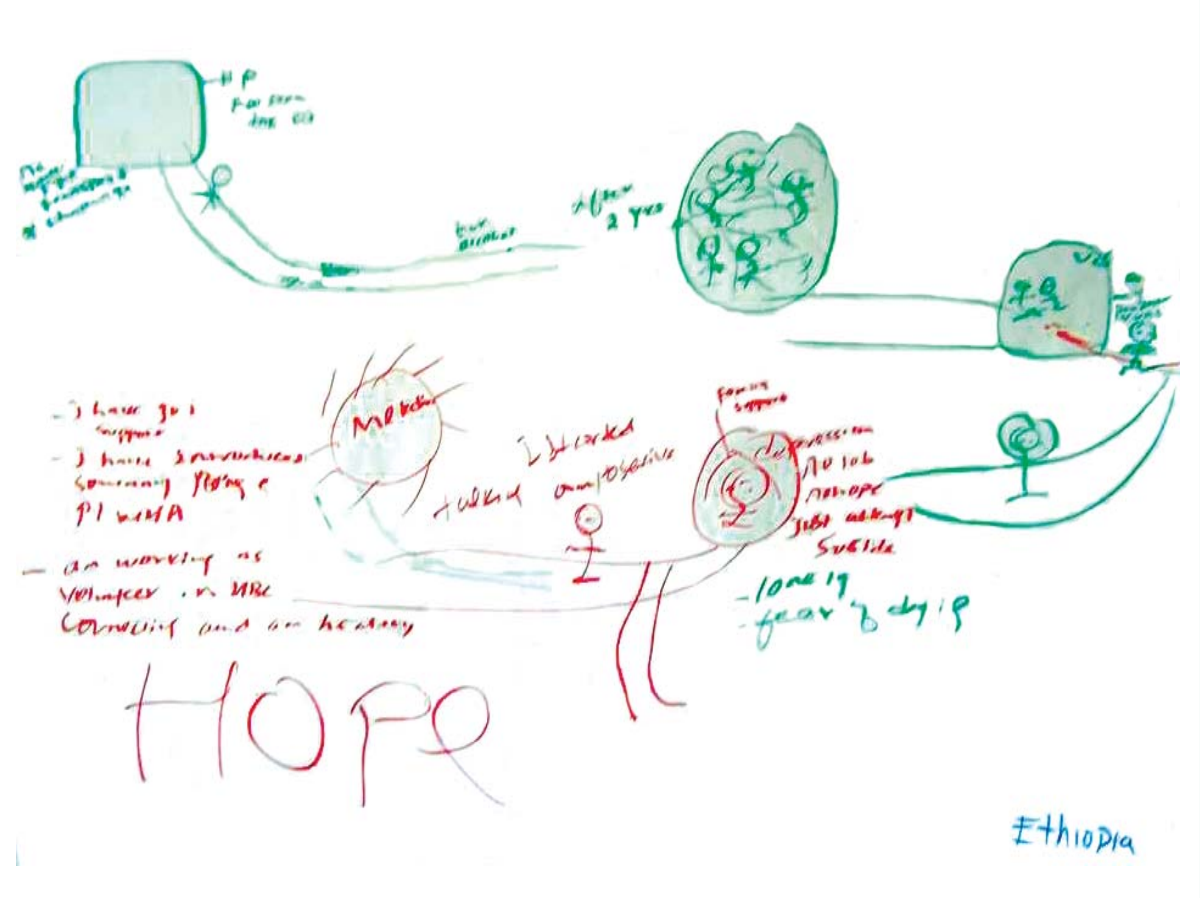
[1] Several stories of women who experienced rape are listed in If I kept it to myself: Young women intervene in a world of AIDS (YWCA & GCWA, 2006).

even if she has a job, she is still vulnerable because of the long distance needed to travel to work. It also tells about the power imbalance of a man with enough resources to give her a ride every day.

The text and the drawings of the map tell this story:

> *"A young nurse was sent to work far from the city. Every day she had to travel long distances to get to her job and then back home. A rich man gave her a ride every day. One day, after two years had passed, he stopped at a bar, drank alcohol with her and then had unprotected sex. Soon after she went to the VCT but he runs away, she is alone. Depressed, without a job, she tried to commit suicide but started talking about her HIV positive status and found the network of PLHA. Today she has support, and works as a volunteer for home-based care (HBC) and there is HOPE."*

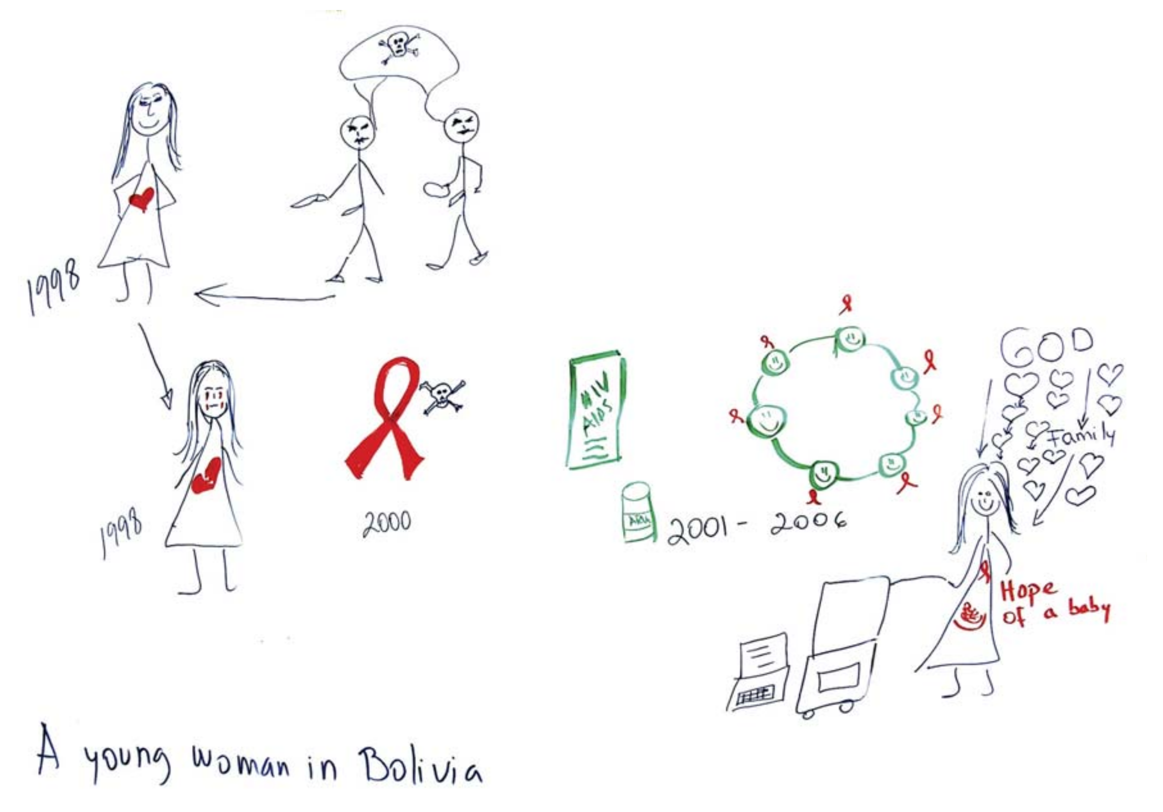
MAP 6: A young woman in Ethiopia (Author: Elizabeth)



The next map tells the story of a young woman in Bolivia:

> *"…who only wanted to fall in love, when two wicked men raped her. As a result, some years later she found out that she was HIV positive. However, with the love of her family and God, there is hope, even hope to be a mother."*

MAP 7: A young woman in Bolivia (Author: Violeta Ross)



Women's vulnerability to the epidemic goes beyond what can be expressed in these two maps. All of the needs of young people living with HIV need to be analysed with a gender lens, in order to assess the different impact on young women and young men.

4. Special needs of YPLHIV

The young people who attended the Blantyre consultation felt that apart from listing the concerns of YPLHIV as a whole, there is need to mention special groups, because of their particular vulnerability. Some of them are listed below.

4.1 YOUNG WOMEN LIVING WITH HIV

The International Community of Women Living with HIV and AIDS (ICW) has produced a brochure about the needs of young women living with HIV.[1] Some of the issues raised in this document[2] include the fact that:

- Young women living with HIV do not have their sexual and reproductive rights protected or fulfilled.
- Young women living with HIV are unable to access ARVs and appropriate screening, prevention and treatment for opportunistic infections.
- Young women living with HIV currently do not have meaningful involvement in AIDS programming.

This Vision Paper not only speaks about the needs of young women but it also provides a framework for action. ICW calls for programmes specifically targeting young women on education and skills-building. ICW also demands: access to care for young women; means to improve their livelihood and education; meaningful involvement in programmes and decision-making; support groups; a human rights approach in HIV/AIDS programmes; research projects oriented towards young women; recognition of inter-generational pressure and power imbalance; sustainable and long-term programmes for schools.[3]

4.2 ORPHANS AND VULNERABLE CHILDREN, AND HOMELESS YOUTH

The issue of orphans and vulnerable children was not on the agenda of the Blantyre consultation, since the consultation focused primarily on young people infected with HIV rather than those merely affected by the virus. Nevertheless young people who attended the consultation raised the issue as one of their concerns. Because the issue of OVC is of such importance, it was decided to further highlight the needs of this group using inputs not directly produced by the informants at the consultation.

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[1] See ICW Vision Paper 1, HIV Positive Young Women (2004).

[2] This document was produced collectively by the Young Women's Dialogue conference in several African countries, with inputs from other regions as well.

[3] See also the collection of personal stories of young women (YMCA & GCWA, 2006), which highlight the vulnerability of young women living with HIV before being infected and after testing positive.

> *"My parents died of AIDS.…The doctor and my grandmother thought I was too young at 14 to know my HIV status. My peers already suspected. I had lost weight, had skin rashes and frequent coughs. It was distressing because I did not know the truth. My grandmother underestimated my ability to understand. After a year of uncertainty she finally told me my status because she knew it was the only way I might get antiretroviral drugs and counselling. I was not surprised, but it was as if my death sentence was confirmed. I was distressed for three months. I saw no reason to live. I could not go out and chat with even my closest friend and if she came to visit me I refused to talk…*
>
> *Our community Medical Assistant counseled me on how to live positively with HIV, and from that I become a transformed person. I decided to live on with HIV. I came out and joined the community. I played with my friends.*[1] *– Kuntana*

In addition to young people being without parents because they have died, young people who are living away from their parents for a range of other reasons are also extremely vulnerable.

> ***Amelia's story***
>
> *"My name is Amelia from Namibia … and I am HIV positive. I have been living with the virus for about 6 years.*
>
> *Well, how I got the virus is through my own mistakes. In 1998 my mother was sentenced to 28 years in prison and at that time I was still in school. I was homeless and the government kicked us out of the home and I had no place to stay. So the only way was to get older men or guys with lot of money to live with. I was depressed all the time for I had to make sure I pleased this guy to have a place to stay, food to eat and taxi money to get to school the following day.…"*

Among the respondents to the questionnaire, one person described her experiences as an orphan but only answered one question on needs. Her story highlights the risk of OVC needing to resort to survival sex thus increasing the probability of becoming infected.

> *"Over time I was mentally struggling. I was becoming more and more paranoid, angry and scared. Things were getting worse; I was offered another bed-sit, but it was in a rough area, tower block estate, nowhere to hide my medicine.*

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[1] See Global Future. A World Vision Journal of Human Development (2006):11.

> *No-one knew about my status, I had no-one to talk and felt so alone and isolated. The pain felt too much. I had turned down the offer of the bed-sit, but two weeks later I got a letter saying as I had turned down the place, the council could no longer help me. No-one told me this at the time. I am still waiting to have somewhere to call home. Life just is not fair, I feel like when you are young, HIV+ and with mental health issues there is hardly anyone that cares about you." – Destiny. Body&Soul Newsletter, The Risk of being Human, Summer 2005, p. 8.*

The fact is that the realities of HIV and homelessness are parallel universes, often invisible to the average health worker. Homeless and HIV-positive young people

> *"… are often hungry, incredulous, exhausted, and dying. They live in a 'parallel universe': a world with a different language, different laws, a different God and a pseudonym. The parallel universe of these youth often is invisible…" – Kaysen cited by Ebner et al. (2003:32)*

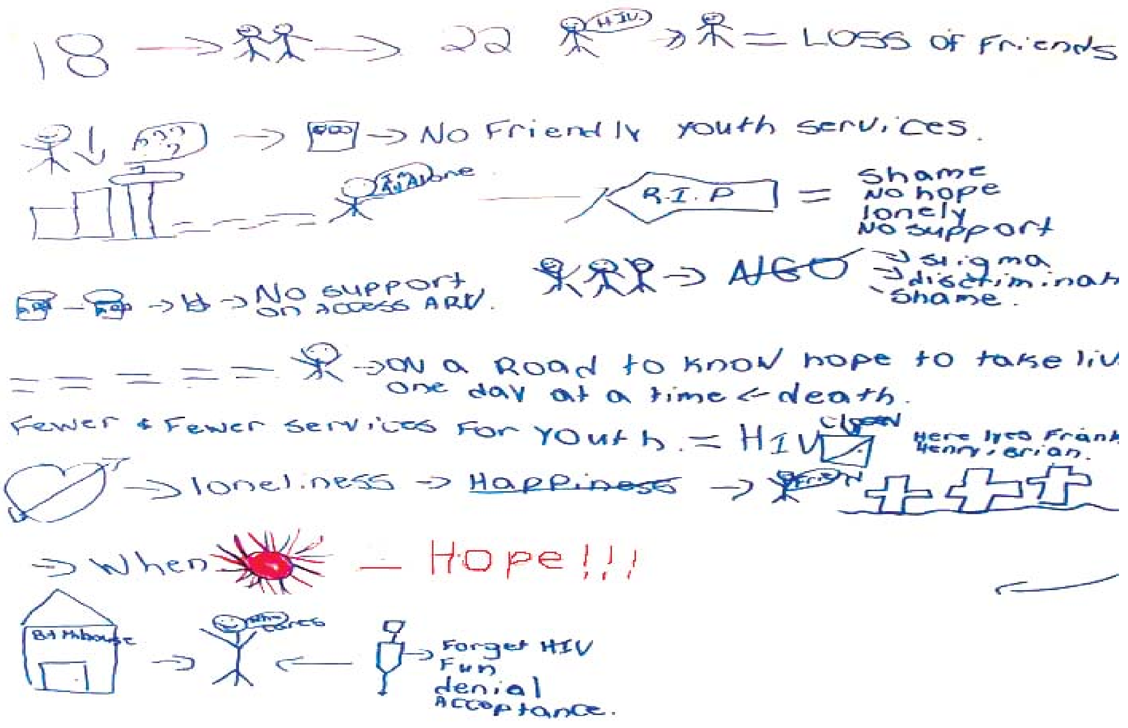
4.3 INJECTING DRUG USE AND CO-INFECTIONS

Though none of the maps deals with the issue of co-infections, during the consultation young people expressed their worries about youth being co-infected with opportunistic infections (OIs) especially with hepatitis C. This is particularly important because of the lack of harm reduction programmes for young people, and even in contexts where harm reduction policies are accepted, the laws and the regulations may not allow minors to access those services.

> *"Before I went into rehabilitation, I was treated in one of the private hospitals in Jakarta. While unconscious and undergoing detoxification in the hospital, the doctor tested me for HIV and Hepatitis C. It came out that I was co-infected. I returned home. It was a horrible experience, as I did not receive any information about HIV. All I felt was fear, uselessness and anger." – Frika, Indonesia (YWCA & GCWA, 2006), p. 20.*

After finding out that they are HIV positive, young people may see drug use as a solution to their problems, when they are invaded with feelings of isolation and loneliness. The next map, by Marco Gomes from Canada, tells the story of young people living with HIV, often alone, seeing friends who die, walking in the streets without really knowing where to go; drug use seems a fast solution and a quick means to have fun and to forget.

MAP 8: YPLHIV in Canada (Author: Marco Gomes)



4.4 GAY AND TRANSGENDER YOUTH

During the consultation there was tremendous concern about gay and transgender youth living with HIV, and their access to heath care services and even testing services. YPLHIV are aware of the stigma and discrimination surrounding these groups and the difficulties of reaching them with services.

> *"…I had the ability to adapt to the new situation of being an HIV positive person … it is better to speak openly about sex and sexuality … being young with HIV somehow questions our entire life giving it a new sense … we need more opportunities, but not only because we are young and HIV positive but also because we are able to think, act, feel with maturity. Key positions and decisions have to be consulted with young people, the same for all the programmes for youth. Also in the gay community we need a new paradigm that includes youth that assume their sexuality as gay men, so that we can have programmes to strengthen healthy practices to avoid HIV because there is still data that the gay community is still the most affected by HIV." – Juan Carlos, Bolivia*

It is important to note that questionnaires received for this paper had a good deal of input from gay youth, but only from North and South America.

4.5 SEX WORKERS

Young people who attended the consultation were also concerned about the needs of youth who are engaged in sex work. None of the respondents or young people in the consultation had direct experience of this, but because of the importance of this group, we reproduce a piece published in *Global Aids Link* on young girls and HIV:

> *"In 2002, visiting a dusty rural village in Sierra Leone, ravaged by the country's 10-year war, I talked to Fatmata, who asked me to use her real name to tell her story to the world so that other girls would not have to endure what she had. Abducted by the Revolutionary United Front (RUF), at age 12, she had become the 'wife' of her captor and was forced to provide sex on demand within the group … she was also a mother to a two-year-old child. She had contracted HIV and her baby was also HIV positive. Then 17 years old, but without an education or livelihood and feeling stigmatized by her community after the war, she asked, 'How will I be able to feed my baby and buy the medicines we need?' … Returning girls also face major stigma from their communities by being harassed and called 'kolonko' or 'prostitute' by the villagers. In the Northern Province, the girls were told they had 'unsteady minds', which in the local language idiom meant spiritual impurities as a result of their sexual violation in the bush. Local people said 'they cannot eat off the same plate' and viewed the girls as unmarriageable and 'damaged goods', largely because they have STIs and HIV/AIDS." – Mike Wessels. Global AIDS Link, January/February 2007, 101: 16, 17.*

4.6 PERINATALLY INFECTED YOUNG PEOPLE

> *"'I am sorry Lynn, but the reason why you are taking all this medication and why you have been so ill is because you are HIV positive'. My whole life was flashed before my eyes, the shock took over my body, I was numb, I felt nothing. The feeling of death clouded my mind, I could not think of anything else." – Lynn, 22.*

Perinatally infected children and adolescents have a number of specific needs, for example at what age to disclose to them that they are infected with HIV, in terms of their psychosocial development, or the fact that in addition to their own illness they have to deal with the illness and imminent or actual death of their parents. None of the respondents to the questionnaire or the young people attending the consultation had direct experience with YPLHIV who had been infected perinatally. Thus information about them was proactively looked at in organizations that specifically work with these young people. The following text has been adapted from a document prepared by Body & Soul staff. Body & Soul is a charity in the United Kingdom that supports children, teenagers and their families who are living with or are closely affected by HIV, providing services for children and teenagers independent of adults.

> *"Since I have come to this group, I have learned about what HIV actually is and how it affects the body – it was good because we were showed pictures that helped explain. I have been able to talk to other children like me and it has really helped." – Joshua, 12.*

The majority of young people who are living with HIV at Body & Soul were infected through mother-to-child transmission. Many of them have endured threatening illness and maintained a strict treatment regimen for a very long time. The physical and psychosocial effects of vertical transmission become more apparent as young people live longer with the illness. In a developed country like the United Kingdom, it is the psychosocial effects that are most evident.

A number of the young people were orphaned at a young age; are themselves carers for sick parents and siblings or younger children in the family; have been living on their own from a young age; have lived in disruptive homes; live in poverty; and have no support networks apart from Body & Soul.

Children who are born with HIV often experience anger, frustration, sadness and loss of confidence. Watching parents fall ill or die, instills fear and anxiety about the future. Stigma and discrimination make it impossible for them to speak openly about their status, so they live in silence and isolation.

Body & Soul holds monthly groups for HIV-positive teenagers and children on treatment updates, adherence to medication, HIV and the body, controlling anger, managing conflict, keeping healthy, coping with bullying and dealing with loss. For many of the young people, it remains the only place that they can talk openly about HIV with others who are the same age. It offers them a safe space in which they can learn about HIV, share their experiences, their fears and ultimately be there for one another.

> *"I thought I was going to die. I had no one to talk to. Mum is HIV positive as well, and we never speak about it. I don't want to upset her. She has her own worries. Before I started coming to the group I used to block everything out. I thought if I did that the HIV would just go away." – Anna 12.*

Issues of disclosure are complex for young people infected since birth, because sometimes they "discover" the news of being HIV positive by accident when adults around them do not want to address the news straightforwardly. Other times, young people discovered they were HIV positive in hospital. The abrupt news of this discovery for many of them marked a turning point and the assumption of another identity in their teen years.

> *"When I tested positive, it came out of the blue because I had been so well all these years and I was just 15 and looking forward to having girlfriends and enjoying life. My parents had suggested that I be tested because my mum is positive and it was just to do with being totally certain that I was OK before I reached 16. My mum and dad told me the result because they had received the results first. My first reaction was to burst into tears and ask – 'does that mean I'll never be able to have children?' Luckily my mum, who has been positive for years – and my siblings and I knew that – was immediately able*

> *to tell me about sperm-washing, so that was reassuring. At least I knew that I would be able to live a healthy life because my mum has been fit and well on drugs for years. So I think I was lucky that they were the ones telling me the news and not some counsellor who would have had much less first-hand knowledge. But it was all still a huge shock and my mum felt dreadful about it because she must have infected me through breastfeeding. So I had to hide my shock from her a bit, so as not to make her more upset". – Daniel, United Kingdom.*

Body & Soul believes that it is essential that disclosure to perinatally infected children should be carried out before the age of 13. The organization has mostly had positive experiences of disclosure to the infected adolescents. Wherever possible a relationship is built up with the parent prior to the event and there is an agreed plan of action to counter negative disclosures. Body & Soul suggests that families lay literature and HIV information around the house to prepare the young person with general knowledge about the illness.

> *"I was told about my dad's HIV status straight after my mum died. It was really hard to take in at that time. I believe parents should tell their children before anything serious happens and before it is too late."*

A workshop with Teen Spirit[1] members showed that young people felt that:

- they had the right to know about their health, and what was happening to their bodies; they wanted honesty;
- trust plays an important role in planning who discloses (parents or a professional);
- the process of disclosure should start long before the naming event;
- the different needs of the individual should determine how the young person should be told.

> *"Disclosure is not a one-off moment, it happens over time and information should be given gradually in relation to their age."*

4.7 YOUNG PEOPLE WITH DISABILITIES

Though none of the respondents to the questionnaire had direct experience with young people with disabilities, a message was received from a network of deaf youth asking if there were other means to collect the information (a field visit or similar), because the youth they were working with were not able to respond to the questionnaire within the budget and time available. However, it highlights the fact that there are many groups not represented in this paper, including the many young people who cannot access and respond to questionnaires sent by list-serves.[2]

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[1] Teen Spirit, the support group for 13-19 year olds, empowers teenagers to make healthy life choices, combat stigma and discrimination and prevent onward transmission of HIV.

[2] People with disabilities are often excluded from prevention care programmes simply because of their disability. See http://www.cbm.org/en/general/downloads/27115/Africa_Campaign_Booklet.pdf, accessed 3 April 2008.

4.8 IMPRISONED YOUTH

Some of the respondents had experience with young people living with HIV in prison.

Again issues of vulnerability are evident among these young people:

> *"Sheryl is a 15-year-old African-American youth from the Bronx … she is one of a growing number of youths with HIV/AIDS living in youth lock-ups. Sheryl comes from a family infected with HIV/AIDS, and is an orphan of the AIDS epidemic. While in the care of her custodian, she turned to delivering street drugs for the neighborhood dealers rather than going to school … Each year the juvenile justice system continues to receive HIV-infected youths who, for various reasons, have wound up in group lock-ups … For infected youths, chronic illness sometimes entails recurrent or chronic stresses, such as hospitalization, poor self-esteem, loss of peer status, decreased competence, impaired bodily functioning, and possible disfigurement. HIV-infected youths are usually exposed to other family members who are dying or have HIV/AIDS, and may react to the impending or actual loss with marked behavioral disturbance, despair, detachment, as well as helplessness, hopelessness and depression". – Carbone (2001:1,2).*

4.9 MIGRANT YOUTH

One of the issues related to migrant youth is human rights and discrimination on the basis of their status.

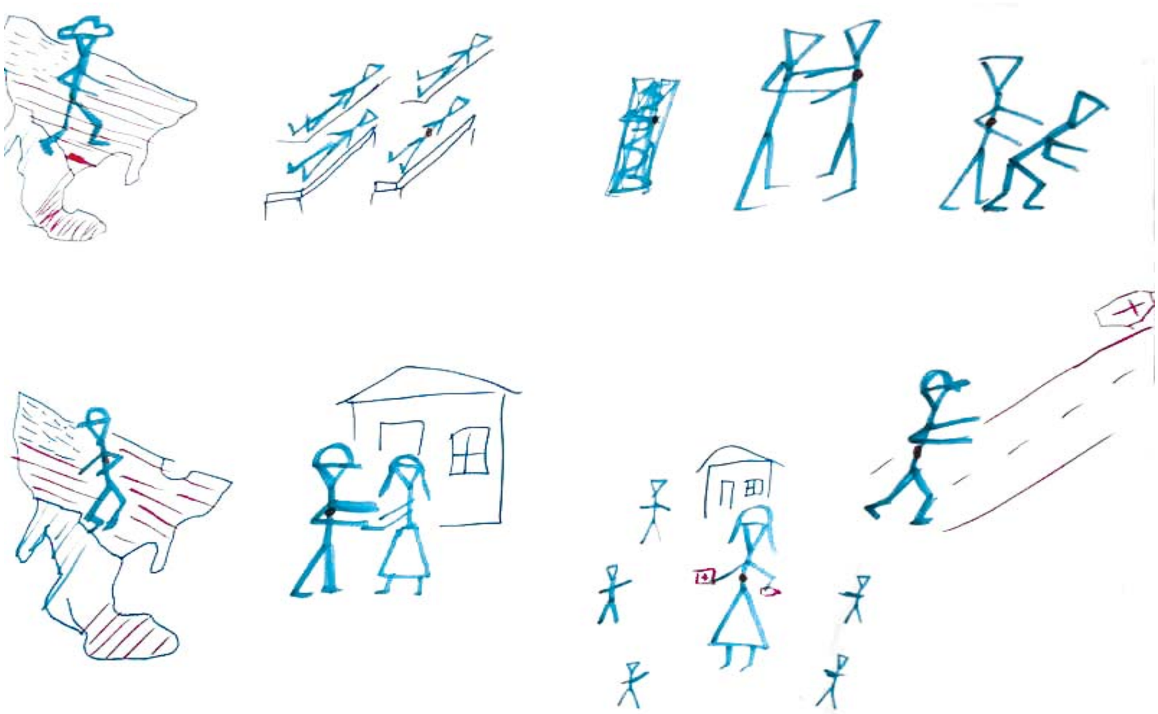
> *"I came to the UK with a dream. Like any one from a poor, small island like Jamaica I came for a better life. Did what I could to make ends meet so I could send a few pounds back home, never breaking the law. I only over-stayed because there was nothing to go back home to, we could hardly ever feed ourselves, so I took a chance in 2002. I got ill really bad. I was in and out of hospital for the better part of three months, and then I found out that I was HIV positive … One day in October I went to report as usual and was told to go the door at the side, that some one wanted to talk to me about my case … I sat for a while until an officer called me into a room and told me that the next day I was going to be deported. I was shocked. I started to panic and felt unwell … I was taken to Gatwick at 2 am to be deported on a 10.30 am flight, when the time came to board the flight I told the escorts that were with me that going back was a death sentence for me, that I was being sent home to die. One of the escorts, a female, turned to me and said 'That is what you*

> *people do, come here to live off the tax payers money, you overstayed and you are a criminal'." – Charles:* Body&Soul Newsletter, The Risk of Being Human*, 2005:9.*

Another issue related to migration is the transmission of HIV between different communities and countries. This map by Ricardo Baruch deals with migration of men from Mexico, who cross the border to work in the USA. While in the working camps, the conditions encourage men to engage in sexual intercourse with other men, including married men.

> *"So after the working season finishes, this man returns home without knowing he is already HIV positive, and he transmits the virus to his wife, still without knowing his status; he goes back to the US to work but falls ill and dies on the road."*

MAP 9: Mexican young migrants (Author: Ricardo Baruch)



5. Young people's proposals for change

5.1 INTEGRATION OF SERVICES

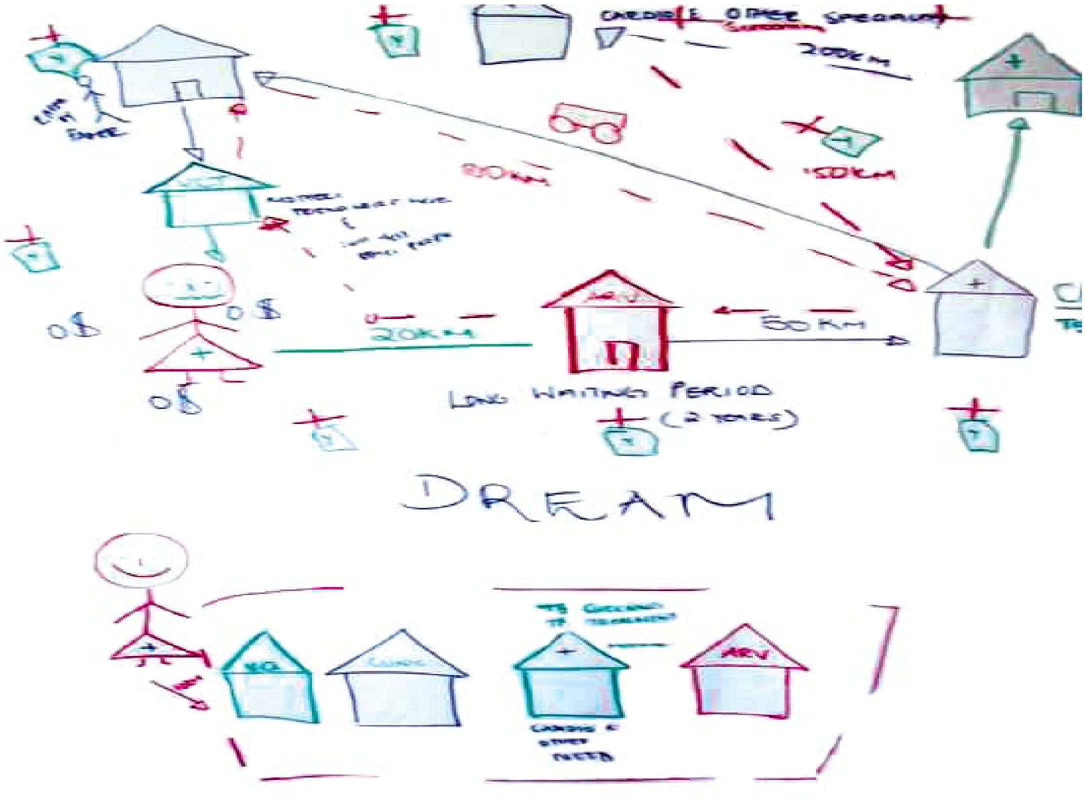
In the questionnaires, the young people were asked to tell about their experiences of integration between the health sector and other sectors. Some good experiences were mentioned by the respondents:

- Civil society advocacy: Work is done on integrating affected and infected young people by such organizations as *Mesa de Adolescencia y Juventud* (Committee for Adolescence and Youth) in Peru.
- Schools: In Peru and Brazil the Health Promotion through Schools generally provides information about HIV prevention, although less about care for YPLHIV.
- Integration of youth, health providers and governments: These groups are represented in discussion committees such as Coordinating Country Mechanism (CCM).
- Informal: Some young people have been involved in informal conversations to sensitize health providers.
- Special forums: Young people with international advocacy experience value forums where YPLHIV are seen as key actors in the AIDS response, e.g. International AIDS Conferences, as well as discussions on e-forums and committees. These practices were possible with the support and facilitation of FBOs, United Nations agencies, PLHIV networks, ASO NGOs and CSOs and some media representatives. Such opportunities should be expanded.

However, the young people pointed out that a greater integration of services is needed. This map by Thokozile Budaza tells the story of a young girl in South Africa who has been raped by her father.

> *"She is willing to seek VCT services but she is afraid a woman working at the VCT centre will tell her mother the news. She also needs to go to the ARV centre which is at least 20 km away, and she has no money. She also needs to visit the TB clinic but this is also far, and she does not have money to pay the transport. Meanwhile she tries to make her way through the services; 2 years have passed and youth are dying on the street (represented by a coffin drawing with a Y in the middle). This young woman has a dream, it is to have the VCT, the ARV, the TB clinic and other services all in one place."*

MAP 10: A young woman in South Africa has a dream of integrated services (Author: Thokozile Budaza)



5.2 SUGGESTED CHANGES FOR HEALTH PROVIDERS

"Stop being mothers or fathers, be health providers." – Yebo, Zambia

Only two young people (from Canada and Uganda) remembered meeting a good health provider. The young participants suggested that the weaknesses in health services for young people living with HIV are due to health provider's lack of knowledge on youth issues, their judgemental attitudes and their lack of commitment.

The major perceived challenge is the attitude of the health providers. Basically the whole health care system needs to become youth friendly. Quality of care and a warm interaction with patients are crucial. The health system needs to implement a work place policy on HIV/AIDS. Stigma must be addressed and the services need to become more effective. More resources are needed in order to expand services and for them to become more youth friendly. In addition, young people with HIV should be trained so that they can help with and support the provision of services.

"Let the people that are positive be health workers for they know what the other is going through." – Amelia, Namibia

The young people participating considered it essential that health providers should:

- be informed and regularly updated on the issues of HIV, including ARVs and working with young people;
- not discriminate on the basis of sexual orientation, and work to protect the rights of YPLHIV;
- involve YPLHIV in providing health care;
- listen to the health needs of YPLHIV; use simple words to explain treatment, avoiding clinical jargon; and have sufficient training to deal with physical and mental needs when YPLHIV experience side-effects from ARVs.

It is essential to highlight the fact that some health care providers might be limiting access to VCT services or care opportunities due to their own personal perspectives on who is at risk of being infected or not. This type of attitude needs urgent change. The following story of a young woman from Zimbabwe shows the impact of this type of prejudice:

> *"Three weeks after I was infected my glands came up all over my body and I got flu-like symptoms – early signs of early HIV infection. I went to my doctor and asked for a test. He said to me 'you are not promiscuous, you are white, you come from a good family and you are really healthy – why do you think you have HIV?' At the age of 18 I did not have the courage or the strength to deal with the situation and it was easier for me to try to forget about it rather than deal with it. Five years later… I was sitting at home reading the paper and read that my ex-boyfriend had died. Consumed with fear, I could no longer live without knowing my status and so I went to another doctor and asked for an HIV test. To my surprise he said exactly what the first doctor had said five years prior to this. I was shocked and angry with him and had to insist on being tested." – Mary, Zimbabwe.*

5.3 SUGGESTED IMPROVEMENTS TO THE HEALTH SYSTEM

Based on past mistakes, when initiatives have not been effective because young people were not adequately involved, the young people identified several areas that need improvement. They felt that in addition to training service providers, involving YPLHIV more effectively, and countering marginalization and stigma, it was important to:

- carry out local needs assessments of YPLHIV;
- produce protocols for identifying YPLHIV as soon as possible after they have become infected;
- identify bottlenecks to prevent late deliveries of ARVs;
- strengthen the capacity of the network of ASOs, especially on issues of side-effects and pharmacovigilance;

It may be useful to revisit the concept of "youth-friendly" in the context of discussions about services for YPLHIV. Table 1 provides an overview of what a youth-friendly[1] service looks like, based on suggestions for VCT services (FHI and YouthNet), with additional suggestions made by positive youth.

TABLE 1: Youth-friendly services definition and additional suggestions by YPLHIV

Youth friendly for VCT	Additional characteristics suggested by YPLHIV
Providers trained to communicate with young people and to understand the issues	*"Involvement of health providers who are themselves living with HIV"* *"Involvement of YPLHIV as peer counselors"*
Providers have a respectful, non-judgemental attitude	*"Respect human rights of YPLHIV"* *"Special training on young MSM"*
Facilities have policies of confidentiality and privacy for young people	*"Develop policies based on the experiences of YPLHIV"*
The facility has convenient hours and location for both in-school youth and those who work all day	*"Specific clinic times for young people living with HIV/AIDS"*
The facility has a comfortable, non-threatening environment	[To make services] *"A place where I can go when I need help. Physically and emotionally"*
The fees are affordable	*"Services should be improved and made free and readily available in most areas (including rural communities)"*
Young people participate in the policies and implementation of the services through advisory boards, as peer educators, and in other roles	*"Let people that are positive contribute to the provision of services because they know what the other is going through"*

Young people participate in the policies and implementation of the services through advisory boards, as peer educators, and in other roles *"Let people that are positive contribute to the provision of services because they know what the other is going through"*

5.4 PERCEIVED CHANGES IN HIV TESTING AND COUNSELLING

The experiences at the time of testing are crucial for any person living with HIV because the experience can mark a trend and tendency to seek or avoid health care. Young people were asked to assess if they had observed any changes since the time they were tested. Fortunately, the respondents perceive positive changes since that time (5-6 years ago), but they remark that a lot still needs to be done.

- The young people agreed almost unanimously that changes were seen in the testing services. There are more testing technologies that reduce the period of waiting for results. Some health providers in some NGOs are more sensitive and better trained, and are not as judgemental as they were 6 years ago. However, rapid tests need to be viewed with caution, because of the negative consequences that may arise if adequate pre and post counselling is not available, including the risk of feeling very alone and even committing suicide.

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[1] FHI/ YouthNet (2005:31). HIV counselling and testing for youth. A manual for providers.

- The protection of confidentiality was considered to have improved but the revelation to other people of an HIV positive result without the young person's permission is still a problem. Stigma has not disappeared but there is less discrimination than 5 years ago.
- In relation to their constituencies, the young people said there is no visible change in the services for young gay men or male sex workers.
- There are more young people willing to go for VCT, and some VCT services offer free HIV tests to young people. Married women in some countries are also freer to obtain a test without their husbands permission.
- There is more general awareness and acceptance about the issue of HIV/AIDS, more radio and TV programmes, more people giving their name when calling in to a talk show, for example.
- Some leaders in the church, and other leaders in rural areas, are working on the issue. Some countries have operated outreach HIV testing programmes, for example VCT for street kids.

5.5 POLICY CHANGES REGARDING RISK AND VULNERABILITY

Interventions that aim to prevent, treat and care for HIV among young people need to respond to issues of *vulnerability* and *risk*, as these relate to individuals and communities.

Many factors increase young people's vulnerability to becoming infected with HIV or their being unable to access appropriate treatment and care. Some of these factors are individual in nature, such as knowledge, age and gender, and some are underlying factors in the social, cultural and economic environments in which the young people live, for example poverty, cultural attitudes or discrimination. Risk is mostly related to individual behaviours. However, decisions about such behaviours do not always benefit from sufficient information about HIV transmission or the availability of services, and health-promoting behaviours may be undermined by negative pressures from peers, parents and other adults, and from society at large.

It is therefore very important when planning policies and interventions that, in addition to influencing individual behaviours through developing knowledge and life skills, efforts are directed to some of the factors that make young people particularly vulnerable, for example dealing with societal violence and sexual coercion, introducing supportive migration and labour policies, and supporting programmes directed to poverty alleviation and decreasing exploitation and discrimination.

6. "Good practices" on services for YPLHIV

The good experiences mentioned by the young people are scarce. Most of these positive developments were implemented in 2006 or later. All of these experiences are from NGOs and CBOs.

Some “good practice” mentioned by young people who responded to the questionnaire are:

- A civil society organization to support YPLHIV in Peru, Programa de Soporte a la Autoayuda de Personas Viviendo con VIH (PROSA), offers counselling and training for young people (started in 2006).
- An NGO in Bolivia, Instituto para el Desarrollo Humano (IDH) provides information and care services for PLHIV.
- Family Options (IPPF initiative) in Kenya, started in 2006, offers a comprehensive care package for YPLHIV.
- An outreach programme for street kids and injecting drug users (IDUs) in Indonesia (PITA), initiated by YPLHIV and IDUs themselves, provides support for families to deal with issues of HIV and drug use, as well as co-infections.
- The AIDS information Center in Uganda offers good counselling services for YPLHIV, supports sharing of stories and experiences of YPLHIV, and drama activities.
- Positive Youth Outreach in Canada offers prevention services, promotes health among IDUs, condom use, sexual and reproductive health; “it is very good, supportive for youth”.
- Teen Spirit in London: offers counselling, workshops, activities for young people. Young people are also supported to lobby parliament for change in policies and practices in relation to youth. A new building offers massage, music-making workshops, a drop-in centre and other activities.[1]
- In Haiti, *La-Maison L’Arc-en-Ciel*, an orphanage and house for children affected by HIV and AIDS, integrates family members in the care of the children, thus not breaking ties with the natural family, as many orphanages have done. It was qualified as a best practice by UNICEF and UNAIDS due to its outreach work mobilizing communities to care for OVC without creating further stigmatization.[2]
- *Saver Viver Jovem* is a magazine and service for YPLHIV in Brazil offered by GIV *Grupo Incentivo Pela Vida* and supported by the National AIDS programme. This magazine is one the best resources produced by YPLHIV themselves.
- Young Positives brings together the experiences of YPLHIV across the world. It supports YPLHIV in concrete ways, e.g. setting up a support group, and advocates for YPLHIV rights and needs, e.g. youth-friendly support and services directed to young people’s realities, meaningful involvement and, in general, addressing youth roles, issues and challenges. As a key principle, Young Positives tries to understand and reduce vulnerability, based on individuals’ dreams and desires, and celebrate diversity.

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[1] See http://www.bodyandsoulcharity.org/ (accessed 3 April 2008).

[2] Information available at http://www.maisonlarcenciel.org/ (accessed 9 March 2008).

7. How can we support young people living with HIV?

"We learnt to be strong, to fight to get what we need." – Jessica, Bolivia

Five areas of change that will support the work of YPLHIV follow.

7.1 INVOLVEMENT OF YPLHIV AND STRENGTHENING OF THEIR ROLE

- Develop guidance to reach out to and support the greater involvement of young people affected by HIV (GIYPA).
- Promote the active participation of YPLHIV, including a focus on equal partnerships with adults and involvement at all levels, not only "as the receiving end".
- Support the involvement of YPLHIV in global and national programmes and activities, including policy, planning and budgeting, monitoring and evaluation, and primary prevention.
- Support and fund programmes for YPLHIV started and run by YPLHIV.
- Recognize the very important role that YPLHIV are playing in the global response; give them credit.
- Promote the creation of an international network of YPLHIV, including the implementation of a networking strategy.
- Document and share the experiences of YPLHIV.

7.2 TRAINING AND EMPLOYMENT OF YPLHIV

- Carry out an assessment in countries to identify the needs for training and technical support for YPLHIV.
- Build the capacity of YPLHIV in health service provision, and see this as an opportunity for "task shifting".
- Provide YPLHIV with training to strengthen their advocacy skills.
- Ensure that YPLHIV are adequately remunerated for the work that they do.

7.3 IMPROVEMENT OF SERVICES FOR YPLHIV

- Ensure that the needs of YPLHIV are given adequate attention as ARV programmes are rolled out in countries.
- Include youth-friendly information and health promotion, in addition to curative services, including increased access to free male and female condoms.
- As services are developed, ensure that there is a focus on the needs of most at-risk groups of YPLHIV, such as young MSM and young injecting drug users.

- Develop training materials for health providers and for young people using youth-friendly language.
- When focusing on YPLHIV, promote attitudes that emphasize the “YP” and not just the “LHIV”, and do not pressure for self disclosure.

7.4 COORDINATION OF EFFORTS THAT TARGET YPLHIV

- Make sure that everybody is contributing to a shared goal, so as not to waste resources.
- Develop programmes based on lessons learned and good practice.
- Consult young people living with HIV for input in programme design.

7.5 ADDRESS THE VULNERABILITY OF YPLHIV

- Advocate for policies and legislation that include a focus on the specific needs of YPLHIV.
- Develop job protection guidelines for YPLHIV.
- Create housing and other support services for YPLHIV.
- Strengthen referral services to make the passage from VCT to care facilities as smooth as possible.
- Support the transitioning from adolescent care to adult care.
- Design special programmes for YPHIV with physical disabilities.

8. Conclusion

The ultimate goal of this paper is to help readers understand the needs of young people living with HIV and the urgent need to work with them.

Issues such as powerlessness, inequality, poverty, social and economic vulnerability, homelessness, being an orphan, gender inequality, gender-based violence and the total absence of necessary support and care systems mentioned in this paper are part of the daily lives of thousands of young people living with HIV.

Therefore the conclusion will not be a list of numbers or cases, but a call for a change of attitude and the generation of a new attitude (at individual, policy and programmatic levels) towards young people living with HIV. Young people need "adults" to take their needs and voices seriously.

There are several NGOs currently working for young people but unless more people listen to the young people and work more closely with them, stories like those presented here will keep filling our documents.

One of the most deeply felt concerns among the respondents of the questionnaire is the feeling of loneliness and abandonment. Young people living with HIV do not perceive someone is there to support them. They declared their need for help: they clearly stated that they feel alone in fighting the impact of HIV on their lives. The response will depend on whether we are listening to these voices or not.

As adults also working in this field, we must help these young people to make *"safe passages to adulthood"*.

Contributions

List of YPLHIV that contributed inputs

Name/ Pseudonym	Country
Julio César Aguilera	Bolivia
Erickson	Peru
Makoti	United Republic of Tanzania
Marco Gomes	Portugal/Canada
Violeta Ross	Bolivia
Henry Luyombya	Uganda
Kingsley Essomeonu	Nigeria
Frika Chia	Indonesia
Vera	Kenya
Yebo	Zambia
Jessica	Bolivia
Fernando Cisneros	Peru
Amelia	Namibia
Valeria	Bolivia
Daniel	Britain
Juan Carlos	Bolivia
Therese	Rwanda
Mary	Zimbabwe

List of NGOs, CBOs working with YPLHIV that contributed inputs

Organization/ NGO/ CBO/ Network	Country
Grupos Amigos con VIH	Mexico
Youth Association for Dissemination of Development (YADDI)	Rwanda
YOCED Youth Groups	Kenya
LVCT Kenya	
GYCA	Mexico
YouthCo AIDS Society	Canada
GYCA	USA
GYCA	Canada
Youth in Development Trust	Zimbabwe
Positive Youth Initiative	Nigeria
Red YPREVE y Foro Red de Salud	Chile
Family Health Options	Kenya
Positive Youth Outreach Project	Canada

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Annex 3

A health provider's perspective on strengthening care, support, treatment and prevention for young people living with HIV/AIDS

WHO/UNICEF Global Consultation on Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV

13-17 November 2006
Blantyre, Malawi

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Acronyms

ARRM	AIDS Risk Reduction Model
AIDS	Acquired immunodeficiency syndrome
CDC	Centers for Disease Control and Prevention (USA)
HAART	highly active anti-retroviral therapy
HIV	human immunodeficiency virus
IMAI	Integrated Management of Adolescent and Adult Illness (WHO)
PEPFAR	The US President's Emergency Plan for AIDS Relief
PIDC	Paediatrics Infectious Diseases Clinic
TB	tuberculosis
UNICEF	United Nations Children's Fund
WHO	World Health Organization

1. Introduction

HIV continues to make a major contribution to the global burden of disease, and the number of adolescents infected with HIV is on the rise. Adolescents are a unique population whose health care needs have to be addressed in a special way. As of 2007, more than 30 million people were living with HIV, 5.4 million of whom were young people 15-24 years of age.[1] Each day another 5000 young people are added to this growing number. It is estimated that there are almost 2.5 million children infected with HIV,[2] many of whom are likely to survive to adolescence, which will further increase the rising numbers of adolescents living with HIV.

The HIV epidemic varies greatly in different regions of the world, but in all regions young people are at the centre, in terms of both new infections and being the greatest potential force for change, provided that they can be reached with effective interventions. In 2002, UNICEF, WHO and UNAIDS published a report entitled *Young People and HIV/AIDS: Opportunity in Crisis* which clearly identified young people as the key population in curbing HIV transmission. Unfortunately, global estimates show that many young people do not have access to the interventions that they need to prevent transmission and decrease their vulnerability to HIV. In addition, only 16% of young people living with HIV know their serostatus *(1)*, which has major implications for further transmission and for their ability to access services for care, support and treatment.

As antiretroviral treatment reaches more and more HIV-infected children in Africa and other regions, affording them the opportunity to live longer and have higher quality lives, this subset of successfully treated children will require specialized transitional care to support their unique needs as they progress through adolescence into adulthood. The exclusively child- and adult-focused HIV care systems currently in place are often ill-prepared to provide this care. In addition to comprehensive clinical services, young people's care should be complemented by peer support groups, in order to help adolescents build a supportive community, discuss their issues and challenges, obtain information and awareness about sexuality and reproductive health, and learn the skills that they need to live their lives to the full. Concerted efforts to establish effective health care delivery systems for these young people need to be undertaken urgently, and such efforts are only likely to be successful if the full extent of the scope and dynamics of the HIV epidemic in young people is appreciated.

This paper will synthesize what we know and what we don't know about the provision of care, support, treatment and prevention for young people living with HIV, in order to provide guidance to health workers and the health sector in general for strengthening the response to this vulnerable group of adolescents and youth.

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[1] The statistics have been updated since the Malawi consultation, and this presents the new updated estimates.

[2] See http://data.unaids.org/pub/EPISlides/2007/2007_epiupdate_en.pdf (accessed 15 February 2008).

2. HIV among adolescents

2.1 CHARACTERISTICS

The natural history of HIV disease in adolescents is highly dependent on the onset of HIV infection. For those individuals who contract HIV during adolescence, through unsafe sex, intravenous drug use and other high-risk behaviours, the disease progresses much like in an adult. For perinatally infected adolescents, the disease course will depend on whether they are 'slow progressors' or 'fast progressors'. Repeated opportunistic infections, and the long-term effects of HIV infection, will often result in stunting and increasing ill health. However, in countries where a paediatric service infrastructure exists and antiretroviral medication has been provided, perinatally infected adolescents are able to thrive (for example, in the United States, there are an estimated 8000 perinatally infected children moving through adolescence *(2)* with some of them entering their third decade).

With the global scaling up of antiretroviral therapy, more and more perinatally infected adolescents in developing countries are also surviving into their second decade. In Uganda, for example, more than 15% of the 5200 HIV positive people in care at the Paediatrics Infectious Diseases Clinic (PIDC) are aged between 10-23 years. In addition, slow progressors may not even manifest their illness until adolescence. For example, a Kenyan cohort of perinatally infected children showed that 10% are considered to be long-term non-progressors who do not develop symptomatic HIV disease until after age 10. As of 2007, 5.4 million young people were living with HIV.[1] Only a small percentage of these young people know they are HIV-positive. More than 13 million children under age 15 have lost one or both parents to AIDS. The overwhelming majority of these AIDS orphans live in Africa. By 2010, their number is projected to reach 25 million.[2]

Adolescents with perinatally acquired HIV have a clinical course that reflects long-term infection. One study reported that among such children surviving to adolescence, approximately one fifth remained asymptomatic or with a CD4 count above 500 cells/mm *(3, 4)*. Many perinatally infected adolescents are confronted not only with their own illness, isolation and stigma, but also with the illness and death of their parents. At the same time, they face all the challenges of adolescence. Furthermore, sometimes they are not told of their diagnosis until after they reach puberty, which makes things even more difficult for them *(5).*

Perinatally infected children who have slow progression of their disease may not be diagnosed until adolescence. For this reason teenagers who are children of HIV-positive parents need HIV testing if their infection status has not been confirmed previously.

Adolescents with HIV pose several challenges for programmers and policy-makers, who must ensure appropriate timing of testing and follow-up, especially for those who are asymptomatic. Moreover, the testing must be accessible and acceptable to the young people, ensuring confidentiality, and yet promoting linkages to care.

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[1] These are the new updated estimates.

[2] UNFPA. Population issues: supporting adolescents & youth: Fast facts (www.unfpa.org/adolescents/facts.htm, accessed 10 Feb 2008).

2.2 SELECTED ISSUES

The 2002 WHO–UNICEF report called for a focused effort to partner with youth in designing and providing young people with effective health information, sound life skills training, and accessible health services. These young people need to be identified through respectful and private counselling and testing services and then linked to comprehensive care that not only addresses their medical needs but teaches them prevention skills as well. Such efforts will be key to breaking the cycle of infection. Adolescents are often unable to fully comprehend the potential gravity of infection and their individual risks, and gender norms influence the way males interact with females and how they perceive sexual relations. For example, in many African settings, a girl's status is recognized when she has a sexual relationship and demonstrates her ability to have a baby, which for young people who are already infected poses a high risk of transmission. A growing number of perinatally infected adolescents are becoming pregnant, and this has serious implications for the spread of HIV among sero-discordant couples in this age group. The PIDC in Mulago has registered 21 pregnancies over the past two years, among girls aged 14–21 years.

In some countries, particularly in sub-Saharan Africa, there is a significant amount of inter-generational sex, and it is becoming increasingly common for adults to engage in sexual relationships with virgins in an effort to 'rid' them of HIV. Propagation of this myth places adolescent girls at high risk.

For adolescents who are already infected, individual and contextual factors place them in a complex situation, where they can become re-infected with other sexually transmitted infections, infect others who are not infected, and have unwanted pregnancies. Furthermore, youth who have been living with perinatal infections are generally no different than their peers in terms of their high-risk behaviours. A recent study of 75 adolescents in the United States who were infected perinatally (ages 12-21), found that the infected adolescents were just as likely as their peers to engage in high risk behaviours and, despite less sexual activity, the female perinatally infected teens were more likely to have had a pregnancy than their non-infected peers *(2)*. In a recently completed study in Kampala, it was shown that the younger adolescents were more likely to abstain from sexual activities when compared with older adolescents *(6)*. This has implications for the organization of services. In order to minimize peer pressure and influence from older adolescents, appointments can be pre-arranged in an effort to have a near-to-homogenous age group for routine and scheduled clinic visits.

2.3 HOW ARE ADOLESCENTS DIFFERENT FROM SMALL CHILDREN AND ADULTS LIVING WITH HIV?

The following attributes define the ways in which adolescents are different from adults and smaller children, and place adolescents living with HIV in a unique category of patients with specific needs.

The hallmarks of adolescent development are:

- sense of immortality
- risk taking the norm
- emerging sense of identity
- emerging sense of autonomy and independence
- challenging authority figures
- experimentation with sex and gradual development of sexual identity

- experimentation with substance use
- peer pressure
- focus on body image
- mobile population.

Irrespective of their situation, young people need access to information and need to be taught skills to negotiate safer sex. Integration of sexual and reproductive health into the care package for young people is very important.

3. Care issues

3.1 LINKAGE TO CARE

There is no doubt that the HIV/AIDS epidemic has put an enormous additional burden on the health systems of most countries, and those countries where the burden is greatest are often the countries with the weakest health systems. The resultant supply gap will remain a major challenge for years to come, and this will be compounded by efforts that are taking place at the same time to scale up comprehensive youth-friendly services for young people.

There is a general consensus to suggest that health providers often lack skills and correct knowledge about basic concepts and the latest research findings. They are rarely given training in human rights and ethics, lack counselling skills and are not comfortable talking about sex.

The nature of the HIV pandemic, and societal responses to people living with HIV, require that health workers have specific preparation and support to enable them to respond to the needs and rights of young people living with HIV, including sexual and reproductive health care. Preparedness of health care workers must go beyond ensuring and reinforcing positive attitudes towards all patients, and there are implications both for health workers and for the development and implementation of policies. There is a need to have specific guidelines and tools for the health sector, nongovernmental organizations and health professionals to promote access by young people living with HIV and the means to reach different target audiences. The care of adolescents and young people with HIV needs to be driven by low cost and innovative approaches that contribute to attracting this group of patients into care, and retaining them once they have made contact with the health services.

High quality of care must be assured, which includes non-judgmental attitudes by service providers regardless of their own beliefs and values; sensitization to issues of stigma, fear and discrimination; and the need to redress the power imbalance that exists between health care providers and patients. People providing sexual and reproductive health and HIV services need to have the skills to respond to HIV-related stigma and discrimination, and to the desire of young people living with HIV to have children, including HIV testing and counselling, pregnancy care, delivery, and infant feeding.

The health problems that young people living with HIV present for care depend very much on the mode of HIV transmission, their general health, nutrition and socioeconomic conditions, and the other infectious diseases prevalent in their community.

Young people who are have been living with HIV since birth in developed countries have generally been identified and engaged in care since early childhood. This is almost always true for HIV-infected youth with haemophilia. On the other hand, youth infected as adolescents through sexual or drug-taking behaviours are generally asymptomatic and unaware that they might be infected. They come to care for problems common to their age group (which may be occurring more frequently or more severely than expected), for example acne vulgaris, recurrent upper respiratory infections, or sexually transmitted infections. Their HIV infection may therefore only be detected through the awareness of astute clinicians. Occasionally, young people infected perinatally may present for the first time as adolescents. Young people living with HIV are prone to contract infectious diseases prevalent in the community, such as tuberculosis.

3.2 ADOLESCENT-CENTRED CARE

A needs assessment survey conducted by the adolescent working group in Kampala found that 92% of the adolescents interviewed preferred to have a separate clinic from the paediatric or adult clinics, and as a result a model adolescent HIV clinic was started. Over the past three years the clinic has recruited over 500 adolescents between 12 and 18 years of age *(7, 8)*. When health providers have an interest or commitment to care for adolescents separately, efforts can be made to facilitate such care.

Adolescents prefer to be seen by the same providers for reasons of trust and confidentiality, both of which are essential for the provision of comprehensive care. They also prefer health care settings that are oriented to their age group and providers who are attuned to their needs *(9)*. The state of the art for adolescent care is a 'one-stop shop', multidisciplinary model that integrates primary care with HIV, mental health, prevention, and case management services *(10)*. Many programmes cannot create adolescent programmes separate from those for children or adults, but it may be possible to create a provider team that understands adolescents, and wants to work with them. Availability of flexible appointments that do not conflict with school or work, attention to payment barriers, and walk-in opportunities for youth (who may not plan ahead) can facilitate adolescents' participation in health services. Although there are some examples of services for adolescents being developed in countries where significant resources are available, there are very few specialized adolescent care centres in resource-poor settings, and adolescents continue to fall between the cracks in paediatric and adult care services. Basic model programmes are being developed in some resource-poor countries, and such approaches can provide the foundations for adolescent-centred services that would cater to the needs of this special section of the population.

Tailor-made service

Irrespective of the mode of transmission, for youth-friendly services, either independent or integrated, we suggest three different models:

- integration/adaptation of the paediatric model
- integration/adaptation of the adult model
- adolescent-centred care.

Key issues for adolescents living with HIV are:

- transitioning from paediatric care
- adherence to treatment (ART)/other aspect of care
- disclosure
    - to the adolescent himself/herself
    - to the adolescent's sexual partner
    - to the adolescent's caregivers and peers/others
- issues of long-term treatment (perinatal/behavioural)
    - body image change such as lipodystrophy and lipoatrophy
    - resistance, and
- age appropriate sexual health programming.

Recommendations for access to health care for adolescents living with HIV

As health care providers there is an ongoing need to lobby for universal access to a basic level of health care for all adolescents. In addition, it is important to empower individual communities to decide how and where to provide confidential, appropriate care for their adolescents living with HIV. Providers must address the concerns of their adolescent patients, which are likely to include issues relating to normal physical and psychosocial development during puberty. The following characteristics are desired for potential youth-friendly clinics, including those that will be specifically for treating adolescents and young people living with HIV.

Availability:

- Age-appropriate services and trained health care providers must be present in all communities.
- Location of services and hours of operation should consider the demography and activities of the target population.

Visibility:

- Health services must be recognizable and convenient, and their use should not require extensive or complex planning by parents or adolescents – there is a need for services on a spontaneous basis.
- Outreach, including education about how to use the services and about the need for preventive care is an important component of adolescent health services.

Quality:

- A basic level of service must be provided to all youth, and adolescents should be satisfied with the care that they receive.
- Health professionals must be able to deal confidently with a broad range of adolescent health concerns and should demonstrate a basic level of competence.

Confidentiality:

- Adolescents should be encouraged to involve their families in health decisions whenever possible; however, when such involvement is not in the best interest of the adolescent or when parental involvement may prevent the adolescent from seeking care, confidentiality must be assured.

Affordability:

- Employment-based proposals for health insurance reform must include cover for adolescents, either as employees or as dependants.
- Public and private insurance programmes must provide adolescents with preventive services designed to promote healthy behaviours and decrease morbidity and mortality.
- Provider reimbursement must reflect the additional time and intensity needed to provide appropriate care to adolescents.

Flexibility:

- Services, providers and delivery sites must consider cultural, ethnic, social and other diversity among adolescents (for example age, sex, marital status).
- Providers must be able to assess an individual adolescent's developmental readiness and to assist youth in making the transition between paediatric and adult care.

Coordination:

- Service providers must mobilize and link with the comprehensive services that are needed to influence the health behaviours of adolescents.
- When services are categorical, mechanisms must exist to help adolescents pay for and obtain necessary care from multiple sites and providers.
- Providers must understand and facilitate entry to specialized services for those adolescents who require them.

3.3 LEGAL ISSUES

Not all providers are aware of minors' right to consent on their own *(10, 11)*. This right exists because adolescents may avoid the care that they need if they first have to obtain their parents' permission *(12)*. In the case of HIV, providers must make a careful assessment of an adolescent's ability to understand HIV-related information and try to involve a supportive adult in his or her care, while recognizing that this disclosure may take months. Additionally, the possibility of neglect and abuse of adolescents necessitates awareness of local child protection services and regulations.

Laws addressing marriage, divorce, child custody and inheritance are often classified as family law. Although such laws also concern adult men, in general it is women and adolescent boys and girls who continue to face the brunt of inequality in family law, something that is compounded in the context of HIV. Issues such as marital rape, gender-based violence, and inheritance laws (especially for widows) all have serious negative consequences for people living with HIV. Many of the underlying reasons why women and adolescents are not able to access sexual and reproductive health care information and services are because of legal and policy constraints, which are grounded in social and cultural norms. These norms have found their way into family and customary law, even when they exist side by side with national laws and policies that contain explicit guarantees of non-discrimination and equality.

3.4 PHYSICAL EXAMINATION

Privacy is an important feature of the adolescent physical examination because adolescents often have a high level of modesty (caused by anxiety about physical changes and a lack of understanding of their anatomy). Pubertal assessment using the Tanner staging system (based on breasts, genitalia, and pubic hair characteristics) is helpful in interpreting normative blood values and choosing appropriate drug doses. When adolescents need to be clinically examined it is important to have a same sex chaperone present.

3.5 SEXUALLY TRANSMITTED DISEASE SCREENING, AND IMMUNIZATIONS

The high prevalence of sexually transmitted infections in this age group warrants integrating sexually transmitted diseases' care and providing routine screening for human papillomavirus, Chlamydia, gonorrhea, syphilis, *Herpes simplex* and hepatitis B, whenever possible. When blood is taken for routine haematological and immunological assessments this should be explained to the adolescents in order to improve compliance to the procedure.

Tuberculosis screening should also be done annually according to guidelines for HIV-positive adults, using purified protein derivative. Appropriate immunizations for HIV-positive adolescents should also be ensured in order to minimize opportunistic infections.

3.6 TREATMENT ADHERENCE

HIV medication regimens require strict adherence to prevent the emergence of resistant HIV. The role of adherence in preventing the development of resistant virus is vital, since adolescents and youth are a vulnerable population for transmission and reinfection. Unfortunately, incomplete adherence and consequent development of resistance remains a problem among HIV-positive youth, with adherence levels going as low as 70-85 % in some cohorts in Uganda *(31,32).* Common reasons for missing doses are side-effects, the inconvenience of taking so many pills, forgetfulness, and the feeling that medications continually reinforce the reality of being HIV-infected. Adolescents often blame the complications of daily life for their inability to follow dosing schedules *(13)*.

BOX 1: Adherence: Using your EARS

Engage

- Establish therapeutic alliance and build trust - the goal is active participation by the adolescent in all aspects of treatment.
- Address immediate needs (health, housing, insurance, family, partners).
- Educate about HIV infection: transmission, disease course and highly active antiretroviral therapy (HAART).

Assess

- Stage the HIV infection.
- Assess mental health and cognitive abilities.
- Assess physical ability to take medicines.
- Assess support systems and disclosure issues: family and friends.
- Assess readiness to begin medications (using stages of change model).

Readiness

- Decide with the adolescent on a regimen that integrates clinical needs with lifestyle; show different pills/combinations.
- Strengthen support systems: family and/or treatment buddy.
- Practice the chosen regimen with surrogate vitamins; distribute medications into a weekly medication planner, program a one-day pill timer (if available) with the adolescent.
- Address adherence barriers discovered in practice run.

Support

- Provide ongoing support with frequent clinic visits and phone or sms contact.
- Acknowledge and address side-effects.
- Develop strategies to ensure tolerability and regularity.
- Facilitate interactions with other youth taking medications.

As with any successful effort to provide adolescents with comprehensive care, the first step to ensuring adherence is establishing a therapeutic alliance between patients and health care staff. The Montefiore Adolescent AIDS Program systematically addresses adherence issues using the acronym EARS (Engage, Assess, Readiness/Regimens, Support). See Box 1.

While twice-daily medication regimens have been common in the past, once-daily schedules are now available for some antiretrovirals, for example the recently introduced ATRIPLA (TDF, FTC, EFV). There are also fixed dosed combination tablets like Triomune (d4T, 3TC, NVP), which can be prescribed twice a day to improve compliance. When considering prescribing options for adolescents, aspects of adherence coupled with efficacy need to be taken into consideration. Adolescent females in the reproductive age group must be cautioned against continuing with potentially teratogenic drugs, such as Efavirenz, when they become pregnant, and programmes should include pregnancy testing in their schedules. The frequency of pregnancy testing for HIV-positive young women and adolescents is not well established; however, clinicians are encouraged to enquire about missing periods at every visit.

4. Psychosocial issues

4.1 FIVE KEY ISSUES

Understanding adolescent development is crucial for viewing the adolescent as a health care client and participant in treatment. In addition to the physical changes of puberty, adolescence consists of a series of cognitive, emotional and psychosocial developmental phases. The Montefiore Adolescent AIDS Program has observed five key issues for HIV-positive adolescents coping with their changing health status *(10).*

Being informed of HIV status

In helping youth cope with their HIV infection, it is necessary to simultaneously instil hope and provide support for the challenging years ahead. Many adolescents are still concrete thinkers. They have difficulty comprehending the concepts of disease latency and asymptomatic infection. Young people without apparent symptoms must learn to strike a balance between unhealthy denial of their condition and morbid preoccupation.

The complexities inherent for all adolescents in the process of integrating sexuality into self-identity are compounded for HIV-positive youth, and there is still a lack of evidence to support the adoption of either individual or group counselling to support youth living with HIV. Individual counselling should be offered to those youth with specific issues that are identified by the health caregivers. Psychosocial support networks offer numerous benefits, including reduction in stigma, coping with the infection, and having hope for the future. Subdivision into age-categorized groups that are moderated by trained adult facilitators enables young people to express their thoughts, and this empowers them to make important life decisions.

Disclosure and partner notification

A major initial hurdle confronting HIV-positive adolescents is deciding when and to whom they should disclose their status. Although the involvement of a supportive adult (preferably a parent) is ideal, many youth fear losing the love of their parent or hurting them. The need to rely on adults because of illness often sharply contrasts with the developmental need to establish independence and identify with one’s peer group. For gay or substance-abusing youth, disclosure to a parent is especially threatening because they may have to reveal their HIV status, sexual preference, or drug use simultaneously, which could lead to rejection, harassment or violence (*14*).

Disclosure becomes a particularly salient issue with advancing disease because it is difficult to conceal medications from the people with whom one lives. Adolescence is one of the most ‘observed’ times of life. Young people often do not have much space to call their own. Privacy is compromised especially for adolescents living in crowded homes or residential programmes. Even in schools, institutional bathrooms provide no seclusion for taking medication.

Disclosure to sexual partners is ethically compelling but complicated. The aim should be to ensure that HIV-positive adolescents inform any sexual partners and always engage in safe sex (i.e. consistent, correct condom use). Young people face several unique issues when disclosing their HIV status, however. First, because adolescents' social world is much smaller and more intense than that of adults, confidentiality is compromised more easily. If one person knows, soon everyone in the group may know. Adolescents greatly fear that their current partner will reject them if they disclose. Disclosure and partner notification should therefore be well planned. Providers can help the adolescent to 'play out the scenario' and offer to participate in the disclosure process as well as make available existing health department partner notification programmes. Providers must be aware that young people in the earlier stages of their sexual lives have had fewer partners than adults and that the notified sex partner may deduce the source of the exposure. The CDC's prevention plan places an increased emphasis on 'prevention with positives', highlighting the importance of this aspect of clinical work.

A new compelling phenomenon among HIV-infected adolescents is that there is a growing desire to have children of their own, in order to 'propagate and pass on their genes' and often they will not disclose to their partners for fear of rejection.

As children with perinatally acquired infection grow into adolescents, it is of paramount importance that health providers begin the process of disclosing their HIV status to them if they have not already been informed of their diagnosis. Disclosure in this sense is essential if the adolescent is to become a partner in the therapeutic alliance. It helps to bring the adolescent to terms with their disease condition, promote adherence, increase risk reduction for reinfection, and decrease treatment failure. Even for adolescents who have acquired HIV through sexual and other means, many times they may not initially be informed of their status, and the disclosure process takes long. In both situations, it is preferable that someone who is emotionally close to the adolescent makes the first move to disclose, and this should be done with the assistance of a qualified counsellor. HIV-positive parents may often be faced with feelings of guilt for infecting the child and may therefore prefer that they are not the ones to disclose the information.

Learning about viral load and CD4-cell marker changes

Given the prognostic significance of these markers, adolescents need to understand how viral load and CD4-cell counts relate to the course of their HIV disease. Viral load and CD4-cell counts vary widely and even when they change significantly for the worse, a satisfying and productive life remains possible. This may be difficult to comprehend for young people who still think in concrete terms.

Becoming symptomatic

The presence of HIV-related symptoms often induces anxiety. Developing concrete symptoms can pierce denial in those who have only superficially understood or accepted their infection. For some young people, the appearance of symptoms increases their determination to fight their disease and makes them willing to consider treatment. When symptoms occur, it is important to explore their meaning, correct any misconceptions, and ensure that adequate services and supports are in place.

Death and dying

Many adolescents have naive notions about death and dying. Like adults, they often avoid the topic. If the end of life becomes a real prospect, providers can assist by exploring the perceptions of dying and helping a young person plan for that time. Discussions should include options for dying in the hospital or at home, as well as planning for funeral or memorial services. For HIV-positive adolescents who are parents, a critical consideration is child custody or permanency planning, including the creation of 'memories' for their children. Resolving relationships with family, close friends and others is another important task. Introducing the topics of living wills and health care proxies are practical ways to initiate such discussion when the adolescent patient has advanced disease but death is not imminent. More so than adults, young HIV-infected individuals may have feelings of frustration, hopelessness and despair, because their future has been curtailed. There are many reported cases of suicide and psychological disorders among HIV-positive youth, and it is estimated that suicide attempts take the lives of more than 90 000 adolescents each year.

4.2 MENTAL ILLNESS AND SUBSTANCE USE

Mental illness and substance abuse are frequently seen co-morbidities for HIV-positive adolescents, because they both increase an adolescent's vulnerability and exposure to the virus, and also because they may be one way in which adolescents respond to the fact that they are HIV positive, or to some of the underlying causes of infection. For example researchers have found a frequent history of sexual abuse among HIV-positive adolescents: a study done in New York City reported that 30% of the males and 35% of the females described childhood sexual abuse (*16*).

Failure to identify and address these issues will hobble a patient's ability to cope with his or her disease. Furthermore, adherence to antiretroviral treatment is likely to be problematic. Several case studies indicate a high prevalence of depression, bipolar disorder and anxiety in HIV-positive adolescents *(15).* In the REACH study, 6% of the girls and 17% of the boys reported using illicit drugs beyond marijuana in that period *(17).* In Uganda, Kinyanda et al. *(33)* have described a high incidence of mental illness among HIV-positive adolescents including major depressive illnesses such as bipolar disorder. Mental health practitioners should ideally be part of the clinical team and should intervene as needed with such therapies as medication and individual and peer group support. In resource-poor countries where the availability of specialized psychiatrists is limited, every effort should be made to identify and refer patients who need specialized care.

5. Age transitions

Medical care continues to improve, and a considerable number of HIV-positive adolescents will be healthy enough to 'graduate' from paediatric to adolescent services, and finally to adult care programmes. Emerging adults require programmes that address their specific needs. They face the concurrent challenges of health care maintenance, medication adherence, and illness within the context of maturing sexuality and establishing an independent life. The concept of transition from paediatric and adolescent to adult health care settings has been described in the literature for other chronic illnesses *(18, 19, 20)*. However, little has been written about introducing HIV-positive adolescents to adult health care systems.

Young people can be reluctant to leave their established providers. In response, many adolescent HIV programmes have expanded their upper age limit from 21 to 24 years. Inevitably, however, transfer to adult care is appropriate. Adolescent HIV programmes frequently start addressing transition months before it takes place. Patients and programme staff need to conduct an intensive effort to formulate the patient's life and treatment goals, and the patients should have opportunities to consult with their future providers before the move.

In Africa and other developing countries there is very little information regarding efforts to transition care, as most programmes have only recently introduced HAART, and the benefits to long-term survival while on HAART are yet to be realized. Even with less than 5 years experience in providing ART to adolescents at the PIDC Clinic in Kampala, there are already more than 90 youth older than 19 who do not want to be transferred to adult care. In this category, a few young women who have become pregnant, and therefore cannot continue follow-up in the regular adolescent clinic, have been transferred to the recently developed 'Family Clinic'. There is a need to separate the young adolescents from the older ones, in order to minimize peer pressure, which may potentially escalate into high risk sexual behaviour.

The other group facing transition is perinatally infected youth. New medications allow them to survive into their teenage years and beyond. As adolescents they face the usual struggle to achieve independence, but for them, rebellion often includes a self-destructive decline in treatment adherence. Also, young HIV-positive teenagers develop sexually, just as other adolescents do. They need specific training on communicating with sex partners and on risk-reduction strategies. Their health care providers need to expand the scope of their services or collaborate with adolescent health specialists. Alternatively, they can work towards transferring their maturing patients to adult HIV programmes that are able to respond to the specific needs of adolescents. Inviting counsellors and clinicians from an adult clinic to participate in their care, and linking up with gynaecologists and other specialists to support their sexual and reproductive health, will go a long way towards creating a transitional and yet acceptable transfer of care.

6. HIV counselling and testing, prevention and outreach

6.1 HIV COUNSELLING AND TESTING

With the increased scaling up of antiretroviral therapy, and the approval of ‘point of care’ rapid HIV testing (where negative and reactive results are known within 20 minutes), people will increasingly learn their test results on the day of testing, heightening the need for immediately available support and referral services. Are we ready for provider-initiated testing and universal offer of testing for adolescents? Health care providers and policy-makers need to give this question careful consideration, bearing in mind the labile nature of adolescents, and the important issues of assent and consent. The scaling up of provider-initiated testing should be coupled with scaling up of youth-centred services which offer holistic care.

The promise of new advances in HIV care, in the context of continued HIV transmission among adolescents, heightens the need for routine HIV testing among young people in more settings than antenatal care. While adolescents engaging in high-risk behaviours often do not believe that they are at risk, it is a myth that adolescents are likely to refuse HIV testing or that they do not want providers to ask personal questions. In fact, many young people prefer clinicians to initiate such discussions *(21, 22)*.

HIV-testing programmes must be accessible to young people to have any chance of success. In addition to primary care sites, venues that should consider offering routine HIV counselling and testing include mobile units, school-based health clinics, drug treatment facilities, and family planning programmes. Services need to be youth-friendly, flexible, free, or low cost, and help overcome barriers such as transportation. Young people need special help with the implications of partner notification. They should be made aware of the availability of anonymous HIV testing, although the patient–provider relationship, which is confidential but not anonymous, establishes a stronger clinical bond. It establishes the momentum for youth-sensitive follow-up, including treatment and counselling.

In addition to providing basic HIV information, assessing risk and obtaining consent during the pre-test counselling visit, the health provider can promote preventive healthy behaviours, assess substance use and discuss family planning issues. The counselling session is an invaluable opportunity to educate teenagers about condom use and safer sex, whether or not testing occurs. Effective HIV counselling for adolescents should be culturally sensitive and tailored to the developmental needs of young patients. Youth considered potentially self-destructive or impulsive require careful assessment before testing. Special measures to preserve confidentiality should be taken in settings such as foster care, residential institutions, or detention facilities *(23)*.

Counselling adolescents poses particular challenges, for example special sensitivity is required to address their level of sexual and emotional development. Even ensuring that adolescents return for a follow-up visit, when they receive test results, calls for special effort, such as telephone/sms reminders, or provision of transport reimbursement.

Ideally, broad-based information and skills-building to form healthy behavioural patterns should occur before adolescents become sexually active. Providers can assess the quality of the programme to which they might wish to refer their adolescent patients by examining several key elements. Beyond providing basic information, such programmes should use interventions that increase self-esteem, individual competencies and psycho-social skills. They should also incorporate a peer-support model, and take advantage of adolescents' inherent abilities to diffuse the information and skills they acquire into the community at-large.

6.2 PREVENTION

For HIV-infected adolescents and youth, the term 'prevention' must be looked at from the broad aspect of preventing early and unwanted pregnancies; preventing sexually transmitted infections; and preventing the development of a resistant viral strain while on treatment. Other basic preventive measures should also be part of the holistic care package, including provision of clean water and insecticide-treated mosquito nets.

A comprehensive prevention strategy requires multiple levels that target young people's various psychosocial and health care needs. These include primary care contacts, education in schools, open discussions in religious and community organizations, and public service announcements.

Comprehensive programmes that teach sexual decision-making (including declining to have sex and negotiating condom use) are urgently needed *(24, 25, 26, 27)*. As long as sex education remains a cultural battleground, however, the lack of adequate programmes will continue to facilitate the transmission of HIV. Abstinence-only messages or delay of sexual behaviours are validating for many young people, but not effective for those who are already sexually active. The range of prevention can be briefly summarized as "ABC": abstain, be faithful, and use condoms. Although each of these steps is important, none can stand alone or is perfect for all adolescents all of the time.

The AIDS Risk Reduction Model (ARRM) *(28)* has been a widely applied approach to primary prevention programmes for high-risk youth, and has also been used for secondary prevention to decrease transmission and reinfection among those who are HIV positive *(29)*. ARRM maintains that to change behaviour, one must first label that behaviour as risky, then make a commitment to change or reduce the behaviour, and, lastly, take action to perform the desired change. Fear, anxiety and social norms influence movement between these stages.

6.3 OUTREACH

Community outreach is critical for programmes focusing on HIV in young people. It is essential for raising awareness regarding HIV care and prevention services among at-risk youth, and their providers. Given that most adolescents living with HIV are unaware of their infection, linkages with agencies serving high-risk youth are crucial for the success of facility based services. These connections are not by themselves sufficient to identify HIV-positive youth and bring them into care, however. Social marketing campaigns that span the continuum from HIV prevention through testing and care can make a major contribution *(30)*. One example, from the United States called 'HIV. Live with it. Get Tested' uses youthful sex slang, such as 'knockin' boots' or 'gettin' busy' to talk about the links between unprotected sex and HIV, and the importance of HIV testing. Local artistes in Africa have sung popular songs about HIV and condom use, and this comes close to the hearts of the youth who are able to resonate with such messages. In addition, using adolescents and youth as peer educators and distributors for the condoms makes it more acceptable for their peers.

7. Conclusions and recommendations

7.1 CONCLUSIONS

HIV infection in adolescents continues to challenge health providers, policy-makers, and advocates for youth, both in developed and developing countries. Unless there is a concerted global effort, there is not likely to be any rapid relief from its complexities. Primary care providers are in a unique position to use effective HIV prevention and care interventions, and up-coming programmes need to move beyond moralism to realism, beyond opinions to scientific evidence. There is an urgent need to develop effective strategies for responding to the needs of young people living with HIV for care, support, treatment and prevention.

Successful programmes have shown a willingness to engage young people and their families in a sensitive dialogue about a range of issues, including sexual development. Young people living with HIV need intensive individual and group interventions to remain healthy and to reduce transmission to others.

To protect their patient population, health care providers will need to commit time and effort to making adolescent services visible, flexible, affordable, confidential, culturally appropriate and universally available.

In this era of HAART, programmes need to look beyond initiating patients on antiretroviral therapy, but they also need to look at issues regarding adherence to long-term therapy while preventing early treatment failure, and secondary transmission to uninfected partners.

A great deal has been learnt during the past few years about responding to the needs of people living with HIV in resource-poor settings. With the introduction of antiretroviral therapy, people living with HIV can hope for prolongation of life and a greatly improved quality of life. However, the physical and psychosocial effects of long-term use of antiretroviral therapy on adolescents are yet to be established.

As adolescents grow into young adults and desire to be sexually active and to have children of their own, simple correct information needs to be given to them, and they need to have opportunities to develop life skills, so that they can deal in a positive way with the many challenges that will surround them. They also need a supportive environment and services that are able to meet their specific needs.

In addition, in the trials that are taking place of new interventions for prevention (e.g. HIV vaccines and microbicides) and treatment, it will be important to ensure that the specific needs of adolescents are given adequate consideration and that they are adequately involved in – and can benefit from – these developments.

7.2 RECOMMENDATIONS

Among recommendations from the WHO/UNICEF Global consultation held in Blantyre Malawi (November 2006), the meeting pinpointed the need to:

- bring adolescent HIV care into both national and global agendas/work plans;
- harmonize scale-up of adolescent-centred care with resources and infrastructure;
- involve youth in programme planning; and
- develop reproducible models of comprehensive adolescent care at multiple levels of the health system.

With regard to training and service provision, it was agreed that there was a need to:

- integrate adolescent issues into current training modules for HIV care and treatment;[1]
- offer attachment services and support full integration of sexual and reproductive health services into HIV services;
- integrate psychosocial and mental health services at point of service, and identify and refer to local psychosocial/mental health services when these cannot be integrated;
- create age and developmentally appropriate peer support groups;
- utilize youth as paid programme staff;
- utilize existing community-based services for young people;
- develop effective linkages/referrals to services, in order to ensure comprehensive care;
- ensure antenatal care, and treatment and follow-up of tuberculosis chemotherapy; and
- provide supervision of care for the adolescent/young person living with HIV.

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[1] See for example the adolescent module that has been developed for WHO's IMAI/ART training that is being rolled out in many resource constrained settings in order to achieve the global goals of universal access.

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