BACKGROUND: THE ROAD TO HLM

The Global Network of People Living with HIV (GNP+) and The World AIDS Campaign (WAC), building on the young people living with HIV (YPLHIV) consultations and the establishment of the GNP+ Y+ Programme in 2010, intend to further refine key advocacy messages for the YPLHIV community to influence the process leading up to the 2011 High Level Meeting on AIDS.

Despite great strides forward in responding to HIV/AIDS since the 2001 UNGASS Declaration, and the 2006 Political Declaration, the particular needs of YPLHIV remain precariously unaddressed. It is the purpose of this briefing document to draw together the existing data and evidence from several global consultations, surveys and reports that assessed the needs of YPLHIV with regard to service provision, rights, safe disclosure, treatment access, leadership. The aim is to distill the key issues and challenges particular to YPLHIV highlighted in recent research to develop a set of advocacy messages.

Young people are increasingly the face of HIV/AIDS – according to the 2007 UNFPA and GYCA Young People and HIV Factsheet approximately 7 million children and young people aged 0-24 years are living with HIV. Despite the extent of the epidemic among young people, there is a pervasive lack of “support to and the meaningful and engaged participation of youth living with HIV (YPLHIV) in the design and implementation of responses to the epidemic. Even though there is a highly active youth movement, YPLHIV are not proportionately represented.”

In the 2006 Political Declaration on HIV/AIDS, countries committed to universal access to HIV prevention, treatment, care and support services to all those in need by 2010. Five years on, it is clear that the road to Universal Access is littered with pitfalls – chief amongst these is a failure to appreciate and respond to the unique needs of diverse groups of young people. Despite the large number of young people infected by HIV and the vulnerability of this population, the needs of YPLHIV have often been overlooked in the development of national HIV/AIDS strategies.

Several recent global consultations on service provision for Young People Living with HIV (YPLHIV) have highlighted the multiple and persistent gaps which make it impossible for some
YPLHIV to live healthy, happy and productive lives. However, the new UNAIDS strategy contains a series of achievable goals for the global response over the next five years and young people are an important focus within this strategy\(^2\). Furthermore, a recent review of school-based and adult led programmes showed clear evidence of reduced early sexual behaviour while programmes in health facilities led to increased utilisation of services when made more youth-friendly. Community-wide programmes and those specifically targeting young people also showed promise.\(^3\) The next step is to scale up these responses and ensure that they are effective for YPLHIV.

The 2011 High Level Meeting on AIDS presents an unparalleled opportunity, in this instance, to “galvanize Member States to commit to a transformative agenda that overcomes remaining barriers to effective HIV services and builds inclusive, country-owned sustainable responses.”\(^4\) An explicit recognition of the specific and complex challenges of YPLHIV and a clear commitment to meaningfully involve young people living with HIV in developing a comprehensive response tailored to specific contexts, key populations and the individual\(^5\) should be at the heart of such a transformative agenda.

Several consultations prior to the High Level Meeting will provide opportunities for young leaders to demand and support efforts to achieve universal access for HIV prevention, treatment, care and support for YPLHIV. It is a decisive time in the response – AIDS funding is flattlining or decreasing in the face of the global financial crisis, competing global development priorities and donor complacency in the light of recent successes. Efforts to focus the policies and interventions on the diverse experiences of young people living with HIV, and to meaningfully engage young people at all levels must be redoubled.\(^6\)

Recent focuses on the needs of young people have emanated in a substantial body of research highlighting the complex and nuanced situations of YPLHIV in various epidemic contexts. We have identified 5 fundamental issues from a literature review, key informant interviews and a survey with 168 YPLHIV respondents from 55 countries.

### 1. UNIVERSAL ACCESS

“Few interventions are targeting this group [YPLHIV] here in Uganda, yet it is a time bomb since many young people were born with the virus and apparently they are growing with it – something that will affect the future generation dangerously.”

*Respondent from Y+ “Have your Say” survey, March 2011*

There are two key groups of YPLHIV; those infected perinatally or in infancy and those who acquire HIV during adolescence through sex or drug use.

One of the critical challenges of achieving universal access for YPLHIV is recognising the specific needs of those who are born with HIV and responding to their changing psychological and physical needs as they grow into adulthood. It is in this group that questions of identity, sexual awakening, and reproductive rights are most critical and programmes need to effect a smooth transition from the all-encompassing care of paediatric services through to youth-friendly services that can respond to the complex psychological and physical needs of adolescence.

“As young people, we fear to transit. We want to stay young every year because we are not sure of the availability of the services after we have left this group. Sometimes, we are forced to lie about our age.”

Respondent from Y+ “Have your Say” survey, March 2011

Equally critical is a health service that responds to the complex challenges of young key affected populations, such as people who use drugs, men who have sex with men, transgender people and sex workers. A respondent on the Y+ “Have Your Say” survey stated:

“We young homosexuals living with HIV, we are left to ourselves, there is no specific programmes for us, we experience stigma and discrimination every day, our Congo association has no headquarters, no funds, we are underground”

Universal Access is not confined with improving health services – every part of the government has a responsibility to make Universal Access a reality for young people. Laws and policies requiring parental consent for testing, treatment and care work against Universal Access for all young people. Given the importance and central role of education (formal and non-formal) in the lives of children, adolescents and young people, the education sector represents another critical entry point for achieving Universal Access as educational institutions have potentially important links to local communities and to social welfare services and resources. Moreover, schools have crucial social functions in terms of promoting equality and inclusion.

2. SAFE DISCLOSURE

“Should we continue disclosing and getting rejected or we keep silent and infect only one person, our loved ones? It is still a very big challenge to us as young people growing with HIV. We need a solution to this.”

Respondent from Y+ “Have your Say” survey

Safe environments for disclosure are the bedrock of an effective and expanded response. Laws that criminalise HIV transmission or require disclosure for school registration disempower young people. The continuing ownership and leadership of the response by HIV-positive people can only be achieved if emerging young leaders feel safe to disclose their HIV status at home and abroad.

However, the issue of safe disclosure is plagued with a number of complex and difficult questions: When and how should young people reveal their HIV-positive status? To whom should they reveal it? What kind of support do they need in making this decision and following through? What resources are available to protect them against discrimination at school, in their neighbourhood, or in their family? Where can they seek support? Who will identify and discuss with them unnecessary restrictions in their plans for the future? Support is also needed for

7. UNESCO, GNP+, IPPF, 2011, Guidance for Education Sector to Address needs of YPLHIV (Draft).
8. UNESCO, GNP+, IPPF, 2011, Guidance for Education Sector to Address needs of YPLHIV (Draft).
parents and care givers in disclosing to their children - a process that requires time, compassion and understanding.

“The issue of if, when, how and to whom to disclose our HIV status is a personal decision that must be respected. We must have all the elements necessary to create a safe and conducive environment for these rights to be realised and all the support we need to build our own skills and manage our own disclosure strategies”

The choice to disclose or not can only be said to be a matter of personal choice when young people feel equally no pressure to disclose and no fear of reprisal. An immediate and comprehensive repeal of all national laws and policies that criminalise HIV transmission and make disclosure compulsory would be a significant first step in promoting safe disclosure. Equally, national governments and non-governmental organizations (NGOs) should recognise that safe disclosure can promote mental well-being; support emerging young leaders and advocates; unlock access to testing, treatment, care and support and normalise the lives of YPLHIV.

3. RIGHTS

The issue of safe disclosure is closely related to the promotion and protection of the rights of YPLHIV. “Anti-discrimination laws and policies need to be in place. UNAIDS, USAID, Global Fund, IMF and all other international bodies need to work with governments to ensure that these laws and policies are passed. Use human rights education, diversity campaigns and legislation to make society aware of the rights of HIV positive people and other invisible people and communities.”

Creating laws and policies that promote and protect the rights of YPLHIV is one part of the equation. Rights literacy delivered at critical entry points into treatment and care such as voluntary counselling and testing is crucial. This means that health professionals and educators require training in rights literacy too. The development of national advice and guidance on rights, especially for key affected populations and YPLHIV who were infected at birth or infancy vertically are important planks of a rights-based response.

A 2006 Brazilian review found that with respect to sexuality, there was very little frank, objective, or practical discussion, and misinformation was even in evidence regarding fundamental aspects of prevention and reproductive life.

“Most of our young interviewees reported planning to have children and families of their own, although none of them had had the opportunity to openly discuss these plans at home or with their health care providers.”

YPLHIV will only be empowered when they understand the rights due to them. These rights include protection from discrimination, compulsory and secondary disclosure and access to quality health and education services and the most basic set of human rights: sexual and reproductive rights. Every person living with HIV is entitled to these rights and they are necessary for the development and well-being of all people and the societies in which they live.

4. MEANINGFUL INVOLVEMENT

A recent review of the involvement of YPLHIV found that the most common way that YPLHIV are involved in the HIV response is as volunteers and staff in PLHIV Networks and youth-focused organizations. With the exception of Eastern Europe and Central Asia, YPLHIV are more likely to volunteer than be employed. Furthermore, very few youth are involved in organizational governance and young women living with HIV are less likely than young men living with HIV to be involved in all positions.\(^\text{13}\)

There are numerous benefits to YPLHIV involvement; at the individual level – chiefly building the foundation for positive living, community and policy levels. YPLHIV involvement contributes enormously to effective responses in their own communities. Despite the explicit desire expressed by YPLHIV to be involved in local, national and regional responses, and the simultaneous wish for NGOs and PLHIV networks to involve YPLHIV, a key barrier to YPLHIV involvement is the availability of financial resources to support youth programmes in general and to facilitate the involvement of YPLHIV in the HIV response.\(^\text{14}\)

Meaningful involvement which is not adequately resourced can be a double-edged sword where YPLHIV fall into organisational roles which have no scope for professional development. The YPLHIV surveyed in the review therefore “encouraged their peers to reflect on why they want to get involved and what they hope to accomplish; to take the initiative to seek out opportunities to be involved and the skills and knowledge they need to be effective; to be patient and persevere; to find mentors; and to avoid burn out”.\(^\text{15}\)

“The most critical challenges that limit the long term participation of young people living with HIV, include burnout and the over engagement of those already involved. Lack of institutional support and funding for initiatives led by young people living with HIV need a greater focus in the global HIV response.”\(^\text{16}\)

Apart from involvement in youth-led initiatives, PLHIV networks and other platforms, there needs to be a general recognition that we should be moving towards normalising a positive HIV-status for young people during the next phase of the HIV response. This means making spaces for YPLHIV to participate generally in their communities and countries with the same rights and opportunities as other citizens.

5. LEADERSHIP

“It is really hard to build capacity in Botswana because everyone is afraid to be affiliated with HIV.

A lot of information is given on mentoring and capacity building and we also network, but the problem is other people have to make decisions for us because we are young and also access to bursaries is difficult”.

*Respondents on Y+ “Have your Say” survey*

Leadership has to be representative of those it purports to lead. Good leadership comes from those who share the experiences of their constituencies. The aids2031 Young Leaders Summit declared that success in the world’s long-term response to AIDS depends on addressing the stigma and discrimination that make young people particularly vulnerable to HIV. This success also depends on supporting and preparing existing young leaders to lead the response.\(^\text{17}\)

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we gear up to meet the challenges of the next 5 years, identifying, developing and retaining a
generation of new young leaders in the positive community to shape and deliver an effective
response is essential. This means ensuring that potential YPLHIV leaders have access to
educational opportunities, training, mentoring, and job opportunities. It is our collective
responsibility to ensure that emerging leaders are nurtured and sustained to lead the response
effectively. Good leadership needs investment to develop and we must accept that sometimes
good leaders have to fail before they develop. Leaders are not managers or advocates. Managers
and advocates are not necessarily leaders, but good leaders need to know how to manage and
advocate effectively. The right training and development opportunities are crucial.

Emerging young leaders need to be protected from burn-out. Have older advocates mentor
young people beginning to get involved in AIDS to ensure transfer of knowledge, and to help
stop burn-out for younger activists. Equally, we need to create spaces in the YPLHIV movement
for the skills and experiences of previous leaders. The phenomenon of “aging out” weakens
the movement.

New leadership can benefit from looking outside the sometimes narrow remit of the HIV
response to other sections of civil society that are innovating within their spheres of influence.
Skills in social media, community engagement and new technologies can inject new momentum
into the response.

CLOSING STATEMENT

Something needs to change. Thirty years into the response, HIV-positive people
are still feared, stigmatised and discriminated against on a daily basis.

YPLHIV endure a triple jeopardy – being young, positive and often, part of a
stigmatised group that sits on the margins of society. The ubiquitous prevention
campaigns stigmatise YPLHIV, particularly those who were born with the infection.
Ill-considered laws and poorly planned policies that breach confidentiality or
require disclosure amplify stigmatising and discriminatory attitudes.

The action we are calling for is only possible if we make a concerted effort to
address stigma in all its forms. Efforts directed towards decreasing HIV-related
stigma and discrimination have been largely successful in addressing obvious
cases of discrimination. We now need to recognise and understand the varied
and subtle ways in which stigma manifests itself. YPLHIV are particularly
vulnerable to internalised stigma at a time when issues of self-esteem and self-
confidence can be challenging.

Young people living with HIV need to be at the centre of the global, regional and
national HIV responses in the next decade. This is the key to realizing their human
rights and achieving universal access targets and normalising a life with HIV.

18. aids 2031 2nd Young Leaders Summit.
www.aids2031.org/pdfs/2009%20young%20leaders%20summit%20meeting%20report.pdf
THE POLITICAL DECLARATION OF 2006 CONTAINS THE FOLLOWING STATEMENTS CONCERNING CHILDREN AND YOUNG PEOPLE:

#8 Express grave concern that half of all new HIV infections occur among children and young people under the age of 25, and that there is a lack of information, skills and knowledge regarding HIV/AIDS among young people.

#9 Remain gravely concerned that 2.3 million children are living with HIV/AIDS today, and recognize that the lack of paediatric drugs in many countries significantly hinders efforts to protect the health of children.

#26 Commit ourselves to addressing the rising rates of HIV infection among young people to ensure an HIV-free future generation through the implementation of comprehensive, evidence-based prevention strategies, responsible sexual behaviour, including the use of condoms, evidence- and skills-based, youth-specific HIV education, mass media interventions and the provision of youth-friendly health services

#32 Commit ourselves also to addressing as a priority the vulnerabilities faced by children affected by and living with HIV; providing support and rehabilitation to these children and their families, women and the elderly, particularly in their role as caregivers; promoting child-oriented HIV/AIDS policies and programmes and increased protection for children orphaned and affected by HIV/AIDS; ensuring access to treatment and intensifying efforts to develop new treatments for children; and building, where needed, and supporting the social security systems that protect them.

#34 Commit ourselves to expanding to the greatest extent possible, supported by international cooperation and partnership, our capacity to deliver comprehensive HIV/AIDS programmes in ways that strengthen existing national health and social systems, including by integrating HIV/AIDS intervention into programmes for primary health care, mother and child health, sexual and reproductive health, tuberculosis, hepatitis C, sexually transmitted infections, nutrition, children affected, orphaned or made vulnerable by HIV/AIDS, as well as formal and informal education.

To find out more about the Y+ Programme visit www.gnpplus.net, or www.worldaidscampaign.org and to join the Y+ list serve send a blank email to ypluslistserv+subscribe@googlegroups.com