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# Abbreviations/Acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AED</td>
<td>Academy for Educational Development</td>
</tr>
<tr>
<td>AFHS</td>
<td>Adolescent-friendly health services</td>
</tr>
<tr>
<td>AFSRH</td>
<td>Adolescent-friendly sexual and reproductive health services</td>
</tr>
<tr>
<td>ALHIV</td>
<td>Adolescent living with HIV</td>
</tr>
<tr>
<td>ANC</td>
<td>Antenatal care/clinic</td>
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<tr>
<td>ARSH</td>
<td>Adolescent reproductive and sexual health</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>ASRH</td>
<td>Adolescent sexual and reproductive health</td>
</tr>
<tr>
<td>CATS</td>
<td>Community adolescent treatment support</td>
</tr>
<tr>
<td>CBAS</td>
<td>Community-based adherence support</td>
</tr>
<tr>
<td>CBO</td>
<td>Community-based organization</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>CHW</td>
<td>Community health workers</td>
</tr>
<tr>
<td>COE</td>
<td>Centre of excellence</td>
</tr>
<tr>
<td>CRC</td>
<td>Convention on the Rights of the Child</td>
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<tr>
<td>DCC</td>
<td>Day care centre</td>
</tr>
<tr>
<td>DTHF</td>
<td>Desmond Tutu HIV/AIDS Foundation</td>
</tr>
<tr>
<td>ECUO</td>
<td>East European and Central Asian Union of People Living with HIV</td>
</tr>
<tr>
<td>EECA</td>
<td>East European and Central Asia</td>
</tr>
<tr>
<td>ESA</td>
<td>East and Southern Africa</td>
</tr>
<tr>
<td>FHI</td>
<td>Family Health International</td>
</tr>
<tr>
<td>HCT</td>
<td>HIV counselling and testing</td>
</tr>
<tr>
<td>HIMS</td>
<td>Health information management system</td>
</tr>
<tr>
<td>HPV</td>
<td>Human papilloma virus</td>
</tr>
<tr>
<td>IDU</td>
<td>Injecting drug use</td>
</tr>
<tr>
<td>IMAI</td>
<td>Integrated Management of Adolescent and Adult Illness</td>
</tr>
<tr>
<td>IMIP</td>
<td>Instituto de Medicina Integral Prof. Fernando Figueira</td>
</tr>
<tr>
<td>IPPF</td>
<td>International Planned Parenthood Federation</td>
</tr>
<tr>
<td>LIT</td>
<td>Leader in training</td>
</tr>
<tr>
<td>MDG</td>
<td>Millennium development goal</td>
</tr>
<tr>
<td>MOH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>MNCAH</td>
<td>Maternal, newborn, child and adolescent health</td>
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<tr>
<td>MSM</td>
<td>Men who have sex with men</td>
</tr>
<tr>
<td>MUg</td>
<td>Mildmay Uganda</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-governmental organization</td>
</tr>
<tr>
<td>OGMAC</td>
<td>Our Generation Mildmay Adolescent Club</td>
</tr>
<tr>
<td>OI</td>
<td>Opportunistic infections</td>
</tr>
<tr>
<td>OVC</td>
<td>Orphans and vulnerable children</td>
</tr>
<tr>
<td>PIDC</td>
<td>Paediatrics Infectious Diseases Clinic</td>
</tr>
<tr>
<td>PITC</td>
<td>Provider initiated testing and counselling</td>
</tr>
<tr>
<td>PLHIV</td>
<td>Person/people living with HIV</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of mother to child transmission</td>
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<tr>
<td>PSC</td>
<td>Positive speakers club</td>
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<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>PSS</td>
<td>Psychosocial support</td>
</tr>
<tr>
<td>PTSS</td>
<td>Post-test support services</td>
</tr>
<tr>
<td>QA</td>
<td>Quality assurance</td>
</tr>
<tr>
<td>SADC</td>
<td>Southern Africa Development Co-operation</td>
</tr>
<tr>
<td>SRH</td>
<td>Sexual and reproductive health</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually transmitted infection</td>
</tr>
<tr>
<td>SYC</td>
<td>Safe youth Club</td>
</tr>
<tr>
<td>TAG</td>
<td>Technical Advisory Group</td>
</tr>
<tr>
<td>TAP</td>
<td>Treatment Action Project</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary counselling and testing</td>
</tr>
<tr>
<td>WKU</td>
<td>WhizzKids United</td>
</tr>
<tr>
<td>Y+</td>
<td>Young people living with HIV programme (of GNP+)</td>
</tr>
<tr>
<td>YFS</td>
<td>Youth-friendly sexual and reproductive health services</td>
</tr>
<tr>
<td>YPLHIV</td>
<td>Young people living with HIV</td>
</tr>
</tbody>
</table>
Background

By the end of 2011, there were an estimated 2.2 million adolescents living with HIV—85% of them in sub-Saharan Africa and 60% of them girls. A minority of these adolescents are aware of their HIV status or enrolled in a treatment and care programme. There is strong consensus on the need to improve the quality of health services for adolescents living with HIV (ALHIV), to scale them up and to increase access to and use of those services. This was explicitly mentioned in the resolution from the 2011 UN General Assembly High Level Meeting on HIV (Political Declaration on HIV/AIDS - intensifying our efforts to eliminate HIV):

68. Commit to develop and implement strategies to improve infant HIV diagnosis, including through access to diagnostics at point of care, significantly increase and improve access to treatment for children and adolescents living with HIV, including access to prophylaxis and treatments for opportunistic infections, as well as increased support to children and adolescents through increased financial, social and moral support for their parents, families and legal guardians, and promote a smooth transition from paediatric to young adult treatment and related support and services;

In addition, there is consensus about:

- What needs to be done, from different perspectives, ranging from service providers to ALHIV (see for example the meeting report from the 2006 Malawi meeting, the 2010 Kampala Consensus Statement, the work carried out by AED and FHI, and recent publications by IPPF and Y+);
- The need for a framework for thinking about the channels that can be used by health facilities, families/care-givers and communities to provide health services to adolescents.

<table>
<thead>
<tr>
<th>Services</th>
<th>To be delivered by:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis/ HCT (Pre-/post-test information and counseling)</td>
<td>Health Facility, Family/Carers, Community</td>
</tr>
<tr>
<td>Disclosure/ Counselling/ Support</td>
<td></td>
</tr>
<tr>
<td>Initiation/ Adherence/ Retention for ART and OI Treatment (Including TB)</td>
<td></td>
</tr>
<tr>
<td>Primary Care*: ASRH, pregnancy care, mental health, nutrition</td>
<td></td>
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<tr>
<td>Prevention of high-risk behaviours, including harm reduction</td>
<td></td>
</tr>
</tbody>
</table>

- The need to focus on some key cross-cutting issues, such as: integration, for example with PMTCT, ASRH and AFHS, where these exist; referral between the different service provision settings and with other sectors; transitioning from paediatric to adult care; and strengthening linkages to other sectors and organizations, such as the education sector/schools, and HIV prevention programmes for young people (something that will be increasingly important as the treatment-as-prevention agenda gathers steam), including prevention for key affected populations.
- The need to improve the estimates for ALHIVs in terms of mode of transmission. The disproportionate number of HIV infections among adolescent girls indicates that sexual transmission plays a significant role in the adolescent HIV epidemic and underscores the need for improved contact and quality of prevention and testing/counselling services for adolescents, as
well as the need for improved integration and referral between services that provide a continuum of prevention, diagnosis, treatment and care.

- The need to ensure that the development of services for ALHIV supports national health systems to achieve national commitments to universal access to ART, and to be able to respond more effectively to meeting the specific needs of:
  - Adolescents in general;
  - Adolescents living with chronic illness.

Numerous global and national advocacy and programme support materials are under development that will make important contributions to accelerated action in countries for the diagnosis, treatment, care and prevention of HIV among adolescents living with HIV. However, the following operational questions remain largely unanswered:

1. How to best deliver interventions and services for adolescents living with HIV?
2. How to integrate lessons from best practice into existing systems given limited resources and capacity?
3. How to increase the quality, coverage and equity of services for adolescents living with HIV in a resource-constrained operating environment?
4. How to increase cost-effectiveness and sustainability?

Objective and Methods of the Field Lessons Initiative

The overall aim of these Field Lessons is to provide examples of interventions in resource poor settings that aim to improve the coverage and quality of health services for ALHIV, with an emphasis on “how it was done”. These examples are intended be a resource for countries as they develop and scale up programmes to improve the provision and use of services for ALHIV.

Although emerging areas of programming may lack a substantive evidence base from which to develop programme guidelines, pilot experiences can provide valuable lessons to guide immediate problem-solving. In addition to informing country programmes, the lessons documented in this report are thus intended to complement the systematic reviews undertaken to inform the Guidelines on HIV Testing and Counselling for Adolescents, and the Treatment, Care and Prevention for ALHIV, currently being developed by WHO in collaboration with UNICEF and UNFPA.

While the lessons learned in this publication are not intended to be a comprehensive overview of all projects and programmes aimed at improving the quality and access to health services for ALHIV, rather it will act as a living document, providing the basis for subsequent additions that will stimulate and guide accelerated action to meet the needs of ALHIV.

Methods Used

Several approaches were explored to identify good practices from which to synthesize lessons learned. A global technical advisory group (TAG) made up of service providers (multiple disciplines), programme implementers (government and non-governmental organizations), researchers, representatives of funding agencies, and UN agencies supported this process. The TAG was responsible for providing recommendations on key questions, programmes, and resources/references to consult and for reviewing information collection tools and outputs from the initiative.
A number of tools were developed for use by regional consultants for the assessment of programmes that could provide lessons to be shared (see Annex 1 – further details available from: http://knowledge-gateway.org/youngpeople_hiv/library). At the same time, efforts were made to obtain details through national workshops that simultaneously contributed to the review and development of national programmes for ALHIV (see Annex 1). However, in order to coordinate the Field Lessons Initiative with concurrent processes, the programme reviews were delayed and a different methodology was ultimately adopted (the tools that had already been developed were subsequently absorbed into these other processes).

The discussions on operational issues held during the WHO Expert Meeting for the development of the Guidelines generated a clear consensus around the on-going need for examples of successful programmes and lessons learned for the continuum of testing, treatment, care and prevention for ALHIV. At the same time it was clear that the AIDSTAR-One in-depth mapping project, that will document policies, national programme content, innovative approaches for responding to the needs of ALHIV, funding and opportunities for integration, would benefit from a wider collation of successful programmes for ALHIV, as envisaged by the UNICEF Field Lessons Initiative.

To this end, the UNICEF Field Lessons Initiative was modified to carry out a rapid identification of promising and successful models/approaches and programmes-support tools that would feed into these other two on-going processes, and also to build on several other programme-support tools under development, such as the AIDSTAR-One Tool-Kit on transitioning support for ALHIV. As a first step, members of the UNICEF ALHIV Field Lessons Initiative TAG and the Expert Guidelines Development Meeting (many of whom overlap) were requested to provide examples of successful or promising programmes with the potential to be taken to scale. Contributors were asked to provide:

- A brief description of what is being done: target group and setting; overall aims/objectives; core strategies/activities; achievements
- The reasons why it is considered to be successful
- Three factors that contributed to its success
- Three challenges/obstacles (which could include obstacles that the programme could have dealt with, and those beyond the control of the programme)
- Contact details about where additional information and any related programme support tools can be obtained

A total of nineteen programmes were identified and documented, and these are presented in two parts:

Part 1) Synthesis of lessons learned
Part 2) Description of Models of care for ALHIV
Part 1: Synthesis of Lessons Learned

Overview

The lessons learned from the programmes described in the previous section are synthesized and structured below. The headings are to some extent arbitrary, and there are significant linkages and overlap. At the same time it needs to be recognized that each programme and each lesson learned is not necessarily representative of, or even relevant to all situations. Some will be very generalizable and others may be more distinct to specific programmes/contexts.

The table below presents a summary of the key actors involved in delivery of care in each model and the primary services delivered through the documented models. Almost all programmes (3 – 7, 10 – 13) were based at health facilities and focused exclusively on diagnosis, initiation and management of treatment in the adolescent patients. A few of the models (1, 2 and 9) focus exclusively on bridging support between health facilities and communities to enhance adherence, coping skills and quality of life. Some models documented (14 – 17) are research programmes focused on adolescents living with HIV and one initiative documented (18) is focusing on advocacy.

Overview of Programmes

<table>
<thead>
<tr>
<th>ACTOR FOCUS</th>
<th>CONTENT FOCUS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Linking Testing, Treatment, Adherence, Disclosure</td>
</tr>
<tr>
<td></td>
<td>Positive Living, Primary Care and Transitioning</td>
</tr>
<tr>
<td></td>
<td>Centres of Excellence</td>
</tr>
<tr>
<td></td>
<td>Integrating with routine services and prevention</td>
</tr>
<tr>
<td></td>
<td>Research</td>
</tr>
<tr>
<td>Service providers (e.g. doctors, nurses)</td>
<td>3, 6, 7, 8, 14, 15</td>
</tr>
<tr>
<td>Lay Counsellors (Task shifting/sharing)</td>
<td>1, 2, 3, 8</td>
</tr>
<tr>
<td>Support Groups (Families and communities)</td>
<td>4</td>
</tr>
<tr>
<td>ALHIV Peer Educators/ Support</td>
<td>3, 4, 6, 7, 8, 14, 15</td>
</tr>
<tr>
<td>Other Community Groups</td>
<td>8, 15</td>
</tr>
</tbody>
</table>
The programmes provide rich experiences from individuals and organizations trying to improve diagnosis, treatment, care and prevention for ALHIV. They provide examples of initiatives designed to strengthen the continuum of care: diagnosis/testing, disclosure, initiation and retention in care, adherence, primary care and prevention, including the prevention of high-risk behaviours.

Adolescent-centered continuum of care

At the same time, the experiences highlighted in this report highlight many of the successes and challenges related to operationalizing interventions, in terms of integration, linkages/referral, task sharing/shifting, and engaging different sectors and partners. While there has been significant progress in the past few years, it is clear that a number of challenges remain, including: transitioning to adult care and effective linkage to other services to address the evolving needs of adolescents; continuity of care from diagnosis to treatment/care and prevention; and different levels of scale.

Adolescents

1) Start from the reality of the life of adolescents living with HIV

The life of an adolescent living with HIV can be extremely difficult, and for some of them, HIV-related issues are not necessarily a priority in the lives since they are too busy coping with numerous other life challenges. In addition, they are subject to stress, stigma and discrimination. These factors have profound implications on their sense of empowerment on issues such as adherence, and need to be taken onto consideration when developing and implementing interventions. At the same time, some ALHIV are able to overcome these challenges, especially when they have support from family, community and service providers.
2) Participation of ALHIV: planning and implementation

Involving ALHIV is crucial: nobody understands their problems better than they do. It can also help strengthen personal development. For example, empowering young people living with HIV to serve as peer educators, counsellors, trainers or advocates, not only improves programme through their enthusiasm and creativity, but provides young people living with HIV with skills, confidence, and knowledge. Furthermore, providing adolescents with a space that “belongs” to them helps to build a supportive long-term relationship, and demonstrates that the community is interested in addressing their health needs.

Support

3) Parents and caregivers

It is important to give adequate attention to providing support for the parents and caregivers of ALHIV, so that they are better able to support their adolescents, and to recognize and resolve conflicts. These conflicts may often arise between ALHIV and peer educators and counsellors in relation to issues such as disclosure and questions such as what to do as a peer supporter or counsellor if an ALHIV becomes sexually active, is not adhering to treatment or care regimens, or becomes pregnant. Continuous support and counselling/education of the carers of ALHIV is critical to success of programme in order to ensure that (acknowledging the tension between autonomy and protection) the best interests of the adolescent, and the adolescents’ needs/rights are given precedence over the preferences of parents/caregivers in all interactions and joint problem-solving.

4) Support Groups for ALHIV

Support groups clearly play a key role in a range of areas. However, ensuring that such groups can be scaled up in a sustainable way remains a challenge. Segmentation of support groups by age, gender, sexual activity and their stage of knowing about and coping with their infection (not withstanding the fact that those who are recently infected or informed may learn a lot from those who have passed through the challenges they are facing for the first time)...is an important practical measure for positive outcomes in adolescents in many aspects of the care process.

Integration

5) Integration with government staff, other stakeholders and health systems

If programmes are to be scaled up in a sustainable way it is important to work with and through the existing systems and structures. National training materials, guidelines and government-led training initiatives offer the best opportunity to achieve scale in the efforts to strengthen provider knowledge, skills and quality of care. Government health systems provide facilities through which services can be delivered, and integration of lessons on adolescent care into tools and guidance used to strengthen these services helps to ensure that other chronic illnesses and vulnerable groups can benefit from the efforts to strengthen services for ALHIV.
One challenge mentioned in several programmes is the absence of relevant national policies and guidelines related to specific core issues in ALHIV care, for example the lack of a clear policy for the care of adolescents living with HIV or more specifically the lack of a policy on disclosure to children and adolescents. Furthermore there is also a lack of specific national standards and guidelines relating to adolescents living with HIV, for adherence and psychosocial support, for example. Many countries now have such guidance for small children but these documents are often not relevant to adolescents, especially older adolescents.

6) **Links to existing programmes**

Programmes for/with ALHIV should link with programmes that provide health services to young people more generally, including other chronic illnesses and programmes for ASRH, and to prevention interventions directed to young people. Linking ALHIV programmes and services to existing national programmes that are well known and successful helps adolescents to be aware of and have confidence in the services, and can increase the participation and retention of adolescents in prevention, testing and services. It can also engage NGOs that are focusing on adolescents in general to contribute to efforts to improve services for ALHIV, and help to ensure that ALHIV benefit from these programmes. In addition, providing services for ALHIV through general services may help to decrease stigma, by providing access to adolescent-friendly health services, including HCT, without the stigma attached of going to an “HIV clinic”.

**Programme planning**

7) **Adequate planning and management**

It is perhaps self-evident that effective programmes require adequate planning and monitoring systems, including, for example, the establishment of a project steering committee to oversee the project implementation; clarity about the core strategies; approaches to decentralization and transport for ALHIV who live long distances from available services; how the school terms may interrupt peer-to-peer follow up; and incentives for participation (e.g. the provision of refreshments by the implementing site for teen club activities). One of the main constraints to effective planning is the absence of age and sex disaggregated data, which is critical for effective planning of services to meet the evolving needs of adolescents.

8) **Strategies for adherence**

Similar to other chronic diseases in adolescence, ensuring adherence in adolescents to a daily antiretroviral regimen is a challenge. Three approaches in particular were highlighted: (1) working to ensure that relationships with health staff are in place to establish partnerships with patients’ guardians and the adolescents themselves; (2) providing home visits by health workers, lay counsellors and ALHIV peers to support the ALHIV and their families; and (3) developing support groups for ALHIV.

9) **ASRH and ALHIV**

ASRH services for ALHIV need to have a strong focus on disclosure and building self-esteem. Many young people living with HIV are sexually active and some make the choice to have children. ASRH
programmes need to stress knowledge among ALHIV about effective interventions for prevention of HIV transmission and on taking responsibility for their own (and their partner’s) sexual health. Balancing positive living and exploring sexuality is a challenge for this age group, particularly in terms of disclosure to a potential partner for fear that they may be put off by their HIV positive status. ALHIV also have rights to a pleasurable and healthy sexual and reproductive life, and to programmes that respond to their different needs.

10) Consent

A challenge that has implications for many aspects of programming and research is the issue of consent. Obtaining the necessary informed consent can take significant time, and needs to be built into the planning of the programme. Informed consent needs to be based on human rights principles (e.g. best interests of the child, evolving capacity of the child) and involve ALHIV, parents, caregivers and health care providers. Many different aspects need to be considered, for example informed consent for health workers to start using a paediatric disclosure tool with children and adolescents, or to allow health care providers to engage an NGO to provide training for ALHIV, and their caregivers; consent for ALHIV to voluntarily enrol in teen clubs.

Resources

11) Advocacy

Implicit in many of the programme descriptions and lessons learned is the importance of being able to make a compelling case for specific attention and resources to be directed to ALHIV. There is an ongoing need for strong advocacy to highlight the specific needs of ALHIV and the implications of these special needs for the planning, funding and delivery of services. This advocacy is critical as difficult choices are made on continued funding of critical elements that affect outcomes of treatment and care for adolescents. Although initial investments to establish the systems and capacity may be considerable, once the foundation is in place the cost per client will ultimately drop, and may result in less of a burden on the health system in the future. This “economies of scale” argument has been seen with other HIV interventions.

12) Sufficient technical support and funding

A number of programmes highlighted the importance of ensuring that sufficient technical assistance is available to support the development and implementation of the interventions. Adequate funding is also a major issue. These programmes require long-term funding, which is a challenge in the face of the global economic downturn and the fact that adolescents are often a relatively neglected group in national treatment/care programmes, and in the health system more generally.

13) The importance of human resources and capacity development

In addition to technical assistance and funding, having sufficient staff that are trained to understand and respond to the needs of adolescents living with HIV is crucial to the successful implementation of programmes. This requires attention to the capacity strengthening, supervision and motivation of a range of actors, including health care providers, parents and caregivers, and ALHIV themselves. In cases
where specific types of staff may not be available (e.g. psychologists), some programmes have used
task-shifting or task-sharing to fulfil some of these duties.

Capacity is also clearly a major challenge, with some countries facing a lack of partners in the field of
ALHIV and weak government services in related areas, such as the provision of critical social services.
Strengthening national responses to ALHIV may require leveraging existing government investments in
adolescent health in general and finding creative ways to ensure quality services to ALHIV.

**Scale**

14) **Meeting the demand for services and support**

In most situations there is a gap between the need, demand and supply of services for ALHIV.
Integration with government facilities will help to decentralize and expand access to services. However
other approaches may also be needed, such as the use of outreach mentoring programmes or outreach
teen clubs that expand opportunities for disclosure, adherence and retention support through activities
implemented in partnership with local community service organizations and ART clinics.

Stronger and more visible partnerships and linkages with on-going programmes should also address
stigma and discrimination, which remains a challenge for access to quality services for ALHIV. Services
and support for adherence can be offered through home visits conducted by community health
workers, or peer programmes. In addition to these partners, the education sector and schools reach
ALHIV every day and can play an important role in influencing their health outcomes through the
support provided for ALHIV within the school environment and through school-community
partnerships. Through school health programmes, schools may also provide a potential venue for some
services for ALHIV.

15) **Quality control**

Although decentralisation and scale up improves ALHIV’s access to support, it is essential to ensure that
services are of good quality. Programmes report that rolling out services in a coordinated manner can
be achieved through robust coordination systems and standardised materials (e.g. regular meetings
with youth service providers for planning and supportive supervision; training manuals and standard
operating procedures in line with national and international guidelines). Conducting frequent needs
assessments allows the programme to adapt to meet the changing needs of adolescents. Ensuring that
mechanisms are in place to check that the manuals and standards are actually being used (quality
assurance) is also important.

**Innovation and Research**

16) **Flexibility and space for innovation**

There is no ‘one-solution-fits-all’ approach to responding to the needs of ALHIV. Several of the
programmes emphasized the importance of being innovative and flexible, and thinking outside the box
(although this is often easier for NGOs than government health systems). NGO programmes can inform
government programmes, and governments can be supported to implement demonstration projects with the intention of scale up from the beginning.

17) The importance of research

Several examples of research have been included in this report to highlight its importance in developing and evaluating interventions. Although research in this area is growing, there is clearly a need for more analysis and research on questions such as modes of transmission of HIV and the relative contribution of these modes to the burden of infections in this group; the effectiveness and potential use of new technologies in improving care and care outcomes (e.g. mobile phones); operationalizing programmatic links to care for other chronic diseases in adolescence, and the emerging issues outlined below.

A number of challenges exist related to research on ALHIV, including:

- Consent, including definition of a “guardian” who can consent on behalf of minors for study participation, including HIV testing;
- Conducting research in school-based settings (e.g. involvement of and support from Ministries of Education);
- Research on efficacy of complex interventions that combine biological, behavioural and structural elements, which pose questions relating to feasibility of implementation and sustainability;
- Definition of objective outcomes appropriate to the different elements within the continuum of care for ALHIV;
- Financing research that goes beyond the focus on “Treatment” or ART provision to ALHIV;
- Defining the characteristics of ALHIV globally by mode of transmission, age groups, etc.
- Adolescents are often considered a lower priority for HIV research in low income settings than children and adults
- Strengthening the evidence base on effectiveness and cost effectiveness of approaches to care and support for ALHIV to contribute to improve programme monitoring and implementation, particularly around psychosocial interventions.

18) Emerging Issues

There are a number of emerging issues related to the care of ALHIV. Although these issues will likely differ depending on the epidemic scenario and country context, programmes should plan for how to address and respond to these issues:

- **Managing complications from long-term care**: A better understanding is needed for how to address long-term metabolic complications (e.g. renal, bone, hypercholesterolaemia, endocrine). Better screening methods need to be developed to improve detection of and understanding of the prevalence of these complications
- **Managing treatment failure and non-adherence**: This includes addressing both treatment interruptions as well as non-adherence. It also entails investigating why some ALHIV are failing and understanding the pharmacokinetics of ART drugs for older children in light of limited drug data.
- **Responding to “non-infectious” complications of HIV infection**: Additional experience is needed to understand how best to track, screen for and manage cardiovascular, lung and neurocognitive complications among ALHIV.
• **Responding to disabilities and mental health:** This entails addressing these issues in clinical practice and in communities through better support to parents and caregivers (including enhancement of skills for care of adolescents with disabilities and special mental health needs) and improved linkage to adolescent-friendly mental health services.

• **Supporting transitioning to adulthood issues:** Care providers need to be supported to effectively plan and implement strategies to help ALHIV negotiate adulthood beyond simply transitioning them to adult health care services. Such strategies could include economic empowerment through vocation/skills building; and support to address substance use.

• **Making second- and third-line treatment available to ALHIV:** Even with perfect adherence to first-line treatment, with increasing survival, increasing numbers of ALHIV are likely to require second-line and third-line treatment, which is often not available in low-resource settings.

**Follow-up recommendations for UNICEF**

1. Disseminate this report widely (including publication in a peer reviewed journal), both to inform individuals, organizations and countries that are developing and implementing programmes with/for ALHIV, and also to encourage colleagues to contribute and share their experiences in future updates of this approach to documenting lessons from the field.

2. Ensure on-going links with the WHO, UNICEF, UNFPA Guidelines development process, in order to benefit from the systematic reviews of the evidence, and also to contribute to the guidance in terms of operational aspects of programme development and delivery.

3. Develop a standardized reporting format to assist countries in documenting the “how-to?” aspects of their programmes (see example in Annex 3) and support the documentation of programmes through UNICEF, UNFPA and WHO Regional and Country Offices.

4. Mobilize and support implementation research on specific operational questions to complement the anecdotal experiences and lessons learned.

5. Seek out examples of programmes that are currently not addressed in some countries, for example, programmes to improve the provision and use of health services by young key affected populations.

6. Keep track of and document experiences in addressing the emerging issues identified in this report in order to ensure that lessons are collated and synthesized as interventions are developed.

7. Develop a process to ensure that this report becomes the basis for a living document: support the collection and collation of documented case descriptions using an agreed template and a process of peer review; and synthesize the lessons learned on a regular basis for dissemination.

**Part 2: Description of Models of Care for Adolescents Living with HIV**

The following description of selected programmes provides lessons learned about turning consensus on good practice into action. It is not intended to be a comprehensive list of recommendations but rather,
it should be considered a rapid review of lessons learned on strengthening service provision for ALHIV from select programmes, and as a contribution to the on-going development of evidence and experience-based programme guidance for ALHIV.

Many of the programmes documented here provide a range of interventions, responding to a range of inter-related issues, through a range of implementing partners. The descriptions are structured to highlight specific issues/challenges. A number of different frameworks could have been used to structure these programmes, and in reading them it may be useful to also consider how they provide guidance for the different components of the continuum of care: diagnosis, disclosure, initiation and retention in care, adherence, primary care and prevention, including the prevention of high-risk behaviours.

Contacts are provided for those seeking further information about these programs.

**Linking Testing with Care**

1. **Group programme for newly diagnosed ALHIV using lay counsellors (South Africa)**

*Hlanganani* is an interactive group program consisting of 3-6 modules that equips newly diagnosed adolescents to link to care. Lay counsellors facilitate the group session, according to a specific training module. Adolescents who took part report enjoying the experience and preliminary data suggest that those adolescents who participated in the programme were more likely to commence ART if eligible than adolescents who did not participate.

While the group approach to counselling may not suitable in all cases, it can be a good support mechanism. Long term follow up will tell whether the adolescents who took part in the programme have better outcomes and retention that those who did not. The plan is to adapt the programme for children infected perinatally to support their transition into adolescent care, and subsequently into adult care.

**Contact information:**
With support from Desmond Tutu HIV/AIDS Foundation (DTHF), the Bronx Adolescent Health Clinic (Donna Futterman) and CDC (SA). A paper outlining the programme and the evaluation is in preparation.
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**Adherence**

2. **Community-based adherence support through lay counsellors (South Africa)**

In this programme, lay community-based adherence support (CBAS) workers to provided adherence and psychosocial support for ALHIV, including home visits to address household challenges affecting
adherence. Family and household members were assessed together with patients, and issues were discussed at clinic multidisciplinary team meetings.

The project was evaluated through a multicentre cohort study using routinely collected clinical data at public ART sites supported by the non-governmental organization Kheth’Impilo. All adolescents and youth (ages 10-25) starting ART between 2004 and 2010 were included. Parameters assessed included patient retention, mortality, loss to follow-up and viral suppression. Adolescents who received the CBAS intervention showed improvements in all areas.

Factors that contributed to success:

- Relationships are developed between CBAS workers and adolescents, which reinforces positive adherence behaviours
- Long-term follow up improves long-term treatment success
- Program is cost-efficient for resource-poor settings

Challenges/obstacles

- Long-term funding challenges for the program in the face of the global economic downturn
- Development of a database specific for community workers is still under development
- Coverage for patients who live long distances from clinics is challenging

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Adherence/Disclosure (to adolescents)

3. Training service providers and lay counsellors, and setting up support groups to improve adherence (Mozambique)

Fundação Ariel Glaser supports the Mozambique Ministry of Health to provide clinical care in all districts in Maputo and Cabo Delgado provinces, which are experiencing a generalized HIV epidemic. In order to improve adherence to ART among adolescents and improve retention of this group in care and treatment services, the Ariel Glaser Foundation, in collaboration with staff from the provincial health directorate, have conducted trainings on paediatric and adolescent psychosocial support for lay counsellors, psychologists and psychiatry medical officers, with an explicit focus on adherence reinforcement and HIV disclosure. in the training also included modules on creating and supporting child and adolescent support groups. These groups are now fully active in 7 out of 8 districts, with each group consisting of about 20 adolescents (10-19 years). To support the training, the trainees were provided with materials, including job aids, an adherence flip chart and a manual on support groups.

Disclosure of HIV status to ALHIV is done individually by the counsellors, after several preparatory sessions involving the adolescent, the caregiver and any other close family members. The active
participation of caregivers is encouraged and there is follow up after disclosure by the lay counsellor at
the health facility and in the support groups. If major difficulties are encountered, lay counsellors refer
the adolescent their family to a psychologist or psychiatric medical officer, depending on the severity of
the problem. The tendency now is to disclose to every adolescent, but there continue to be delays in
disclosure to ALHIV, mainly due to lack of confidence of some clinicians, resistance from family
members/care givers and work overload in the health facilities. Currently an estimated 70% of the
adolescents participating in the groups have been informed of their status and in general they seem to
be responding well. The resistance from family and caregivers to disclosure has been effectively
overcome with strong psychosocial support. There are positive interactions in the support groups
between disclosed and non-disclosed adolescents.

There are differences in adherence among adolescents attending the support groups, and the specific
reasons for non-attendance (e.g. distance, family and/or psychosocial issues) need further exploration.
The support groups seem to positively influence not just adherence but self-esteem and coping with
HIV more generally.

From 2013 F. Ariel Glaser will be supporting youth and adolescent friendly services, known as SAAJ,
now in the process of revitalization by the Ministry of Health, and there are plans to build on and link
with the experiences of working with ALHIV.

Factors contributing to the success of this strategy are:

- Involvement of the provincial health directorate staff
- Technical support to the staff implementing the strategy
- Good acceptance of the intervention among adolescents, parents and caregivers

There are several challenges to the program, the main ones being:

- Lack of a formal policy for adolescents living with HIV
- Lack of a disclosure policy for children and adolescents
- Poor reporting on adolescent-specific data

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4. Adherence and Disclosure for Adolescent Mothers: the Eve for Life Experience (Jamaica)

The non-governmental organization, Eve for Life, has been working with the Ministry of Health to
provide a comprehensive approach to support and care for adolescent mothers who are living with HIV.
Currently, the NGO is working to deliver services in support of adherence and disclosure in the three
parishes with the highest rates of HIV infection.

Recruitment: The Eve for Life Programme has grown increasingly collaborative with the public health
sector. Adolescents are recruited into the programme through public health centres by way of
attendance at antenatal or HIV treatment programmes. Clients are referred by adherence counsellors
or social workers in the public health system, who have deemed them as especially vulnerable and in need of additional support.

**Assessment:** Upon recruitment, a needs assessment is conducted to identify basic needs that must be addressed to improve outcomes for the adolescents and their children. Data collected includes demographic information, knowledge and attitudes related to HIV primary and secondary prevention and treatment, literacy levels, emotional wellness, sexual health and history of forced sex and gender based violence. This assessment assists in the referral of the clients to educational, psychosocial and social security programmes to address their needs.

**Engendering trust:** To engage members of the the PLHIV community to encourage support for adherence is primarily achieved through the engagement of older HIV positive women called “life coaches” and programme graduates called “mentor moms.” These women form a key part of the care and support team. In the event of a breach of confidentiality, a reporting and redress system is in place and the adolescents are informed when action is taken.

**Support groups:** Groups meet on a monthly basis. Clients are able to discuss their challenges and successes in an environment free from stigma, discrimination and judgment. The support group is also the space in which life skills are reinforced.

**Adherence support:** A team approach is taken to support adherence to treatment. With the consent of clients, mentor moms liaise with adherence counsellors and social workers to monitor adherence and address barriers. Attention to psychosocial issues has led to good adherence and fewer than 1% of the adolescent mothers in the programme have repeat teen pregnancies.

**Support for disclosure to parents/guardians and partners:** Disclosure is considered a critical component of successful adherence as it opens up an environment of trust and support. Disclosure to a loved one is an indicator used to measure success in the programme. The programme treats disclosure as a life skill and participants learn about the of the disclosure process and role-play discussions with loved ones. The process involves discussions regarding the selection of the partner(s), family member(s) or friend(s) to whom the participant will disclose, and whether or not they require the assistance of a life coach, mentor mom or trained counsellor. All coaches are required to have disclosed their status to a partner or family member so they can offer optimal support.

**Strategy for Scale-up:** Increased cooperation with the MOH includes capacity building of health care workers to improve their skills in service delivery for ALHIV. Additionally, graduates of the programme continue to be engaged as peer support links for adolescent mothers attending antenatal or HIV treatment programmes in the public health sector.

**Factors contributing to success:**

- Close collaboration with the government
- Government and NGO apply a team approach to adherence to ART for those on treatment
- Peer to peer approaches to support
- Engagement of older women living with HIV as lay counselors/mentors
- Disclosure of status as a key component of the programme
Challenges/Obstacles:

- Limited scope of the programme (operating in only 3 parishes and targeted towards ALHIV who are mothers)
- Funding challenges threaten sustainability

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Integration of treatment and care for ALHIV with routine services

5. Links with adolescent-friendly sexual and reproductive health services (AFSRH) (Mozambique)

Description:
In 2004, the World Bank launched a pilot HIV/AIDS Treatment Acceleration Project (TAP) in Mozambique, Burkina Faso, and Ghana aimed at slowing the epidemic by increasing access to voluntary testing and counselling (VCT) and adherence to care and treatment. In Mozambique, the four-year US $1.25 million Treatment Acceleration Project (TAP) was implemented by Pathfinder International, in collaboration with the Government of Mozambique (Ministries of Health, Education, and Youth and Sports) with additional technical and financial support from UNFPA. TAP built on and expanded the successes of the national Geraçao Biz Program. TAP was implemented in two provincial hospitals that offered youth-friendly sexual and reproductive health services (YFS) in Maputo City and Xai-Xai in Gaza Province.

Through TAP, HIV counselling and testing, ART, and PMTCT were integrated into the YFS package for the first time. Young people testing positive were provided with immediate support and counselling, given a CD4 test, and linked to treatment if needed. Those who were pregnant were linked to PMTCT services. In addition, a trained psychologist spent several hours a day at the YFS offering counselling and support for disclosure as well as positive and healthy living. Young people testing positive were immediately linked with an HIV-positive peer educator who had been trained to provide care and support and “sheltering.” Finally, all clients testing positive for HIV were urged to join a weekly support group at the YFS facility led by peer educators with support from providers and the psychologist.

Over the course of the project, about 12,000 young people were tested for HIV with about one-quarter testing positive, and 656 young people began ART. The program had high levels of retention for ART clients, with only 11% and 16% of ART clients dropping out over the course of the project in Maputo City and Xai-Xai, respectively.

The program was considered highly successful by the MOH and other partners in the country. It was a catalyst for the scale-up of HIV counselling and testing within all of the YFS sites in Mozambique. HIV counselling and testing is now offered at 335 Geraçao Biz YFS sites nationwide and approximately 153,000 young people were tested in 2011. In addition, peer educators living with HIV remain active in the Geraçao Biz Program and in 2011, the Ministry of Health issued guidelines that all YFS facilities should have support groups for young people living with HIV. This is a big step in scaling-up some of the key elements of TAP, although it has yet to be fully operationalized in the country.
Factors that contributed to the success of TAP:

- Building on an existing national program with well-known and successful youth-friendly services allowed young people to be aware of the services and increased participation of young people in the program. In addition, Geraçao Biz was simultaneously implementing the highly effective Time to Know Campaign to motivate young people to seek HIV testing.

- Empowering young people living with HIV to serve as peer educators and play a key role in the program not only improved the program, but provided young people living with HIV with skills, power, and knowledge they didn't have prior to the program. Their enthusiasm and commitment went a long way to making the program effective.

- Support groups and “sheltering” including home visits were crucial to adherence to treatment and maintaining follow up care with YPLHIV.

Challenges:

- Psychologists played a very key role in ensuring a high quality program, but psychologists are limited in Mozambique and not available in remote areas. Peer educators can be trained to fulfil some of these duties, but supervision is required to ensure quality.

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6. Services and support for ALHIV in Namibia

This programme focuses on adolescents aged 10-19 years in the Caprivi and Khomas region of Namibia, including ALHIV, with the aim of strengthening the design, development and implementation of service delivery mechanism for increased uptake and quality of HTC for adolescents and young people, including Post Test Support Services (PTSS), and improving service provision for ALHIV.

Activities include a baseline data collection, collation and analysis; the development of training materials; training of HIV positive adolescent facilitators and the parents, caregivers and health care providers of ALHIV; the establishment of peer support groups and spaces for them to meet; and the use of a disclosure tool with all HIV positive adolescents attending the paediatric ART target site.

In addition, there is an emphasis on HIV testing and counselling (HTC) being entry point to provide prevention, treatment, care, and support services through the following mechanisms:

- PTSS to support both HIV positive and HIV negative adolescents and young people;
- strengthened referral linkages between HTC, PTSS and other prevention, care & treatment, and support services;
- community-based mobilization mechanisms, including interpersonal and mass media communication to reach out adolescents and young people.
The project is currently exploring the potential for replicating the approaches developed in Khomas and Caprivi regions to scale up interventions for ALHIV nationwide through Ministry of Health and Social Services structures

Achievements:
- Established a Teen Club for ALHIV at a district hospital in one region, with more than 140 adolescents enrolled in the club to date;
- Set up a project Steering Committee;
- Reviewed and integrated the AFHS curriculum to include ALHIV components;
- Expanded availability of AFHS-ALHIV national training curriculum for health care providers and the training of trainers on the revised AFHS-ALHIV curriculum;
- Developed, printed and launched national guidelines for ALHIV.

Reasons for success
- The project was initiated in a setting where there was already a functional teen club
- The establishment of the project steering committee to oversee the project implementation
- Availability of technical assistance and funding for capacity building of ALHIV, parent/caregivers, and health care providers
- Incorporating the teen club from the initial stages of the project
- Project was “owned” by the ART site management and hospital
- Wider stakeholder involvement in the development of the national guidelines
- Review and integration of the AFHS-ALHIV curriculum by the national health training centre within the Ministry of Health
- Engagement of NGOs working with children and adolescents on HIV, and SRH matters in the project(s).

Factors contributing to success
- Exposure of staff and adolescents living with HIV to a global consultation on programming for ALHIV
- Committed and dedicated staff
- Availability of space and incentives for participation (e.g. the provision of refreshments by the implementing site for teen club activities).

Challenges/obstacles
- Confidentiality: Parent and caregiver Consent was required to allow health care providers to introduce the paediatric disclosure tool to the children and adolescents, and to allow an NGO to provide training to ALHIV and their caregivers. Consent was also required for ALHIV to voluntarily enroll in the teen club. This process was time consuming and, and delayed project implementation.
- Funding: Project funding came to an end at a time when the need for resources was greater than when the project started (for training and for electronic devices for defaulter tracing)
- Unfriendly space: the space provided for the teen club corner in the implementing facility is in need of refurbishment, painting and extra equipment

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7. Integration of the response to ALHIV into the overall responses to HIV prevention among young people

Africaid is a non-profit organisation based in South Africa that uses football (soccer) to deliver effective HIV and AIDS prevention, and support for treatment and care for young people living with HIV. Since 2006, its primary programme has been WhizzKids United (WKU), a comprehensive youth development and sexual health programme that uses the game of football as an educational medium. To date over 35,000 youth have graduated through its ‘On the Ball’ school-based intervention, with an attendance rate of 99%.

Moving away from the negative connotations of a health ‘clinic’ the WKU Health Academy is a long-term source of holistic care, treatment and support for beneficiaries that compliments the school-based Life Skills programmes, ‘On the Ball’, ‘Team Talk’ (WKU Peer Ed), ‘Game Changers (WKU youth leadership programme) and WKU Mixed Gender Leagues. It is a sexual and reproductive health clinic designed exclusively for adolescents, and offers a full range of professional health and counselling services. ALHIV receive on-going psychosocial support and ARV treatment, while HIV-negative adolescents receive on-going prevention counselling. The programme serves over 8,000 youth per year of which 500 plus receive ARV treatment, with 85% adherence rates.

In order to maximize its appeal to beneficiaries, the Health Academy features a football pitch and a computer resource centre, as well as various organized recreational and educational activities (including a Mixed Gender Football League involving eight local schools). The Africaid Trust manages the WKU Health Academy, although it is predominantly staffed by the KwaZulu-Natal Department of Health, ensuring the Academy long-term financial sustainability. Its core competency is offering one-on-one sexual health risk assessments every three months to each youth to help facilitate healthy development, as well as couples counselling as they mature and engage in relationships.

Achievements:
• Offers a comprehensive Orphans and Vulnerable Children programme, addresses a gap in health service delivery to adolescents, and supports the nationwide effort to prevent new HIV infections
• Provides access to adolescent-friendly health services, including HCT, without the stigma attached to going to a clinic
• Gives adolescents a venue which truly and uniquely belongs to them, builds a supportive long-term relationship with the beneficiaries, and demonstrates to young people that the community is interested in addressing their health needs

Challenges:
• Lack of transport for youth to attend from distances more than 2kms from Academy;
• Lack of credible partners in the field of ALHIV
• Lack of funding from major donors

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Strengthening the continuum of care for children and adolescents with HIV

8. Community-based treatment, care, support and prevention (Zimbabwe)

Africaid, a local Zimbabwean non-governmental organisation, is committed to helping HIV positive children, adolescents and young people from 5-24 years to develop the knowledge, skills and confidence to cope with their HIV status and to live happy, healthy, fulfilled lives. It is achieving this through the development and national roll out of its innovative “Zvandiri” model that provides community-based treatment, care, support and prevention services for HIV positive children and adolescents. These services are integrated within the clinical care provided by government and private clinics. This integration creates a robust continuum of care for children and young people with HIV and their families, and aims to promote both their health and psychosocial outcomes.

Zvandiri (meaning “As I am”) is led by HIV positive adolescents who are trained as peer service providers. Through community support groups, community outreach and clinic-based Zvandiri Centres, these adolescent peer service providers:

- identify children for HIV testing
- link children living with HIV to treatment and care
- provide sustained counselling for children, adolescents and their families
- provide adherence monitoring and support in clinics and homes,
- trace treatment defaulters and provide life skills training for their peers.

The goal of the Zvandiri’s SRH programme is to ensure that young people living with HIV have the knowledge, skills and confidence to make informed prevention decisions and that they are linked to services including STI treatment, family planning services, PMTCT and Zvandiri’s young parents support groups. Adolescent peer service providers also provide training and counselling for caregivers and training of health workers, teachers, social welfare officers, church leaders and community members.

The Zvandiri model is now being scaled up across Zimbabwe under the Government of Zimbabwe’s National Action plan for OVC. In 2012, 1364 HIV positive children and adolescents were being supported through Zvandiri across 4 provinces of Zimbabwe. A team of 60 trained and mentored HIV positive adolescents are providing daily counselling for their peers who are on ART, and some 11,000 children are engaged in adolescent-led advocacy and training activities. Zvandiri has been recognised as a highly effective, innovative model for the provision of sustainable treatment, care, support and prevention services for children and adolescents with HIV. It was documented by SADC in 2012 as a regional best practice and a national best practice by Zimbabwe’s National Action Plan for OVC in 2009.

Successes:

- **Child and adolescent-led**: HIV positive children and young people are at the heart of Zvandiri, taking the lead in planning and implementing services for their HIV positive peers as counsellors, trainers and advocates. Innovations include the CATS model (Community Adolescent Treatment Support), production of their own books and counselling tools (“Our Story” book, “Red Ribbons and Roses”) and DigiART, (digital story telling project).
- **Integration**: Zvandiri integrates community-based treatment, care, support and prevention services within government clinic services, thus complementing clinical care and ensuring a robust continuum of care for children and adolescents with HIV.
From “ground up” to national scale up: Zvandiri was established from the “ground up”, through partnerships with children and young people with HIV, their families, the Ministry of Health and Child Welfare, the Ministry of Labour and Social Services, the National AIDS Council and Africaid’s funding partners. It is now being successfully scaled up in a variety of settings, including urban and rural settings, through provincial, district and community clinics across Zimbabwe. The model has also been successful in reaching out to other vulnerable children in these areas.

Challenges / Obstacles and solutions:

• Improving Access: Providing support to children with HIV required that all Zvandiri services are decentralized at community level
• Meeting Demand for Services: There was considerable demand for the scale up of Zvandiri services to different provinces across the country. This process was made possible by making it a national programme through the Government of Zimbabwe’s National Action Plan for OVC
• Ensuring Quality: Although decentralisation and scale up improves access for children to support, it is then essential to ensure quality control. The roll out of services in a coordinated manner has been achieved through robust coordination systems and standardised materials (e.g. weekly meetings with youth service providers for planning and supportive supervision; training manuals and standard operating procedures in line with national and international guidelines for consistent delivery of quality services).

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9. Responding to the Sexual and Reproductive Health (SRH) Needs of Adolescents Living with HIV and AIDS: The Mildmay Uganda (MUg) Experience

Background
Many ALHIV are sexually active, yet do not protect themselves against HIV or pregnancy. Because of stigma, ALHIV fear disclosing not only their sexual behaviour and desire, but also pregnancy when it occurs.

At the Mildmay Uganda (MUg) program, 2.2% of the 1,042 females aged 15-20 years that attended the clinic from 2004 to 2007 were known to have had a pregnancy in the last 12 months. Yet the assumption that HIV-infected young people are not sexually active meant that counselling and other support for young people before 2007 focused mainly on abstinence and largely excluded SRH.

Although the MUg program initially focused on paediatric and adult HIV care, MUg realized the need to empower young people with skills to address their reproductive health challenges as part of routine care and incorporated adolescent-specific needs into its programming.

Brief description of the Mildmay Adolescent
Since 2007 several structures have been put in place to support SRH of young people (10-24 years) at MUg. Among these are Our Generation Mildmay Adolescent Club (OGMAC), Safe youth Club (SYC) for
15-24 year olds, Positive Speakers Club (PSC), Noah’s Ark Choir, Unique Stars (talent support group), Kisaakye Youth Centre (KYC) and Young Parents Club.

In 2009, MUg established a programme to focus on adolescent reproductive health (ASRH); using a peer-led approach to empower young PLHIV to live positively with their identity and balance the rights and responsibilities including disclosure of their HIV status to significant others. Ten health workers were trained on delivery of adolescent services, who then trained 100 peer adolescent counsellors, who subsequently trained 63 adolescent peer educators across two age groups (10-14 and 15-24 years).

The peer counsellors supported other adolescents in the areas of ASRH information and services, drug adherence advice, positive living, sharing of experiences as HIV+, and general sensitization about HIV issues through the OGMAC, SYC, PSC and Noah’s Ark Choir and Unique Stars (talented group). The project also issued an annual magazine with HIV testimonies. The roles of the trained adolescent peer counsellors/educators included identifying HIV positive adolescents from the communities who need SRH support, which included: giving support-counselling for healthy SRH choices, referring fellow adolescents as appropriate for further SRH support, hold monthly meetings and documenting all ASRH implemented activities, including challenges faced during implementation.

The main services available to adolescents at MildMay Uganda include:

- counselling and support services on HIV prevention and SRH,
- participatory training sessions on life skills,
- IEC materials and health literature
- call-in centre for adolescents to talk to someone about general health concerns,
- recreational activities,
- school/community outreach activities,
- basic health screening and management of STIs,
- family planning services, cervical cancer screening,
- PMTCT,
- free sanitary towels for female adolescents,
- self-aided training on computer programs, including typing tutor, MS Word and Excel,
- indoor and outdoor educational games (in partnership with “Right to Play”),
- adherence and positive prevention counselling services,
- career guidance,
- peer support groups,
- music, drama and sports,
- school monitoring
- access to e-mail and telephone,
- consultations with various technical staff at MUg including counsellors, doctors, nurses, social workers, among others.

In addition to these services, MUg has established linkages with a range of other service providers. Most of the ALHIV in care at MUg started attending the facilities when they were small children, and many have become strongly attached to specific providers at MUg over the years. In the absence of other family support systems these providers, may take on the function of ‘parents’ to these children. In such cases it is important for the adolescent to have options for alternative care when they need it.
Achievements

Over the last five years there was a 56% increase in the number of ALHIV routinely accessing care at MUg. Although there was an initial decline in reported sexual activity after the peak (20%) in 2008, the proportion of adolescents (19%) reported sexual activity remained high in 2012. Programme support has ensured that disclosure to sexual partners has remained relatively high among the adolescents compared to the period prior to the start of the adolescent-friendly programme. The incidence of pregnancy has been recorded at 4% in 2012, compared to 1-2% in the early years of the programme, indicating that more ALHIV are choosing to have a pregnancy. In spite of the relative increase in ALHIV pregnancy over the 5 years of the programme, more adolescents (14%) are accessing FP services compared to an average of only 4% in the earlier years of the programme. Also 85% and 87% of ALHIV who had a pregnancy accessed PMTCT services in 2011 and 2012 respectively. MUg plans to scale up the programme in the 16 districts of the central region of Uganda where the organization supports a health system-strengthening project.

<table>
<thead>
<tr>
<th>Year</th>
<th>Total adolescents in care</th>
<th>Adolescents reporting sexual activity</th>
<th>Adolescents reporting disclosure HIV status to sexual partners</th>
<th>Adolescent pregnancies</th>
<th>Adolescents accessing family planning</th>
<th>Adolescents screened for cervical cancer</th>
<th>Pregnant adolescents accessing PMTCT services</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
<td>1356</td>
<td>18%</td>
<td>40%</td>
<td>16</td>
<td>0</td>
<td>No service</td>
<td>No data</td>
</tr>
<tr>
<td>2008</td>
<td>1425</td>
<td>20%</td>
<td>51%</td>
<td>22</td>
<td>12</td>
<td>No service</td>
<td>No data</td>
</tr>
<tr>
<td>2009</td>
<td>1625</td>
<td>16%</td>
<td>71%</td>
<td>9</td>
<td>13</td>
<td>2</td>
<td>No data</td>
</tr>
<tr>
<td>2010</td>
<td>1575</td>
<td>14%</td>
<td>95%</td>
<td>9</td>
<td>34</td>
<td>36</td>
<td>No data</td>
</tr>
<tr>
<td>2011</td>
<td>1534</td>
<td>14%</td>
<td>91%</td>
<td>27</td>
<td>47</td>
<td>47</td>
<td>23</td>
</tr>
<tr>
<td>2012</td>
<td>2117</td>
<td>19%</td>
<td>84%</td>
<td>87</td>
<td>286</td>
<td>164</td>
<td>76</td>
</tr>
</tbody>
</table>

Factors that have contributed to success

- Integration of adolescent-friendly sexual and reproductive health services into routine HIV care,
- Strong programme focus on individual responsibility, disclosure and building self-esteem.
- Training of health workers in ASRH opened communication between adolescents and health workers.
- A peer-led approach led to increased referral and uptake of services (e.g. in 2010/2011, 147 males and 271 females were referred to Mug for ASRH services and other service providers.
- Linkages established with other ASRH service providers allowed wider choice of service providers for adolescents, increasing uptake of services beyond MUg.
- Segmentation of support groups by age, gender, sexual activity status and socio-economic status (a special peer support group, the Safe Young Club, was established to support young people from more socio-economically advantaged families, as this population with access to e-info has different needs.
- Education and counselling/education caretakers of ALHIV
- Continuous needs assessment allowed the programme to adapt to meet the changing needs of the target population.

Main challenges
• **Stigma:** Balancing positive living and exploring sexuality is a real challenge for this age group.

• **Conflicting desires and expectations:** Some caretakers may persuade pregnant ALHIV to have an abortion, sometimes choosing unsafe environments.

• **Interruption in services:** School terms may interrupt peer-to-peer follow up, especially for those ALHIV who have to spend time away at boarding school and who are not connected to e-mail or do not have telephone access.

• **Scaling up:** Most facilities do not have sufficient staff capacity to provide comprehensive ASRH. Recommendations have been made for strengthening capacity at Health Centre IVs and Hospitals, to deliver ASRH. Implementation of this recommendation particularly in the 16 districts of the central region of Uganda where Mildmay is mandated to support the health facilities, will accelerate scale up of care for ALHIV through a Health System Strengthening approach.

**Conclusions**

1. ASRH services for young PLHIV should have a strong focus on disclosure and building self-esteem.

2. Many young PLHIV may make the choice to have children and therefore ASRH programmes should have a strong focus on their responsibilities for their sexual and reproductive health.

3. Stigma remains a challenge to accessing to quality services for ALHIV. Services should include support for caretakers, as well as for adolescents.

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10. **Working with ALHIV: The Experience of Uzbekistan**

The overall aim the of this programme is to improve quality of life through the following three mechanisms:

• **Provision of information** (HIV/AIDS, modes of HIV transmission, ART, adherence to treatment, CD4 count, viral load, prevention and treatment of opportunistic infections, nutrition, hygiene, reproductive health, mental health);

• **Education** (prevention for positives, life skills development, leadership/volunteering, development of skills relating to specific interests); and

• **Comprehensive psychosocial support** (individual psychological/social counselling, self support groups, information/education materials).

Services for ALHIV have been integrated into the existing system of services for HIV-positive children and their families through the day-care centres (DCC) for children and families affected by HIV in Uzbekistan. More than 100 ALHIV are now attending the DCC, although only about 40 of them have are fully aware of their HIV status. The objectives of the services are to:

• Provide psychosocial support for ALHIV and their families;

• Coordination of the various types of care for ALHIV and facilitating the transition to for adult services;

• Strengthen the connection between ALHIV in different regions of Uzbekistan to exchange experiences and provide mutual support.
The interventions target ALHIV, parents/guardians of ALHIV and service providers (paediatricians, infectious disease specialists, and specialists of organizations working with children). The core strategies/activities include:

- Psychological/social counselling, especially to support disclosure;
- Conduct regular support groups for adolescents who know their HIV status;
- Hold activity groups for adolescents who know their HIV status, including knitting, beading, computer, and languages (Russian, English);
- Information materials for ALHIV (personal diaries entries, art calendars, HIV/AIDS booklets);
- Education for parents of ALHIV, medical staff from AIDS Centres (paediatricians and infectious disease specialists) to support disclosure of HIV status to adolescents;
- Development of an online platform/network to enhance the relationship between ALHIV from different regions of Uzbekistan (currently, for ALHIV in Uzbekistan there is a closed group "UMID" (Hope) in the Uzbek social network “Odnoklassniki”).

The programme is also in the process of establishing camps/schools for ALHIV to build their capacity, leadership and ability to advocate for their rights. This involves training ALHIV on a number of themes, including:

- Promoting a healthy lifestyle (training on safe behaviour, the basic aspects of reproductive health, nutrition in HIV, basic hygiene);
- Development of active life position (positive thinking, the formation of leadership skills, communication skills, values);
- Skills building to combat stigma and discrimination (also including self-stigma);
- Skills of responsible attitude to their own admission ART and regular monitoring by medical specialists;
- Prevention for positives support trainings (training of trainers).

Planned activities include:

- Implementation of system of transition for ALHIV from paediatric AIDS services to adult AIDS services (using services of AIDS Centers, Maternal and Child Department of the MOH);
- Regulatory support of HIV disclosure for ALHIV;
- Adoption and adaptation of WHO guidelines/protocols on disclosure of HIV status among children.

Reasons why the programme is considered to be a success:

- On a regular basis support groups ALHIV who know their HIV status meet in the day-care centers in Tashkent and Andijan;
- All parents report that after working with DCC staff, ALHIV are more responsible for their health, better adhere to treatment, have developed an interest in life, have less conflict with their parents and are better able to communicate with peers;
- There has been cooperation with partners for work with ALHIV (AIDS Centers, UNDP, GFATM Project, UNAIDS, UNFPA).

Factors that contributed to its success:

- Availability of a team of qualified professionals, including social workers, psychologists, pediatricians, infectious disease specialists;
• Availability of financial support for activities, including self-support support groups, trainings, office supplies, office equipment;
• Mobilization of ALHIV who have become leaders and volunteers to work with the new adolescents, whose status has not yet been disclosed.

Challenges/obstacles
• The lack of an enabling environment for ALHIV (e.g. lack of understanding in the public sector of the importance of working with adolescents, regulatory constraints or lack of regulatory framework for adolescents with HIV);
• Growth in the number of HIV cases among adolescents,
• Delays in seeking help by parents of ALHIV in terminal stages of the disease,
• Parents adolescents facing behavior challenges, such as, including not adhering to antiretroviral drugs, displaying aggressive behavior towards parents and peers. Many parents do not engage in regular contact with DCC staff and the delay disclosing status until the adolescent is older in hopes that their health will improve and they will be better equipped to deal with the situation;
• Lack of support systems for ALHIV after HIV diagnosis. Typically, when the adolescent had an HIV test it was initiated by medical personnel and there was no pre-test and post-test counseling. Only when parents report a HIV-positive result are they able to benefit from a referral to the AIDS Center. As a result, many AIDS Centers initiate contact with ALHIV upon presentation of the ALHIV by their caregivers because of deteriorating health.

Contact details for additional information:
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Living Positively

11. Baylor Teen Club, Swaziland

Swaziland has the highest rate of HIV in the world. The Teen Club was born out of a desire to help adolescents living with HIV become powerful agents of change. Since starting in 2006 with support from the Baylor International Pediatric AIDS Initiative, Baylor Teen Club in Swaziland has grown to include one monthly meeting in each of the four regions of Swaziland. There are currently four teen club centres; Mbabane, Manzini, Hlathikulu, and Siphofaneni.

The mission of Teen Clubs is to empower HIV-positive adolescents to live positively and successfully transition into adulthood. Services offered at the teen clubs include emotional and educational support through structured activities designed to teach life skills, foster relationships, and build confidence. The clubs provide a forum for adolescents to constructively express themselves and discuss issues regarding their condition without the threat of stigma.

Currently the teen clubs have about 1100 members (only HIV positive adolescents). Each month more than 350 adolescents living with HIV attend the support groups on Saturday mornings. Every meeting begins with games and icebreakers that help new members quickly feel comfortable while making new
friends. Teen Club members then participate in educational and empowering activities from the Baylor life skills curriculum. During their meetings, the teens are split into different age groups, allowing for the younger adolescents to participate in activity-based lessons, while the older teens engage in in-depth conversations with a more mature focus. With the help of adult Teen Club coordinators, the lessons are conducted by Teen Leaders, older members of Teen Club who have successfully completed the Teen Leadership Training program. Topics include advocacy, body changes, disclosure, peer pressure, self-expression, safer sex practices, grief and bereavement, self-expression, and realizing your dreams. To help ease the financial burden on members, each teen is provided a snack and travel reimbursement for public transportation.

Baylor cannot do this alone. Sustainability of the Teen Club activities is ensured by strong leadership and partnerships, and the on-going training of adult volunteers and Teen Leaders. With the expansion of support groups and the addition of a Teen Club office and a dedicated staff, Baylor has been able to increase participation of teens while decreasing average costs. Despite the accomplishments made over the past six years, there are still several challenges facing implementation of teen clubs.

**Is it a success?**

When adolescents living with HIV are given a voice and supported to overcome obstacles to good health, their strength, creativity and passion can engender hope, even in the most desperate situations. Teen Club helps build the capacity of Swaziland’s civil society to support Swaziland’s adolescents in the battle against HIV. A recent evaluation of the Teen Clubs has shown that HIV positive adolescents appreciate the services provided through the clubs and they provide a forum in which HIV positive adolescents can come together to share their personal experiences and provide one another the much-needed psychological and emotional support. The teen club members benefit from being able to speak openly and freely with their peers in the clubs about their HIV positive status without fear of being stigmatized and discriminated. Restricting teen club membership to HIV positive teens is believed to be one of the main reason for the success of the clubs.

While there are many benefits of attending Teen Club, the success of what is accomplished is best described by the Teen Club members themselves: “I am not alone and I can help other teens living with HIV.” “I want to learn life skills and how to improve my health.” “I am going to be a leader.”

**Challenges:**

- How best to provide nutritious food within a constrained budget?
- How best to decentralize Teen Club so that more adolescents living with HIV are able to get the vital support they need?
- How to empower the adolescents to successfully transition to adult health care and services?

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Dr Sarah, in charge of the UNICEF supported activities including the Teen Club: sarah_h_banner@yahoo.com
Makhosini A. Mamba, Health Specialist, PMTCT & Paediatric AIDS, UNICEF Swaziland: mmamba@unicef.org Web: [http://www.unicef.org/Swaziland/](http://www.unicef.org/Swaziland/)
Centres of Excellence

12. In concentrated epidemics: Serviço de Imunologia Clínica e Hospital-Dia do IMIP, Instituto de Medicina Integral Prof. Fernando Figueira (IMIP), Brazil

The programme started working in 1987, when the first paediatric AIDS case was diagnosed in the Northeast region of Brazil. In 1988 the service became a national reference centre for HIV infection among children. It trained health professionals locally and from other regions of Brazil, and expanded to incorporate the testing of all pregnant women for HIV, becoming Mother-Child HIV clinics. In 1998 treatment for other adults was added, and in 2003 the move to new facilities made it possible to put together a multi-professional team to offer comprehensive care and day care services for adolescents and children.

Currently IMIP’s Hospital complex provides an HIV reference service, with paediatricians, immunologists, infectious disease specialists, gynaecologists, rheumatologists, psychologists, dentists, nursing staff and social health assistance. Approximately 450 children and adolescents living with HIV have been registered with the service, of which 300 are alive and in follow-up. In addition the clinic is following up 10 children born to HIV positive mothers who themselves were perinatally infected; only one of these children is HIV positive.

Lessons learned:
• Improving the skills of health workers is essential so that they can better understand and treat adolescents, who need strict adherence to antiretroviral drugs
• It is important to have flexible approaches to transition adolescentsto adult services, ideally at the same clinic (at the same clinic)
• Since the beginning of the programme, the "AIDS clinic" was called the Immunodeficiency Outpatient Department and later the Clinical Immunological Service for HIV and non-HIV patients (including primary immunodeficiency, allergy and rheumatology). It is important to call the services something that helps to decrease stigma and discrimination (and in fact, currently the day-care hospital is used mostly by non-HIV patients).

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Instituto de Medicina Integral Prof. Fernando Figueira - IMIP
www.imip.org.br

13. Adolescent Care Group, Instituto de Infectologia Emilio Ribas, Brazil

The Adolescent Care Group was created in 1985, the beginning of AIDS pandemic in Brazil, when the first HIV infected child was referred to the hospital. The team is composed of infectious diseases specialists, paediatricians, nurses, social workers and psychologists.

Expertise was initially developed through medical literature, exchanging experiences with other groups worldwide and the day-to-day learning with our own success and frustrations. This learning approach helped to respond to issues such as disclosure of the diagnosis, HIV testing, treatment adherence and
social inclusion. We searched for solutions as the problems confronted us, since we were the first team in the country to deal with HIV infection in the paediatric population.

Success:
One important success factor in dealing with HIV infected children and adolescents is that the care team members are still the same since the beginning of the AIDS epidemic in Brazil, and it has therefore been possible to establish good partnerships with the patients’ guardians and the children and adolescents themselves. The team members meet on a daily basis to discuss issues. Furthermore, the same team works together on clinical research and on training young professionals, and ensures that all team members have access to the most recent publications and experts from all over the world.

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Instituto de Infectologia Emilio Ribas
Phone: +55.11.30612521
Mobile: +55.11.981217072


HIV testing and counselling or “Screening Clinic” is the entry point into the Botswana-Baylor Children’s Clinical Centre of Excellence (COE). For those who test positive for HIV, the goal of the programme is optimisation of treatment and adherence, retention in care, avoidance of high-risk behaviours and seamless transition into adult care. First opened in 2003, the main clinic in Gaborone now has over 2300 child and adolescent patients, and reaches an additional 4000 unduplicated patients through its decentralised countrywide outreach and mentoring services. Thus the COE is impacting over two thirds of all paediatric patients who are receiving antiretroviral therapy in the country.

To achieve the programme goals, the COE provides various multifaceted but linked interventions that include: a simplified and sequential disclosure process; adherence classes for the primary caregiver and at least one other member of the household; nutritional support and counselling; home visits (in-reach); morning play group; remedial classes for those with low school grades; a week-long annual camp; adolescent support services centred around teen-clubs (fun, life skills and sexual and reproductive health); and structured transitioning programme to usher them into adult care. For adolescents who are parents or pregnant the COE offers a teen-mother support group that teaches parenting skills, encourages them to return to school, income generating activities.

Achievements include the establishment of 10 teen clubs across the country; home visits to over 90% of all patients; loss to follow-up of only 1.8%; annualised mortality of 0.9% despite a predominantly long-term survivor/adolescent population; undetectable viral loads (<400 copies/ml) in 92% of patients; and a lower teen pregnancy rate among those aged 15-19 compared to the national rate in this age group.

Success factors:

Three key factors have contributed to this success.
• HIV is the main focus of the COE
• Innovation and responsiveness of COE staff
• The fact that the COE is an NGO working in partnership with the government has meant that it has space to think outside of the (government service) box.

**Challenges:**

• Reaching out to as many children as possible was a key challenge. This has been done through the outreach mentoring programme and the establishment of outreach teen clubs in partnership with local community service organizations and ART clinics. Airborne Lifeline (an international NGO based in Botswana) has facilitated the provision of free flights to remote parts of the country for the staff of the COE.

• The multifaceted approach to care, particularly the in-reach and caregiver training, has been critical in ensuring excellent retention into care.

• The COE has not yet been successful in meeting its third challenge, integrating these innovations into the government health care system, however talks are underway.

**Contact Information**


Additional information can be obtained by writing the COE at Private Bag BR129, Gaborone, Botswana or emailing ganabwani@baylorbotswana.org.bw.

15. **Centre of Excellence: the Paediatric Infectious Disease Clinic, Uganda**

The Paediatric Infectious Diseases Clinic (PIDC) at Mulago Hospital, Kampala, is the national referral and teaching hospital in Uganda, and is managed by the Baylor-Uganda Clinical Centre of Excellence. Since 1988 it registered approximately 5000 HIV patients, of which 10% are adolescents between the ages of 10-19 years. The long-term goal of the PIDC is to improve health outcomes for ALHIV and reduce HIV incidence among young people in Uganda, using adolescents as change agents. The psychosocial support program at Baylor-Uganda includes the Leaders in Training (LITs) in all aspects of the skills building activities.

The health and longevity of ALHIV is dependent on their ability to manage a chronic illness and live with dignity. At the same time, as they become sexually active, it is important to combat the socio-environmental barriers that threaten HIV prevention efforts. Adherence to medication remains one of the most pressing challenges that ALHIV face. For adolescents in school, barriers to adherence include lack of space and time to take medication privately, lack of trusted support networks, and pervasive HIV-stigma that leads many to stop taking medication altogether. Non-adherence puts ALHIV at risk of developing opportunistic infections and transmitting HIV to others. There is an urgent need for strategies that engage ALHIV as change agents to improve adherence to medication and access to care and create more informed school environments that are supportive of ALHIV and promote HIV prevention.

**The Mulago Teens Club**: In December 2003, a weekly adolescent HIV clinic and monthly support group was created to provide age-appropriate HIV prevention and care for ALHIV. The main aim of the monthly support group was to improve their quality of life, including coping skills, self-efficacy, and intent for secondary HIV prevention. This includes the provision of the psychosocial support necessary for comprehensive care, including: HIV/STD education, promoting healthy lifestyles, fostering healthy coping techniques, risk
reduction and self-esteem. The Mulago Teens Club is comprised of age-specific support groups, including the Kids club (10-12 years), the Sharp club (13-15 years), the Bright club (16-18 years), and the youth club (19 years and older). Each small club has two main adult facilitators, as well as two peer leaders.

Discussion topics are prepared at a monthly planning meeting and quarterly evaluations are conducted. The Support Group curriculum includes growth and development, teasing and self-defence, relationships, sex and sexuality, HIV/STD education, risk reduction, including promotion of adherence, stigma among peers, sexual abuse, defilement and rape.

Other Activities:
- *The library* has over 100 books for adolescents to read as they wait their turn at the clinic. They may take them home for further reading. The Library also has a full time staff member who provides primary education for the children while they wait for their medication.
- *The Mulago Teen Drama Club* has very active and talented young people who often provide ‘edutainment’ for peers and promote positive prevention messages.
- *The Photography Club* offers adolescents the opportunity to use photography to document their life stories. The photos were subsequently sold in a fund raiser in the USA to contribute further to the Mulago Teens Club.
- *The Power of Hope Camp* was initiated in 2006 with the theme “Building Community to Living Healthy and Powerful Lives” in order to address some of the challenges faced by adolescents at the PIDC. The camp has become an annual event: up to 50 adolescents are pre-selected to participate in the 5-day non-residential camp. The major goals of the camp are to:
  1. Increase reproductive health knowledge among teens attending PIDC.
  2. Enable adolescents gain motivation and interpersonal skills for healthy lives.
  3. Educate and equip adolescents with life and leadership skills to reduce risky behaviours.
  4. Explore the importance of creativity and imagination of learning and positive living.
  5. Offer young people living with HIV an opportunity for joy, fun and laughter.

Camp activities include:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Name games</td>
<td>Build group and family cohesion</td>
</tr>
<tr>
<td>2 Story telling and writing</td>
<td>Explore person(s) life, experiences</td>
</tr>
<tr>
<td></td>
<td>Expand creativity and imagination</td>
</tr>
<tr>
<td>3 Dance and drama</td>
<td>Building self-esteem and talents</td>
</tr>
<tr>
<td></td>
<td>Entertainment, fun and joy</td>
</tr>
<tr>
<td>4 Poetry</td>
<td>Expression and expansion of creativity</td>
</tr>
<tr>
<td></td>
<td>Fun and joy</td>
</tr>
<tr>
<td>5 Crafts making</td>
<td>Expression of creativity</td>
</tr>
<tr>
<td></td>
<td>Build talent and skills</td>
</tr>
<tr>
<td></td>
<td>Enhance adherence</td>
</tr>
<tr>
<td>6 Meditation Healing/ Worship</td>
<td>Build relationships</td>
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<tr>
<td></td>
<td>Appreciate relaxation and calmness</td>
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<tr>
<td></td>
<td>Build attitude and personality</td>
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<tr>
<td></td>
<td>Instil hope and reduce stigma</td>
</tr>
<tr>
<td>7 Massage</td>
<td>Healing and relaxation</td>
</tr>
<tr>
<td>8 Sports: Swimming, Football,</td>
<td>Discover and sustain talents</td>
</tr>
<tr>
<td>Running</td>
<td>Physical fitness and improved body health</td>
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<tr>
<td>---------</td>
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<tr>
<td></td>
<td>Entertainment</td>
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<tr>
<td>9</td>
<td>Drama and Theatre games</td>
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<tr>
<td></td>
<td>Build confidence, power and commitment to long-term treatment, and prevention</td>
</tr>
<tr>
<td></td>
<td>Build acting skills, expand imagination and creativity, fun and joy</td>
</tr>
<tr>
<td>10</td>
<td>Theme focused dialogue</td>
</tr>
<tr>
<td></td>
<td>Sharing experiences and exchanging facts and ideas</td>
</tr>
<tr>
<td></td>
<td>Building listening, thinking, and communication skills</td>
</tr>
<tr>
<td></td>
<td>Enhance learning</td>
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</tbody>
</table>

**Achievements:**
- Working with adolescents through creative arts and learning has provided an excellent opportunity for in-depth interaction with adolescents to learn and explore what they think are the most important issues that impact on their lives, and provide an in-depth understanding of their perception of risk and the barriers to consistent reduction of risk behaviour.
- The adaptation and use of a creative facilitation/learning model has enabled the programme to contribute to youth empowerment, train ALHIV in survival and coping skills, and build leadership and friendship among teens of the Peer Support Club.
- Training of reproductive health service providers to respond to the needs of adolescents living with HIV/AIDS; building capacity among health care personnel
- Networking (co-operation with local and regional organizations in SRH)

**Challenges:**
- Out-of-school adolescents need livelihood skills and training in entrepreneurship (e.g. tailoring, hair dressing, car/motor cycle repair, catering and bakery).
- In-school adolescents often lack school fees (about 300 USD per year) and scholastic materials, and although there are organizations that support some of these adolescents, the needs are much greater than the available support.
- The prevention of unwanted pregnancies and sexually transmitted infections (dual protection) remains a challenge: by December 2012 there were nearly 110 recorded pregnancies among the teenage girls attending the PIDC, and 5 adolescents males reported that their partners were pregnant.
- Adherence: many adolescents continue to fail on their treatment regimens, especially those who have poor social support networks.
- Transitioning: even though the teen clubs are age-disaggregated, and there is smooth transitioning from one club to another, the HIV care and treatment of adolescents 15 – 19 and some young adults continues within the paediatric setup.

**Lessons Learned:**
- The baseline survey that Baylor-Uganda carried out indicated that the ALHIV in its care were sexually active, and an intervention therefore needed to be developed that included a focus on sexual and reproductive health.
- Baylor Uganda, in partnership with the Kenya Medical Research Institute (KEMRI) and the Institute of Tropical Medicine in Belgium, carried out a study on the sexual and reproductive health of young people living with HIV/AIDS (YPLHIV), which led to the development developed that is culturally
specific and adapted to fit the needs of young people in Uganda, to promote positive prevention and living with dignity.

- The intervention addresses numerous constraints and needs that YPLHIV are facing, and has the potential of reduce HIV transmission and improve their quality of life, in a manner acceptable to the Ugandan norms and culture. Among other things it aims to increase ALHIV’s knowledge, skills, motivation, self-efficacy and intentions to protect their health and the health of others by practicing safer sex and positive living.
- Baylor-Uganda is currently in the process of developing a trainer of trainer’s manual that will be used by health care providers to roll out the BFS intervention.

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**Research**

16. Research to support service providers: Zimbabwe (Rashida Ferrand et al)

**Objective:** To develop an algorithm for primary-care health workers for identifying HIV-infected adolescents in populations at high risk of mother-to-child transmission.

**Methods:** Five hundred and six adolescent (10–18 years) attendees at two primary care clinics in Harare, Zimbabwe, were recruited. A randomly extracted ‘training’ data set (n = 251) was used to generate an algorithm using variables identified as being associated with HIV through multivariable logistic regression. Performance characteristics of the algorithm were evaluated in the remaining (‘test’) records (n = 255) at different HIV prevalence rates.

**Results:** HIV prevalence was 17% among the attendees, and infection was independently associated with client-reported orphanhood, past hospitalization, skin problems, presenting with sexually transmitted infection and poor functional ability. Classifying adolescents as requiring HIV testing if they reported >1 of these five criteria had 74% sensitivity and 80% specificity for HIV, with the algorithm correctly predicting the HIV status of 79% of participants. Even in low-HIV-prevalence settings (<2%), the algorithm would have a high negative predictive value (‡99.5%) and result in an estimated 60% decrease in the number of people needing to test to identify one HIV-infected individual, compared with universal testing.

**Conclusions:** The simple algorithm that was developed can identify which individuals are likely to be HIV infected with sufficient accuracy to provide a screening tool for use in settings not already implementing universal testing policies among this age-group, for example immigrants to low-HIV-prevalence countries.

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17. Research to support programmes: Zimbabwe (Webster Mavhu)

**Background:** There is a recognized gap in the evidence base relating to the nature and components of interventions to address the psychosocial needs of HIV positive young people. Mixed methods research was used to strengthen a community support group intervention for HIV positive young people based in Harare, Zimbabwe.

**Methods:** A quantitative questionnaire was administered to HIV positive Africaid support group attendees. Afterwards, qualitative data were collected from young people aged 15-18 through tape-recorded in-depth interviews (n=10), 3 focus group discussions (FGDs) and 16 life history narratives. Data were also collected from caregivers, health care workers and community members through FGDs (n=6 groups) and in-depth interviews (n=12). Quantitative data were processed and analysed using STATA 10. Qualitative data were analysed using grounded theory principles.

**Results:** 229/310 young people completed the quantitative questionnaire (74% participation). Median age was 14 (range 6-18 years); 59% were female. Self-reported adherence to antiretrovirals was sub-optimal. Psychological wellbeing was poor (median score on Shona Symptom Questionnaire 9/14); 63% were at risk of depression. Qualitative findings suggested that challenges faced by positive children include verbal abuse, stigma and discrimination. While data showed that support group attendance is helpful, young people stressed that life outside the confines of the group was more challenging. Caregivers felt ill equipped to support the children in their care. These data, combined with a previously validated conceptual framework for family-centred interventions, were used to guide the development of the existing programme of adolescent support groups into a more comprehensive evidence-based psychosocial support programme encompassing caregiver and household members.

**Conclusions:** This study made it possible to describe the lived experiences of HIV positive young people and their caregivers in Zimbabwe. The findings contributed to the enhancement of Africaid’s existing programme of support to better promote psychological wellbeing and ART adherence.

**Contact information**
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Nicola Willis: nicola@maruva.org

18. Research: Lessons Learned about psychosocial support (PSS) in South Africa and Uganda

Efforts in diagnosing and treating HIV infections in children and adolescents contribute to healthier lives, necessitating care beyond basic medical needs. Capacity remains limited for childhood psychosocial support (PSS). Qualitative programmatic research in Uganda and South Africa, including young people with HIV, explored service/care-provider/parental challenges in meeting children’s psychosocial needs. Three areas for childhood PSS support were examined: disclosure, stigma, and grief/bereavement. Gaps, strategies and areas for capacity building were identified.

Five key recommendations are offered for improving capacity to meet the psychosocial needs of children with HIV:

1. Focus on the period immediately following a child’s HIV diagnosis
2. Reduce stigma within children’s “circles of care”
3. Build the capacity of caregivers and children to meet their own PSS needs.
4. Address grief as a process
5. Create fora for interaction and peer support

Contact Information:

Advocacy

19. East European and Central Asian Union of People Living with HIV (ECUO): Mobilization of Adolescents Affected by HIV/AIDS in EECA region

The goal of the ECUO project was to ensure that the needs and concerns of adolescents living with HIV (ALHIV) are recognized by adult PLWH, community leaders, local authorities, service providers, governments and other stakeholders. Project objectives included strengthening advocacy skills in PLHIV networks, increasing knowledge about issues relevant to ALHIV (including adherence, rights to health, education and other social services), and building networks to empower adolescents to advocate for their rights in Ukraine, Russia, Kazakhstan, Uzbekistan, Kyrgyzstan and Belarus. The project included the development and monitoring of social networking platforms, advocacy events where adolescents promoted the rights of ALHIV among national and regional leaders, and strengthening psychosocial and other services. The Project also included “mapping” of organizations that provide health and social services available to ALHIV in and beyond the Project countries.

Lessons learned emerging from the Project include:
• Despite numerous trainings on advocacy skills, participation in local and regional events, support groups, etc. many adolescents still have not accepted their HIV diagnosis. Not all adolescents are ready to talk about their feelings related to HIV, let alone speak about their lives openly. Most of them still operate only with basic information about HIV/AIDS, ARV medications and adherence.
• HIV issues are not necessarily a priority in the lives of adolescents affected by HIV/AIDS since they are too busy coping with numerous other difficult life situations, including poverty, not attending school and not having a stable place to live due to legally-enforced termination of parental rights - many parents are drug users and they often don’t care for their children.
• Adolescents are constantly living in situations of stress, stigma and discrimination, which often lead them to stop taking their ARV medication.
• Weak government support means failure to provide access to critical social services, such as placing ALHIV in foster families or boarding schools. Coordinators of projects and other initiatives end up dealing with the kinds of social issues that the government should be handling.
• By providing social assistance (either from community-based projects or sometimes, from state social services), adolescents affected by HIV/AIDS receive help in solving issues that are not directly connected to HIV/AIDS, but their quality of life still improves.

Further Information:
http://old.ecuo.org/for_about/About_mission_goal/Listovka_A4_eng_final_150.pdf
Annex 1: TAG Update on the September 2012 East and Southern Africa (ESA) regional meeting on adolescents living with HIV (ALHIV), Johannesburg, and the national ALHIV workshops held in Namibia and Zimbabwe

Background

The UNICEF/WHO/UNFPA ESA Regional meeting brought together teams from eight countries from the sub-region (Botswana, Lesotho, Malawi, Namibia, Rwanda, Swaziland, Uganda and Zimbabwe). The teams were comprised of representatives from Ministries of Health, NGOs and UN organizations, as well as young people living with HIV. The main purposes of the meeting were to:

- orient/train participants in the use of the Adolescent Module developed by WHO to accompany the existing IMAI/ART training materials;
- provide an opportunity for participants to feedback and discuss the field visits that had been carried out prior to the workshop (as a contribution to the UNICEF-led Field-Lessons project on strengthening services for ALHIV);
- identify some key activities that countries could implement to strengthen national responses to ALHIV.

The national workshops in Namibia and Zimbabwe brought together key partners involved in the provision of health services to ALHIV (Ministry of Health, NGOs, UN organizations and young people living with HIV) to provide a forum for peer review of the achievements and challenges of responding to the needs of ALHIV (diagnosis, disclosure, ART/adherence, primary care and prevention); and identify priority activities to strengthen the national response.

Outcomes

There was a very positive response from participants to the Adolescent IMAI module, and a number of countries indicated that following the workshop the materials would be adapted and incorporated into existing training materials.

Prior to the meeting the country teams were provided with a PowerPoint template for developing a brief presentation on ALHIV in their country. It was clear from these country presentations that many of the countries in the sub-region face common challenges, and that there are a wide range of activities being implemented through a range of partners (these presentations are available at www.youngpeopleandhiv.org).

The country teams were also requested to carry out a field visit to 2-4 facilities providing services to AHIV, prior to the workshop. The presentations from these field-visits were discussed in working groups, in order to identify the main achievements and challenges.

The national workshops in Namibia and Zimbabwe followed a similar outline and a number of important issues were raised:

Placing health services in a broader context

The ESAR meeting and the national workshops for the Field-Lessons project explicitly dealt with the provision of health services for ALHIV. This focus was to limit the content of the project, not to imply that ALHIV do not have a wide range of needs/rights that need to be met by a range of sectors and organizations. It was also not meant to imply that other sectors and organizations do not have
important inputs to make in terms of providing services to ALHIV—many were itemized in the “community” component of the Kampala meeting framework: facilities, community, parents/primary caregivers. The need to ensure strong linkages across sectors and organizations was emphasized frequently during the meetings, with the education sector receiving particular mention in terms of meeting the educational needs of ALHIV and supporting adherence in relation to testing and disclosure.

Responding to the heterogeneity of adolescents, and their environments
ALHIV share some common characteristics, including the developmental processes that take place during the adolescent years and the changing roles and responsibilities, including for their own care. However, there are also marked differences that need to be considered in the provision of health services. A range of factors need to be taken into consideration, including age, sex, presence of parents/guardians, in school/out of school, urban/rural domicile, mode of infection and age of diagnosis.

Focusing on what can be taken to scale in a sustainable way
The “Centers of Excellence” that have been developed in a number of countries in the sub-region clearly provide high quality services to the ALHIV who can access them. However, during both the ESAR meeting and the national workshops the question was raised as to whether these Centers of Excellence provide models that can be taken to scale in a sustainable way. In both Namibia and Zimbabwe participants were particularly interested in identifying ways to integrate a focus on ALHIV into existing programmes—such as on-going programmes for ART rollout, PMTCT programmes, or efforts to ensure that health systems are more responsive to the needs of adolescents (e.g. adolescent-friendly health services), including responding to the needs of adolescents living with other chronic illnesses. This applies to a range of activities, from training programmes for health workers, to initiating support groups for ALHIV. There are some early experiences of this in both countries, but these examples are not yet sufficiently developed to provide Field-Lessons.

Systematic planning
In both Namibia and Zimbabwe the workshops provided a welcome opportunity to strengthen collaboration, exchange ideas/experiences, and identify ways to promote the ALHIV agenda through existing channels (Zimbabwe) or contribute to the process that had been initiated in the country to develop a specific strategy for ALHIV (Namibia). In this regard it is important to be very clear about specific issues that only affect, or particularly affect ALHIV, rather than adults or small children living with HIV (e.g. consent, privacy, links with schools, etc.).

Vertical and horizontal transmission
Much of the experience to date have been based on responding to the needs of ALHIV who acquired HIV perinatally (and mostly for those adolescents who were diagnosed early – there is less experience with adolescents diagnosed at later stages). It will be important in the generalized epidemics of sub-Saharan Africa to identify those adolescents who have acquired HIV horizontally, who for the most part remain undetected but are almost certainly the majority of ALHIV (based on available epidemiological data).

Data for planning, monitoring and evaluation
In general there is very little concrete data about ALHIV, with countries still using a 0-1, 5-14, 15-49 years age categories for their statistics, which effectively hides adolescents ages 10-19. There are some early efforts to change this (e.g. Zimbabwe), but they are not yet sufficiently developed to provide Field-Lessons. In general, there is not much systematic monitoring taking place (let alone structured
evaluations), and it remains a challenge to balance enthusiasm and anecdote with assessments of effectiveness. There are many unanswered questions relating to ALHIV that countries will need to answer if they are to plan effectively, and there are some good examples of research being carried out that have important implications for diagnosis and treatment in Zimbabwe.

**Diagnosis**
While many perinatally infected adolescents are diagnosed early, late progressors are often not diagnosed until too late and those adolescents who acquire HIV through sexual transmission may not be diagnosed until much later. This is a major challenge. Tracking what actually happens (in both guidance and actual practice) after an HIV test is also a challenge: what happens for those who are HIV negative? Those who are HIV positive who do not yet need ART? Those who are HIV positive and need ART? There is also a need to tease out the implications of “couple-counselling” in relation to adolescents, and an important aspect of diagnosis that appears to have received far too little attention is provider initiated testing and counselling (note research from Zimbabwe).

**Disclosure**
There remains some confusion around the discussions about disclosure. Much of the current attention still focuses on disclosing to adolescents. While this remains important, a major challenge will be the supportive disclosure by adolescents. There are some programme support tools available for disclosure “to” (Namibia) – interestingly, for a number of reasons (including guilt and possible blame) it seems to often be the parents who do not want the diagnosis disclosed. There are also some early experiences with supporting disclosure “by” (Zimbabwe) – it was stressed that ALHIV peers often provide the most useful support for doing this (e.g. role plays, and creative ways to assess the “readiness” of a partner to respond positively to disclosure). Discrimination remains a major problem for ALHIV and this is a strong disincentive to disclosure.

**Adherence**
This is really at the heart of services for ALHIV and needs significant work, both to properly assess adherence (a number of people, including the ALHIV who participated in the national meetings, noted that adolescents are very good at ensuring that their pill count is correct!) and to support it. There are clearly lessons from the Centers of Excellence, but these need to be translated into the routine health systems and services where resources are fewer and more stretched. As with disclosure, ALHIV peers may provide an important contribution in terms of providing guidance and supporting adherence. Within the context of adherence, it is also important to give consideration to the wider issue of retention (for adolescents requiring treatment and for those who are HIV positive but not yet in need of ART).

**Primary care for ALHIV**
In general, these issues were not well addressed during the workshops. People have not given sufficient thought to them and they are areas for further development, in particular sexual and reproductive health, mental health and nutrition.

**Prevention for ALHIV**
It was clear from the national workshops that this remains a challenging aspect of national responses to ALHIV - even ensuring that, at a minimum, ALHIV use condoms when they have sex. There has been some research from Uganda that indicates that non-disclosure and un-safe sex remain high, and that while condoms may be available in clinics they are frequently not easily accessible to ALHIV.
Support for ALHIV and their parents
There was consensus from all of the meetings and from both service providers and ALHIV that more attention needs to be given to the development of support groups for ALHIV (existing PLHIV support groups frequently do not respond well to the specific needs of adolescents) and their parents/primary caregivers. How to do this in ways that are adequate and can go to scale remains a challenge, although there are some early promising experiences in Zimbabwe.

Programme support tools and capacity development
Countries are slowly developing/using programme support materials for training health workers to respond more effectively to the needs of ALHIV; for providing ALHIV with information; and for supporting ALHIV support groups (Zimbabwe). But there is an urgent need to identify and make available materials that are being developed more widely in the sub-region (a number of which were presented in the ESAR meeting) so that countries can learn from and adapt materials that have already been developed, rather than starting from scratch. Hopefully it will be possible to do a better job of this through the new Young People and HIV website:

Use of new information technologies (m-health)
In view of the extensive (and growing) coverage of mobile phones, and the ease with which young people use this technology, countries are interested to explore the potential for m-health in relation to service provision for ALHIV.
1. Overview

HIV among adolescents is an important and growing problem. It is a problem that is in part due to (a) the successful roll out of early infant diagnosis and paediatric AIDS treatment and suboptimal coverage of PMTCT; and (b) unsuccessful HIV prevention among adolescents (sexual--heterosexual and MSM--and IDU transmission). The former cause should decrease as PMTCT programmes become more successful (i.e. it should be a time-limited problem), but in any event adolescents living with HIV (ALHIV) are likely to require attention for at least the next 20 years, as the 400,000 plus infants and young children started on ART transition into adolescence and adulthood.

Many biological and developmental changes take place during adolescence, which are also impacted by environmental factors. This needs to be taken into consideration in the development, implementation and monitoring of interventions for ALHIV.

Three different groups need to be considered:
1. Adolescents who have been diagnosed in infancy and who have been on treatment for many years by the time that they reach adolescence;
2. Adolescents who are “slow progressors”, who were infected perinatally but not diagnosed and who only become symptomatic/recognized by the health services during their early adolescent years;
3. Adolescents who become infected during the adolescent years through sexual transmission (sometimes forced/coerced), through injecting drug use (in generalized epidemics, key affected populations and vulnerable groups of adolescents) and a small and rarely quantified group through nosocomial transmission or traditional practices.

Each of these groups has specific needs and challenges. In sub-Saharan Africa, groups one and two predominate, and in all countries these two groups are likely to predominate in early adolescence. However, little is known about the third group, as few are tested.

In general, adolescents need what adults need. But:

- They are less likely to be tested and less likely to be linked to services if they test positive. In terms of PMTCT, they are less likely to reach ANC services early. (It should also be noted that adolescents who have tested negative for HIV are often not linked to prevention services in order for them to remain HIV negative);
- There are many challenges related to “beneficial disclosure” (i.e. disclosure to a family member/peer to support coping, access and adherence). There are often challenges with disclosure to sexual partners, as the nature of these relationships may differ from a relationship between adults and adolescents often have less developed skills in communication and negotiation than adults in sexual relationships.
- Adolescents may face particularly harsh discrimination, blame, or stigma as a result of being HIV positive;
- Some adolescents who were vertically infected and diagnosed early may have already been on treatment for 10 or more years. They may have been started on sub-optimal HIV regimens, faced treatment interruptions and/or have complex HIV disease with various drug resistance mutations.
• As with other chronic illnesses during adolescence, ALHIV often have serious problems with adherence (most research shows that adherence is worse in adolescents than it is in adults on ART);
• There are major challenges with ensuring that ALHIV protect themselves and their partners from HIV transmission (poor condom use);
• Adolescents may face a variety of chronic illnesses and developmental delays, particularly adolescents who were vertically infected and had delayed or sub-optimal treatment; adolescents who have been on treatment and have drug-related adverse consequences; and ALHIV requiring treatment and care for depression;
• Alcohol, drug use and other potentially risky behaviours that are often initiated during adolescence.

There is an urgent need for mobilization and training in the following areas:
• There are some different things to be done for/with adolescents. For example there are different settings to consider, such as schools and parents, and different issues, for example consent (and opportunities to use different human rights instruments e.g. the CRC).
• There are some adolescents who are especially different, who have particular vulnerabilities, for example adolescents living without parents, facing multiple family losses and stresses, complex life situations, responsibilities and constraints (including adolescent heads of households and adolescent OVCs with high rates of sexual and physical abuse)
• There are some things that need to be done differently for adolescents, for example, adolescents are likely to benefit a great deal from services being brought closer to them, through decentralization, flexible clinic times, for example outside school hours, days for ‘adolescents only’, flexible appointments. However, this will only be effective if health and community workers are trained to respond to the specific needs of adolescents, if support groups for adolescents are similarly decentralized, if there are systems for monitoring the response to ALHIV through the disaggregation of routinely collected data, and if there are effective systems of referral for adolescents who develop complications that require secondary/tertiary care.

It also needs to be recognized that there are MANY issues related to young key affected populations, who are frequently “the neglected of the neglected”: nobody wants to respond to the needs of young IDUs, young MSM or young sex workers/children who are sexually abuse/exploited.

2. Overall Recommendations
Adolescent-related issues that require consideration in the provision of HIV services:

1. Adolescents are not all the same

The heterogeneity of adolescents needs to be recognized, including differences in modes of transmission, gender, sexual orientation, and transitions to adulthood. Service delivery responses therefore need to reflect this heterogeneity

2. Integration not parallel systems, whenever possible

If possible, interventions for diagnosis, treatment and care for adolescents should be integrated with those being provided for adults and younger children, and with efforts to ensure that the health sector
is able to respond effectively to the specific needs of adolescents in general (e.g. “adolescent-friendly health services”)

3. **HIV is an opportunity to move the adolescent health agenda**

Every effort should be made to maximize the opportunities that treating ALHIV provides to focus more generally on strengthening national efforts directed to adolescents with chronic illness, to the provision of services more generally for adolescents (e.g. sexual and reproductive health) and for improving national data collection and analysis (HMIS).

4. **Involving adolescents is essential**

ALHIV need to be involved with many aspects of programming: advocacy, leadership, planning and implementation (for example as peer educators, through peer-support groups, providing ideas and support for disclosure and adherence, etc.), as well as making decisions and choices about their own health care. Ministries of Health need to ensure that adolescents’ contributions to service delivery are formally included and recognized in national plans, and remunerated.

5. **Testing and links to treatment and care**

All adolescents should have access to testing, but it is essential to ensure that those who are most vulnerable and those with high-risk behaviours, including young key affected populations, are supported to access testing. Also crucial is linking testing to adequate post-test counselling (something that is particularly important for adolescents), and, depending on the results of the test, treatment/care and prevention services. While there may be specific programmes developed to test adolescents (e.g. through schools), strategies that are directed to adults also need to take the needs of adolescents into consideration: community-based counselling/testing, PMTCT and PITC.

6. **Training health workers and others responsible for treatment/care**

All health worker training, supervision and support requires adequate attention to adolescents, including a focus on support for disclosure, adherence, prevention and primary care. It is important not only to sensitize them to understand how adolescents are different from adults and small children, but that they are aware of and link with available resources that can support adolescents (e.g. community health workers, NGOs/CBOs, ALHIV peer support groups). There is a need to focus explicitly on:

- Disclosure: Ideally, by the time children reach adolescence they will have been disclosed to about their own HIV status and the status of their parents/guardians/care givers. Adolescents need additional support to disclose (a) to others in order to obtain the support that they need; and (b) to sexual partners in order to contribute to safer sex / HIV prevention.
- Primary care: Chronic illnesses in ALHIV and mental illness
- Prevention: Condoms, adherence, prevention of high-risk behaviours (e.g. alcohol and substance use)
7. Parents and caregivers

Parents and caregivers typically play a central role in the provision of services to ALHIV, including support for adherence. Parents and caregivers need to be supported to carry out this role effectively, through the provision of information, support groups, etc. (though it should be acknowledged some adolescents either do not have parents or have unsupportive or abusive parents – this may a particular issue for adolescent key affected populations and has important implications for informed consent by adolescents themselves)

8. Data

Disaggregation of data remains a challenge (or in many cases not aggregating data as it moves up the reporting system) – there is still very minimal knowledge about ALHIV because of the way that data are aggregated (0-14, 15-24, etc.)

9. Policies and legislation

There are a number of policies that require attention—in particular, policies/legislation relating to informed consent by adolescents (without parental consent) and to adolescent key affected populations.

10. Operations research and documentation

There is a need for more operations/implementation research, and better documentation and sharing of experiences and lessons learned to guide programming in the absence of an extensive research base.

3. Specific recommendations for the Operational and Service Delivery Guideline Development Group Meeting

Community based HIV testing and counselling

This issue is very important for adolescents, as it can increase the likelihood of adolescents being tested (this is particularly important for older adolescents who were horizontally infected as this group is very under-tested in generalized epidemics). Note: late progressors are more likely to be diagnosed through PITC. However, while increasing HIV testing of adolescents is important, it is also essential to give adequate attention to:

- Post-test counselling, links to services (prevention and treatment/care) and consent/confidentiality
- Understanding that adolescents found to be HIV positive may not require treatment yet, but they do need care and retention by the health system
- Special issues for adolescents from key affected populations accessing testing and adequate counselling
Decentralization of HIV care and treatment
Again this is important for adolescents, as this is likely to make their access to services easier. BUT it is important to ensure that:

• Service providers have some minimal training to respond to the specific needs of adolescents, and are able to support adherence and disclosure by adolescents, and prevention (i.e. condom use) and link with others (e.g. community groups and community workers who may be better able to support the particular needs and complex challenged adolescents face);
• Support groups for ALHIV are also decentralized where appropriate (although this may not be the case in all epidemic scenarios and contexts);
• Special consideration is taken for adolescent key affected populations;
• Non-decentralized specialist units are considered for concentrated and low prevalence settings where numbers of ALHIV seen are general care facilities are low;
• There is adequate age and sex disaggregation of routinely collected data for monitoring and planning;
• There are effective systems of referral for problems (e.g. chronic illnesses, depression, SRH, etc.).

Integration of HIV treatment with TB, ANC/MNCH, and IDU services
We need to:

• Have ways to encourage adolescents to go early for PMTCT/ANC and to support them through their pregnancy, to access and adhere to ART for PMTCT and ART for their own health, make safe infant feeding choices, postpartum family planning choices, involve ‘the father’/partners and supportive family members, etc.
• Consider linking to efforts to make health services more responsive to the needs of adolescents (not just MNCH but MNCAH).
• Recognize that young injecting drug users (and other key affected populations) are the least likely to use health services (so HIV treatment needs to be integrated into IDU services) - for all programme issues there are challenges in terms of young key affected populations (including legislative issues).
• Ensure that adolescents are explicitly included in national plans/strategies.

Task shifting for HIV care and treatment
For this to work for adolescents:

• The people to whom the tasks are shifted need to be trained to respond to the needs of adolescents;
• There needs to be strong linkages to NGOs and community groups working with adolescents/ALHIV who can support disclosure, adherence, etc;
• Involvement of ALHIV and parents.

Use of mobile technologies for adherence support, and social support for PLHIV
Mobile technologies have been used successfully for other chronic illnesses among adolescents and this is a technology that many adolescents are familiar with. But:

• ALHIV need to be involved in the development of the programmes
• ALHIV need to be involved in the social support of ALHIV (support groups)
• Parents need to be supported to support adolescents (information, skills, etc.)
## Annex 3: Example of an Outline for Documenting Case Descriptions of Health Services for ALHIV

<table>
<thead>
<tr>
<th>Contact information</th>
<th>Details of key contact persons (phone and email) plus relevant websites</th>
</tr>
</thead>
<tbody>
<tr>
<td>Programme Component</td>
<td>Select from: diagnosis; disclosure (to, but particularly by adolescents); access to treatment; adherence; prevention (with/for ALHIV); primary care (e.g. sexual and reproductive health, nutrition and mental health)</td>
</tr>
<tr>
<td>Setting the scene</td>
<td>Background information about the HIV epidemic with a particular focus on HIV among young people (HIV/YP) and adolescents living with HIV (ALHIV), including trends, projections and disaggregation (e.g. by age, sex, mode of transmission)</td>
</tr>
<tr>
<td>Setting the scene</td>
<td>Background information about the national response to prevention among young people; meeting the treatment/care needs of adults living with HIV; and adolescent health more generally (e.g. adolescent friendly health services)</td>
</tr>
<tr>
<td>Setting the scene</td>
<td>Background information about the organization that is implementing the programme (including experience with HIV/YP and ALHIV)</td>
</tr>
<tr>
<td>Programme description</td>
<td>Details about the programme: when was it started, rationale (any background research), aims and objectives, planning process, level(s) of implementation (facilities, communities, families), links with other sectors/organizations, links with other components, funding base</td>
</tr>
<tr>
<td>Programme description</td>
<td>Progress to date, including achievements, coverage, costs, key partners, working through/integration with existing systems and structures, referral/linkages with other sectors/organizations,</td>
</tr>
<tr>
<td>Programme description</td>
<td>Challenges in terms of planning, implementation, co-ordination, sustainability, resourcing and monitoring</td>
</tr>
<tr>
<td>Measuring success</td>
<td>Quantitative indicators of success: monitoring and evaluating inputs, processes, outputs, outcomes, impact – including as much information as possible on how many ALHIV have been reached with specific interventions</td>
</tr>
<tr>
<td>Measuring success</td>
<td>Qualitative indicators of success</td>
</tr>
<tr>
<td>Measuring success</td>
<td>Perspectives of ALHIV and of key partners (peer review)</td>
</tr>
<tr>
<td>Factors contributing to success</td>
<td>Factors that contributed to &quot;success&quot;: clear and realistic objectives, adequate planning and monitoring, integration with existing programmes, sufficient human resources (including training and supervision) and financial resources, links with other chronic diseases in adolescents</td>
</tr>
<tr>
<td>Factors contributing to success</td>
<td>Factors that have delayed/obstructed progress</td>
</tr>
<tr>
<td>Factors contributing to success</td>
<td>Involvement of ALHIV in planning, implementation and monitoring</td>
</tr>
<tr>
<td>Expansion and replication</td>
<td>What would be needed to increase the coverage or quality of the interventions being delivered</td>
</tr>
<tr>
<td>Expansion and replication</td>
<td>Recommendations for other countries, including any specific contextual factors that have influenced the outcomes</td>
</tr>
<tr>
<td>Expansion and replication</td>
<td>Specific training materials or programme support tools developed/used by the programme</td>
</tr>
<tr>
<td>Conclusions</td>
<td>Overall reflections, including key lessons learned and implications for other countries developing interventions for ALHIV</td>
</tr>
</tbody>
</table>
Endnotes

iii http://www.k4health.org/toolkits/alhiv
iv http://www.ippf.org/resources/publications/healthy-happy-hot
vi Primary care: ASRH (a range of family planning/contraception, sexual violence counselling, HPV screening, pregnancy care, PMTCT, STI screening/treatment), mental health screening/treatment/counseling, psychological support, nutrition education and nutritional support,

viii http://www.aidstar-one.com/sites/default/files/ALHIV%20techbrief%202012July10_AFR%20bureau.pdf
ix http://www.aidstar-one.com/focus_areas/care_and_support/resources/technical_briefs/alhiv_transitions
x http://icap.columbia.edu/resources/detail/adolescent-hiv-care-and-treatment

xii http://www.stopaidsnow.org/sites/stopaidsnow.org/files/PY_Adressing%20the%20needs%20of%20young%20people%20living%20with%20HIV.pdf
xiii http://www.iasociety.org/Abstracts/A200737474.aspx
xv http://www.ippf.org/resources/publications/love-life-and-hiv

xvii Concurrent processes include the Expert Meeting for the Development of the WHO/UNICEF/UNFPA Guidelines for Adolescents and HIV (see Annex 2) and the USAID-funded AIDSTAR-One project mapping services for ALHIV in five countries in sub-Saharan Africa (Kenya, Malawi, Mozambique, Zambia and Zimbabwe)

xviii Programmes related to testing, entry and retention to treatment and care, adherence, prevention for ALHIV (e.g. avoidance of high-risk behaviours) and primary care for ALHIV (e.g. care for chronic illnesses and sexual/reproductive health).

xx With this project, “sheltering” refers to the role of the peer educator in providing support to newly diagnosed young people by accompanying him/her through counseling and medical appointments, providing insight and support related to treatment and adherence to treatment, and offering social support in and outside of the clinic walls. Sheltering also included the role the peer educator served in providing home visits to young clients and their families once the young person chose to disclose.

xxi The programme has received numerous accolades and has been showcased at AIDS conferences around the world. In 2010 the organisation received the prize for Best Sport for Health project at the Global Sports Forum in Barcelona, Spain, and was also awarded one of twenty Football for Hope Centres to be built by FIFA throughout Africa as part of the social legacy of the 2010 FIFA World Cup. The WKU programme is directly committed to six of the eight Millennium Development Goals (MDGs) and as such Africaid WKU is the United Nations Chapter for KwaZulu Natal promoting the MDG’s.

xxii Financial Support: the bi-monthly meetings cost an average of 500 USD, which includes a snack, a drink, transportation allowances, photography and materials for use. Initial funds were from the Bill and Melinda Gates Foundation, then Bead for Life, then from the International Relief Teams. Currently the Mulago Teens Club is part of the PIDC, Mulago (Baylor College of Medicine Children’s Foundation Uganda).


xxiv A significant proportion of clients at PMTCT services are likely to be adolescents, evidence suggests that this population are least likely to attend early, be tested for HIV, etc.