Ending the HIV Epidemic Among Adolescents Requires Responsive Clinical and Psychosocial Services Tailored to Meet Their Unique Needs

The Challenge

Adolescence is a complex and challenging period of transition from childhood to adulthood. For adolescents living with HIV, daily medicines, frequent clinic visits, bouts of illness, and disclosure to family, friends, and partners create additional stresses. Many HIV policies and programs have been designed specifically for children or adults, leaving adolescents without services to meet their unique needs.

Globally, HIV-related deaths have declined dramatically for all age groups except adolescents aged 10–19. There are 1.8 million adolescents living with HIV around the world—with 250,000 new HIV infections among 10–19-year-olds in 2017 alone—yet the majority are not getting the lifesaving, lifelong treatment they need. As a result, HIV remains one of the leading causes of death among adolescents worldwide.

At each step of the HIV care continuum, adolescents lag behind adults. According to survey data in sub-Saharan Africa, only nine percent of boys and 13 percent of girls aged 15–19 were aware of their HIV status. Recent Population-based HIV Impact Assessment (PHIA) surveys, funded by the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) and supported by ICAP, show that viral suppression is lowest among adolescents and young adults. In addition, unmet needs for sexual and reproductive health services mean that adolescent girls and young women living with HIV have high rates of unplanned pregnancies and poorer pregnancy outcomes, including increased risk of mother-to-child transmission of HIV.

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1 UNICEF 2017 data
2 UNAIDS 2018 estimates
3 UNICEF. Turning the tide against AIDS will require more concentrated focus on adolescents and young people. 2016.
ICAP's interdisciplinary approach to adolescents champions the use of data-driven methods to bridge knowledge gaps, ensure data quality, monitor progress, and translate a nuanced understanding of the adolescent HIV epidemic into improvements at all levels of the health system. ICAP's work for and with adolescents spans the HIV prevention and care continua (see Figure 1) and seeks to improve service quality and outcomes at each stage by providing:

**Technical Approach**

ICAP’s interdisciplinary approach to adolescents champions the use of data-driven methods to bridge knowledge gaps, ensure data quality, monitor progress, and translate a nuanced understanding of the adolescent HIV epidemic into improvements at all levels of the health system. ICAP's work for and with adolescents spans the HIV prevention and care continua (see Figure 1) and seeks to improve service quality and outcomes at each stage by providing:

1. **Global leadership** in clinical research, policy development, and implementation science to advance the standards for adolescent HIV prevention, care, and treatment services

2. **Support to ministries of health** to develop, implement, and scale up evidence-based policies and guidelines for high-quality adolescent prevention, care, and treatment services

3. **Health facility-based support**, including adapting ICAP’s generic training curriculum, *Adolescent HIV Care and Treatment for Health Workers,* and providing mentorship to ensure that policies are effectively translated into practices that drive improved outcomes for adolescents

4. **Adolescent peer educator training and mentorship**, including use of ICAP’s *Positive Voices, Positive Choices,* an adaptable training curriculum for young peer workers, and working with ministries of health to implement and monitor successful peer support programs

5. **Opportunities for south-to-south exchange** through multi-country learning collaboratives, including *The HIV Coverage, Quality, and Impact Network (CQUIN),* which supports communities of practice to develop and adapt solutions to common challenges in the delivery of quality differentiated services for adolescents living with HIV

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**FIGURE 1**

ICAP’s Approach to Improving Services and Outcomes for Adolescents Across the Prevention and Care Continua

1. **EXPANDING HIV TESTING**
   - Community-based testing
   - Testing at schools/colleges
   - Testing in maternal and child health services
   - After-school and weekend hours at health facilities
   - Self-testing
   - Peer education and mobilization

2. **LINKING ADOLESCENTS TO CARE AND TREATMENT**
   - Strong linkages from testing to care
   - Escort to ART services
   - Rapid/same-day ART initiation
   - Community ART initiation
   - Using technology (e.g., SMS appointment reminders)
   - Active tracking and follow-up
   - Psychosocial and disclosure support
   - Youth groups and peer clubs

3. **KEEPING ADOLESCENTS IN CARE AND SUPPORTING ADHERENCE**
   - Adolescent-friendly clinics with after-school and weekend hours
   - One-stop shopping, including SRH and tailored psychosocial support
   - Differentiated service delivery for adolescents
   - Behavioral and mental health services
   - Adolescent antenatal and postnatal care
   - Peer education, peer clubs, and virtual peer support via social media
   - Technology to engage adolescent clients (e.g., SMS appointment and medication reminder Apps)
   - Active follow-up from missed appointments
   - Support for caregivers, especially of younger adolescents
   - Transition preparation, planning, and support for older adolescents
   - Linkages to educational and economic strengthening

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4. **PREVENTING NEW ADOLESCENT HIV INFECTIONS**
   - Risk reduction counseling
   - Screening and treatment for sexually transmitted infections
   - Sexual and reproductive health (SRH) services
   - PrEP, including for young members of key populations and others at substantial risk of infection
   - Linkages to PMTCT
   - Adolescent-friendly, gender-based violence services
   - Repeat HIV testing if negative
   - Peer education and mobilization

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5. **95-95-95**
   - **EXPANDING HIV TESTING**
   - **LINKING ADOLESCENTS TO CARE AND TREATMENT**
   - **KEEPING ADOLESCENTS IN CARE AND SUPPORTING ADHERENCE**

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6. **95-95-95**
   - **PREVENTING NEW ADOLESCENT HIV INFECTIONS**
Some deep, underlying issues have been unearthed regarding various barriers the clients go through, both clinically and socially. Clients who had earlier felt alone, ignored, rejected, and with low self-esteem found a ‘family’ where interactions and sharing of experiences helped them feel more stable."

- John Matinde, Social Worker

ICAP built on its existing relationships with the Kenya Ministry of Health and seven participating health facilities to launch the HOPE Project. Key implementation steps included:

- Orienting health management teams and maternal and child health clinic staff to the project and its objectives
- Selecting nurses and hiring age-appropriate mother mentors
- Adapting existing ANC and PNC materials to be more adolescent-friendly, including tailoring group education sessions per national ANC guidelines to address the specific needs of adolescents and incorporating aspects of Kenya’s national adolescent package of care guidelines into ANC and PNC services
- Developing new clinical and monitoring and evaluation tools to capture participation in group ANC and PNC sessions, and to capture reasons for lack of attendance at sessions, receipt of care at other facilities, linkage to community resources (e.g., job training, educational, orphan care), and graduation from the program

Context

Adolescent and young mothers living with HIV experience overwhelming stigma and other barriers to care, with the result that many miss their clinic visits and their antiretroviral therapy (ART) doses, and sometimes drop out of care completely. The Kenya Ministry of Health and district and facility teams in western Kenya recognized the need to tailor antenatal and postnatal care (ANC and PNC) services to adolescent and young mothers’ special needs in order to help them stay in care, take their medicines, and keep their babies healthy and HIV-free.

Approach

The HOPE Project was launched in 2017 to create a supportive, adolescent-friendly care environment for young mothers living with HIV. With support from the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) through the Centers for Disease Control and Prevention (CDC), ICAP is working with staff at seven health facilities in Kenya’s Kisumu and Siaya counties to pilot Group Antenatal Care and Group Postnatal Care. These groups reorganize care for pregnant and postnatal women who are 25 years of age or younger and living with HIV.

Rather than scheduling individual visits, the young women attend monthly group sessions that include all of the clinical care recommended in Kenya’s national guidelines, along with unique support services that help them feel less isolated and more empowered to take care of themselves and their babies. At each group visit, women play an active role in their care by taking their own weight and blood pressure measurements and assessing each other’s ART adherence.

Outcome

So far, more than 300 young women have participated in a total of 11 ANC and nine PNC groups. And their enthusiasm is palpable. Reduced wait times and newfound peer support are increasing retention along the PMTCT cascade, and two-way engagement between participants and clinic staff has led to a deeper understanding of the challenges that young women living with HIV face. The HOPE Project has gained widespread support from the Kenya National AIDS Control Program and there are plans to scale it up nationally. In 2019, ICAP will conduct a rigorous evaluation of the project so that findings can be shared with the global community and contribute to the scale-up of more responsive models of care for adolescents.

Case study

Adolescent and Young Mothers

Find Mutual Support through the HOPE Project in Kenya

“I cannot imagine returning back to individual care since I have made friends here with whom I share my deepest concerns. We remind each other that we are together in this journey and I have not missed any clinic appointments because I look forward to these group sessions.”

-A young mother and HOPE Project participant

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Adolescents living with HIV face unique developmental, social, and health-related challenges. There is a need to move beyond the idea that adolescents are just poorly adherent “big kids” or “little adults.” Following are several considerations for implementing responsive and effective HIV programs for—and with—adolescents.

Adolescents are a diverse group
Younger adolescents aged 10–14 have different needs than older adolescents 15–19, which should also be reflected in the age bands used in adolescent program monitoring and evaluation. Adolescents of different ages and lifestyles—urban and rural adolescents, unmarried and married adolescents, and in- and out-of-school adolescents—need individualized approaches. Adolescent key populations (men who have sex with men, sex workers, or those who inject drugs), also have a special set of needs that will not be met by a one-size-fits-all approach. Through differentiated service delivery, adolescent services can be tailored to meet the needs of this diverse and ever-changing group.

Adolescents deserve to be treated with respect and dignity by health workers
Adolescents living with HIV often face immense stigma and discrimination, including at health facilities. Health workers need ongoing training and mentorship to provide dignified and non-judgmental counseling and support to adolescents in their care.

One-stop health services are important to adolescents
Adolescents are busy with school, work, family, and friends. It is important to offer a range of accessible, confidential services to meet their needs, including non-judgmental sexual and reproductive health services, counseling and mental health services, and comprehensive HIV care—all within a single visit.

Considerations for Implementation

Adolescents must be meaningfully included in the design and implementation of programs intended to reach them. Peer influence and the desire for connection are incredibly powerful forces for adolescents, which HIV programs can leverage through well-designed peer education programs and by providing opportunities for friendship, skill-building, and collective activism.

Go where adolescents are to best reach them
Adolescents are in their communities, at school, and often on their phones using social media. It is critical to move outside of health facilities to engage and serve them, including through the use of innovative technologies.

Psychosocial support is a key element of differentiated service delivery for adolescence
Adolescence is a phase of life characterized by many developmental, emotional, and physical changes, which are compounded by the challenges of living with HIV. Adolescents need ongoing, developmentally appropriate psychosocial support through their highs and lows and as they transition into early adulthood. Further, a holistic approach that considers social protections against abuse and discrimination, educational opportunities, and economic empowerment is needed to ensure that adolescents not only survive, but thrive, well into adulthood.
Latest data from PHIA surveys.
Available at:
https://phia.icap.columbia.edu/

ICAP Viral Load Flip Chart for Adolescents.
Available at:
http://icap.columbia.edu/ptb-vl-flipchart-adol

Available at:
http://icap.columbia.edu/ptb-positive-voices

Available at:
http://icap.columbia.edu/ptb-chw-adolescent

Recording available at:
http://icap.columbia.edu/ptb-dsd-webinar

CQUIN Community of Practice Meeting on Differentiated Service Delivery for Adolescents Living with HIV. October 2017.
Meeting report and presentations available at:
http://icap.columbia.edu/ptb-dsd-meeting

Reif LK, McNairy ML, Lamb MR, et al. Youth-friendly services and differentiated models of care are needed to improve outcomes for young people living with HIV. Curr Opin HIV AIDS. 2018 May;13(3):249–256.
Available at:
http://icap.columbia.edu/ptb-dsd-youth