Challenges and potential strategies for supporting adolescents living with HIV in Ndola, Zambia: Results from a study dissemination meeting

This document summarizes the main challenges and potential strategies for supporting adolescents living with HIV identified by key stakeholders during the October 2013 dissemination meetings for the USAID Preventive Technologies Agreement-funded study called, *HIV Prevention and Family Planning Use among Adolescents on ART.*









CHALLENGES DISCUSSED

Youth programs

- Financial support from hospital administration and outside donors is lacking for adolescent-specific activities.
- It is challenging to hold youth support group sessions or train peer educators given staffs' current responsibilities and skills.
- Many youth attending the clinic are not aware of existing adolescent support groups.

HIV disclosure

- Caregivers and clinic staff find it difficult to disclose a positive HIV status to adolescents.
- Parent/guardians and clinic staff are uncertain about who among them should give youth age-appropriate HIV disclosure messages.

Parent/guardian involvement

- No formal clinic system exists for involving parent/guardians in adolescents' care and treatment. Challenges discussed include parent/guardian work schedules and transportation and the role of guardians, including who is responsible for the adolescent.
- Some parent/guardians lack knowledge or skills on how to care for or talk to their adolescent about HIV and antiretroviral therapy (ART).
- Sexual and reproductive health (SRH) services for adolescents living with HIV
- Clinics do not provide contraceptive methods other than male and female condoms. Staff are not trained to talk with youth about SRH, which could augment sexual education information provided in schools. Concerns exist that some parents may easily misconstrue SRH education for promotion of sexual activity.
- Some frontline health care workers may themselves be judgmental about providing SRH services for adolescents and turn them away. Overall, youth-friendly family planning services are lacking.
- The national family planning training curriculum does not include specific guidance on meeting the needs of adolescents.

Adherence to ART

- When young people do not know their HIV status they do not understand why they are taking antiretroviral drugs; this lack of understanding can lead to incomplete adherence.
- Adolescents often do not want to take ART in front of others due to the risk of unintentional disclosure.
- Alcohol use and peer pressure affect adolescents' adherence to ART.

Other challenges

- Stigma and discrimination against people living with HIV remains a problem; many youth reported a sense of worthlessness and shame about having HIV.
- Youth-friendly mental health and sexual- and gender-based violence (SGBV) services are lacking, especially those targeted toward adolescents living with HIV, who have often experienced multiple traumas in their lives.
- Some raised the issue of female adolescents having sex with older partners for financial reasons, putting them at risk for HIV re-infection and other sexually transmitted infections (STIs).

POTENTIAL STRATEGIES

Youth programs

- Create and strengthen adolescent support groups at ART clinics.
 - Use existing manuals, such as *Positive Connections* (see Resources section below), that provide guidance to adults who lead adolescent support groups, share information, and build skills on such issues like disclosure, adherence, stigma, and SRH.
 - Incorporate fun activities and outings into youth activities create a safe space for young people.
 - Make sure all youth enrolled at the clinic know about existing youth groups and activities.
 - Connect clinic youth programs with livelihood groups, income-generating activities, and local nongovernmental organizations, such as the Ndola Youth Resource Center.
- Train young adults (ages 20–24) living with HIV to lead group sessions or serve as one-on-one mentors for adolescents living with HIV. Mentors can support youth on topics such as disclosure, sexual behavior, mental health, stigma, adherence, etc.

HIV disclosure to youth and disclosure by youth to others

- Enhance dialogue between parent/guardians and clinic staff on disclosure to children and youth using existing guidelines, such as the WHO guidelines mentioned in the Resources section below.
- Train clinic staff and parent/guardians to support youth in developing disclosure skills, including making decisions about disclosure

Parent/guardian involvement

- Create parent/guardian "buddy groups" to provide training and support to parent/guardians on fostering HIV care and management among adolescents living with HIV. These groups could meet quarterly and could incorporate fundraising and/or hospital management support.
- Use participatory approaches to best engage adolescents living with HIV and their families.

Sexual and reproductive health

- Provide comprehensive SRH information to adolescents in clinics.
 - Provide information on all contraceptive methods, including abstinence and demonstrations on how to use male and female condoms; emphasize that condoms are free at the clinics.
 - Use existing information, education, and communications materials for youth about SRH (see Resources below).
 - Share SRH information with parent/guardians.
 - Designate an SRH focal person (peer educator or a clinic staff member) at clinics to provide information for youth.
- Routinely refer youth to STI testing or family planning services.



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Adherence to ART

- Promote discussions with parent/guardians about telling a young person that he or she is living with HIV in order to support their treatment adherence and HIV self-management behaviors.
- Hold adolescent support groups on the weekends when more youth may be able to participate.
- Incorporate adherence messages in discussions and services around SRH (e.g., emphasize the important of adherence to ART to prevent infecting a sexual partner or future children, as well as to support their own health).

Holistic care and support

- Integrate mental health services into HIV care and treatment.
 - Train psychosocial counselors to be youth-friendly and to focus on helping adolescents who are living with HIV accept and cope with their HIV status and deal with HIV care and stigma.
 - Designate a focal person who is trained in youth-friendly mental health counseling.
 - Have a psychologist or psychiatrist at the HIV clinic one day a week (at least one of the study clinics is currently doing this).
 - Explore opportunities to screen youth for depression and sexual- and gender-based violence during routine clinic visits and strengthen referrals for these services.
- Strengthen relationships with and the referral process for medical services and other organizations for youth and families.
- Work with clinics to determine whether there are volunteer opportunities or jobs for adolescents living with HIV in the clinics or hospitals.

POTENTIAL RESOURCES

Positive Connections, a guide for leading support groups for adolescents living with HIV. This resource has a comprehensive list of resources at the end: http://www.iywg.org/sites/iywg/files/positive_connections_pub-v12_forweb_ tocinteractive.pdf

AIDSTAR-One Toolkit for Transition of Care and Other Services for Adolescents living with HIV: http://www.aidstar-one.com/sites/default/ files/AIDSTAR-One_ALHIV_Toolkit.pdf includes tools on mental health, SRH, alcohol and substance use, disclosure, loss, grief and bereavement and positive living. Training Manual for the toolkit for Parent/Caregivers, Providers, and Adolescents: http://www.aidstar-one.com/sites/default/files/AIDSTAR-One_ ALHIV_Training_Manual.pdf

WHO Guidelines on HIV disclosure counselling for children up to 12 years of age: http://www.who.int/hiv/pub/hiv_disclosure/en/

UNICEF's "Zambia U-Report": an innovative, free-of-charge and youth-friendly SMS platform that allows anonymous real-time, two-way communication with trained SMS-counsellors on issues of HIV and sexually transmitted infections (STI). http://www.champzambia.org/projects/read_more/11