

ADOLESCENT HIV CARE AND TREATMENT

A Training Curriculum for Health Workers

Participant Manual

2012

Tayla Colton, Virginia Allread, Elaine Abrams, Anne Schoeneborn,
Beatriz Thome, and Ruby Fayorsey



© 2012 ICAP.

Any component of this document may be reproduced or adapted without prior permission from ICAP, provided that: 1) ICAP is acknowledged and 2) the material is made available free of charge.

Please send a copy of all adaptations to:

ICAP

Columbia University, Mailman School of Public Health

722 West 168th Street, 13th Floor

New York, NY 10032

USA

Illustrations © 2012. Petra Röhr-Rouendaal. All illustrations used with permission.

Foreword

“Give young people a greater voice. They are the future and they are much wiser than we give them credit for.”
- Archbishop Desmond Tutu

Thinking back to the turn of the century, it was unimaginable that the global pediatric HIV epidemic would be so dramatically transformed over the course of a single decade. Images of severely ill, malnourished infants filling hospital wards remain vivid depictions of the most dramatic manifestations of this infection in pediatric populations. However, with the success of the global scale-up of HIV prevention and treatment services, a new paradigm for pediatric HIV is emerging, representing a slow shift from a fatal infection threatening the lives of infants and young children to a manageable, chronic disease affecting adolescents and young adults.

Multiple factors have contributed to this remarkable transformation. Effective antiretroviral treatment (ART) has enabled increasingly large numbers of children with perinatal HIV infection to survive the vulnerable periods of infancy and early childhood. In addition, the scale up of prevention of mother-to-child transmission (PMTCT) services has resulted in more women being reached with ever-more potent antiretroviral regimens and a reduced number of babies being born with HIV infection. Finally, improved access to testing has facilitated the identification of older children and adolescents with perinatal infection, as well as those with behaviorally acquired disease. By 2009, there were an estimated 4.3 to 5.9 million youth aged 15-24 years living with HIV and, currently, an estimated 2,500 new infections occur among youth each day. These figures reflect not only the successful treatment of those with perinatal infection, but also the existing (and growing) HIV burden among youth.

As the number of adolescents (defined as those aged 10-19 years) with HIV increases, doctors, nurses, program managers, parents, caregivers, and communities are beginning to recognize the distinct health, psychological, and social needs of this population. Adolescents living with HIV face considerable challenges and have unique needs and vulnerabilities, as compared with both young children and adults. As a result, questions are rapidly emerging as to how best to address these needs while also ensuring successful treatment, long-term retention, and optimal outcomes during the complex and often difficult transition from childhood to adulthood. Programs are responding by incorporating attributes of youth-friendly services into HIV care, including reproductive and sexual health care, peer-based activities, mental health and psychosocial support services, and other features appealing to young people, such as flexible clinic hours, specific clinic times for adolescents, and the availability of drop-in services. At the same time, health workers — who often play critical roles in the lives of young people — are anxious to enhance their skills to ensure that they are well-equipped to provide optimal health care services to the growing population of adolescents living with HIV.

This training package was developed with health workers in mind and aims to support them in meeting the evolving needs of adolescents with HIV infection. The materials cover a broad range of subjects, including youth-friendly services, HIV clinical care, counseling, psychosocial support, mental health, adherence and disclosure support, sexual and reproductive health, the transition to adult care, and monitoring and evaluation. The curriculum was built with the understanding that services for adolescents must be youth-friendly, comprehensive (including biomedical and psychosocial care and support), multidisciplinary, and integrated to include as many different services and providers under one roof as possible. Adolescent HIV care services should aim to become the medical home for adolescents living with HIV, and health workers should be able to

attend to the broad set of needs that are likely to emerge when providing services to this population. Central to the philosophy of this curriculum is the premise that health workers need to interact with adolescents, both as individuals with unique needs, wants, and hopes for the future, and as parts of families, peer groups, and communities.

In developing this training package, the authors relied on lessons learned by centers of excellence, public health programs, and individuals in the United States and Africa, specifically the Family Care Center in Harlem, New York and the University Teaching Hospital's Department of Paediatrics HIV Centre of Excellence (PCOE), and Dr. Chipepo Kankasa in Lusaka, Zambia. We pilot tested portions of the curriculum at the Centre Hospitalier Universitaire de Kigali (CHUK) Pediatric Center of Excellence in Kigali, Rwanda and are forever indebted to the staff of ICAP-Rwanda, RBC/TRAC-Plus, and the Centre Hospitalier Universitaire de Butare (CHUB) for both their attendance during the pilot sessions and their feedback on our training methods and course content. Additionally, this training package borrowed from other areas of public health that have successfully engaged young people, in particular sexual and reproductive health and HIV prevention programs.

Providing comprehensive adolescent HIV services depends on a commitment to scaling up medical and psychosocial services that meet the unique needs of adolescents, as well as continuously improving the knowledge and skills of health workers so they are equipped to address the specific needs of clients. *Adolescent HIV Care and Treatment: A Training Curriculum for Health Workers* represents a key step in ensuring the rollout of HIV-related services that truly serve the needs of adolescents living with HIV.

I am hopeful that this training package will help individuals, multidisciplinary health care teams, agencies, governments, and organizations in their efforts to provide high-quality health services to adolescents living with HIV, and that these materials will help all of us engage, listen to, learn from, and support adolescents as they travel down the path from childhood to adulthood.

“Guard your light and protect it. Move it forward into the world and be fully confident that if we connect light to light to light, and join the lights together of the one billion young people in our world today, we will be enough to set our whole planet aglow.” -Hafsat Abiola

Elaine Abrams
ICAP
Columbia University

Acknowledgements

Between 2010 and early 2011, ICAP at Columbia University's Mailman School of Public Health developed *Adolescent HIV Care and Treatment: A Training Curriculum for Multidisciplinary Healthcare Teams* with the Ministry of Health in Zambia. Subsequently, in mid-2011, Dr. Elaine Abrams responded to increasing interest and focus on adolescents in ICAP country programs and initiated a process to revise the Zambia training package into this generic curriculum. The principle aim was to facilitate easy adaptation of the curriculum by any country or program wishing to establish or improve adolescent HIV services.

ICAP would like to acknowledge a number of contributors to this generic adolescent HIV care and treatment training package, including independent consultant Tayla Colton and ICAP team members Anne Schoeneborn, Dr. Beatriz Thome, Dr. Ruby Fayorse, Dr. Francine Cournois, Dr. Rosalind Carter, Leah Westra, and Tesmerelna Atsbeha. ICAP would also like to thank the François-Xavier Bagnoud (FXB) Center, School of Nursing, University of Medicine and Dentistry of New Jersey for their contributions to the original and generic training packages, including Virginia Allread, Beth Hurley, Aliya Jiwani, Karen Forgash, Deborah Hunte, Anne Reilly, and Mary Jo Hoyt. Thanks also go to Petra Röhr-Rouendaal for the illustrations used throughout these materials.

Several modules of this generic curriculum were piloted in Kigali, Rwanda in December 2011 at the Centre Hospitalier Universitaire de Kigali (CHUK). ICAP would like to thank the following people for their assistance with this pilot activity, their inputs into the materials, and their active participation in and co-facilitation of this first adolescent HIV care and treatment training held in Rwanda — from ICAP-Rwanda: Dr. Veronicah Mugisha, Dr. Tene Gilbert, Odette Mukansoro, and Didine Munezero; from ICAP-Rwanda/CHUK: Dr. Jean Leonard Hakizimana, Beata Sangwayire, Angeline Ingabire, and Verdiane Umutesi; from Rwanda Biomedical Center (RBC)/TRAC *Plus* Clinic: Sister Marie Josee Maliboli, Malanie Muhizi, and Chantal Umurungi; from Centre Hospitalier Universitaire de Butare (CHUB): Pascasie Mukeshimana and Elisabeth Mukankaka; and special thanks to our three adolescent co-trainers for their active participation in the training and invaluable inputs: Elyse Igihozo, Diane Uwimana, and Romeo Manzi.

The original version of this training package that was developed for Zambia would not have been possible without the technical expertise and contributions of Dr. Chipepo Kankasa and the staff at the University Teaching Hospital's Department of Paediatrics HIV Centre of Excellence (PCOE) in Lusaka, Zambia — in particular, Dr. Mwiya Mwiya, Sylvia Mwanza, Dr. Tomas Rachael, and the adolescent clients and Peer Educators that inspired and informed this work. This generic training package is based on their insights and experiences with adolescent HIV care and treatment. Thanks also go to independent consultant Anne Schley for her contributions to the Zambia training package. Development of the original Zambia training materials was supported by funding from the U.S. Centers for Disease Control and Prevention (CDC) Global AIDS Program through the President's Emergency Plan for AIDS Relief (PEPFAR).

Development of this generic adolescent HIV care and treatment training package was supported through the MTCT-Plus Initiative. ICAP acknowledges the following donors for their financial support of the MTCT-Plus Initiative: the Bill and Melinda Gates Foundation, the William and Flora Hewlett Foundation, the Robert Wood Johnson Foundation, the Henry J. Kaiser Family Foundation, the John D. and Catherine T. MacArthur Foundation, the David and Lucille Packard Foundation, the Rockefeller Foundation, and the Starr Foundation. ICAP also acknowledges the CDC and the United States Agency for International Development (USAID) under PEPFAR for supporting ICAP's country programs across sub-Saharan Africa.

Table of Contents

Foreword.....	iii
Acknowledgements	v
Table of Contents.....	vi
Acronyms.....	x
Module 1: Introduction and Course Overview.....	1-1
Session 1.1: Welcome and Introductory Activity	1-2
Session 1.2: Training Objectives and Ground Rules	1-3
Session 1.3: Training Pre-Test	1-7
Session 1.4: Values Clarification	1-8
Appendix 1A: Sample Training Agenda	1-9
Appendix 1B: Pre-Test.....	1-13
Module 2: The Nature of Adolescence and the Provision of Youth-Friendly Services	2-1
Session 2.1: Stages and Changes of Adolescence	2-2
Session 2.2: Adolescent Vulnerabilities, Risk-Taking Behaviors, and Their Consequences	2-9
Session 2.3: Providing Youth-Friendly Services to Adolescents	2-13
Appendix 2A: Tanner Staging System	2-17
Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services.....	2-19
Appendix 2C: Sample Client Satisfaction Survey for Youth	2-24
Module 3: Clinical Care for Adolescents Living with HIV	3-1
Session 3.1: HIV Acquisition — Modes and Implications for Care and Treatment	3-2
Session 3.2: The Package of Adolescent HIV Care and Treatment Services.....	3-5
Appendix 3A: Laboratory Monitoring Before, During, and After Initiating ART	3-32
Appendix 3B: HEADSS Interview Questions.....	3-33
Appendix 3C: WHO Clinical Staging of HIV Disease in Children with Established HIV Infection	3-35
Appendix 3D: WHO Clinical Staging of HIV Disease in Adults and Adolescents.....	3-36
Appendix 3E: Preferred 2nd line ART Options	3-37
Appendix 3F: ARV Dosages for Older Adolescents and Adults	3-39
Appendix 3G: TB Screening Tool fo Children and Younger Adolescents.....	3-41
Appendix 3H: TB Screening Tool for Older Adolescents and Adults	3-43

Module 4: Communicating with and Counseling Adolescents	4-1
Session 4.1: Establishing Trust and Rapport with Adolescent Clients	4-2
Session 4.2: Effective Techniques for Counseling Adolescents.....	4-5
Appendix 4A: Common Counseling Mistakes	4-21
Appendix 4B: General Tips on How to Talk with Adolescents	4-22
Appendix 4C: Basic Counseling Guidance for ALHIV	4-23
Appendix 4D: Listening and Learning Skills Checklist	4-27
Appendix 4E: Motivational Interviewing.....	4-28
Appendix 4F: Common Counseling Scenarios.....	4-30
Module 5: Providing Psychosocial Support Services for Adolescents	5-1
Session 5.1: The Psychosocial Needs of Adolescent Clients	5-2
Session 5.2: Assessing Psychosocial Support Needs.....	5-10
Session 5.3: Peer Support in Psychosocial Services for Adolescents	5-15
Appendix 5A: Psychosocial Assessment Tool	5-20
Appendix 5B: Starting/Planning a Peer Support Group	5-23
Appendix 5C: Facilitating a Peer Support Group	5-25
Appendix 5D: Ideas for Peer Support Group Activities.....	5-27
Module 6: Adolescents, HIV, and Mental Illness	6-1
Session 6.1: Importance of Mental Health Services for ALHIV	6-2
Session 6.2: Identifying Possible Mental Illness and Providing Basic Mental Health Support to ALHIV	6-8
Appendix 6A: Tips for Health Workers on Identifying Possible Mental Illness.....	6-22
Appendix 6B: Sample Screening Tools for Depression and Suicide.....	6-23
Appendix 6C: Screening for Alcohol Dependency with the CAGE Questionnaire.....	6-26
Appendix 6D: The Drug Abuse Screening Test (DAST)	6-27
Module 7: Providing Disclosure Counseling and Support	7-1
Session 7.1: The Disclosure Process: A Developmental Approach	7-2
Session 7.2: Disclosure Preparation, Counseling, and Support for Children, Young Adolescents, and Caregivers	7-3
Session 7.3: Disclosure Counseling and Support for Adolescents Who Know Their Status	7-13
Appendix 7A: Guidance for Developmentally Appropriate Disclosure.....	7-18
Module 8: Supporting Adolescents' Retention in and Adherence to HIV Care and Treatment	8-1
Session 8.1: Introduction to Retention and Adherence	8-2
Session 8.2: Supporting Retention and Adherence to Care.....	8-7
Session 8.3: Providing Adherence Preparation Support to ALHIV and Caregivers.....	8-9
Session 8.4: Assessing Adherence and Providing Ongoing Adherence Support	8-16
Appendix 8A: Adherence Support Tree	8-21
Appendix 8B: Adherence Preparation and Support Guides.....	8-23
Appendix 8C: Adherence Assessment Guides	8-26

Module 9: Positive Living for Adolescents	9-1
Session 9.1: Supporting ALHIV to Live Positively and Maintain a Healthy Mind.....	9-2
Session 9.2: Supporting ALHIV to Live Positively and Maintain a Healthy Body.....	9-7
Appendix 9A: Web Resources for ALHIV	9-17
Appendix 9B: Life Skills Training Resources.....	9-18
Appendix 9C: Basic Food Groups	9-20
Appendix 9D: Key Components of a Nutritional Assessment.....	9-21
Appendix 9E: Nutritional Management of Common Symptoms Related to Advanced HIV Infection	9-22
Module 10: Sexual and Reproductive Health Services for Adolescents	10-1
Session 10.1: Values Clarification and Introduction.....	10-2
Session 10.2: Adolescent Sexuality and HIV.....	10-3
Session 10.3: Supporting Adolescent Clients to Practice Safer Sex.....	10-9
Session 10.4: Integrating Sexual Risk Screening, Risk Reduction Counseling, and STI Services into Adolescent HIV Services.....	10-18
Appendix 10A: Journal Article.....	10-26
Appendix 10B: Adolescent Sexual Abuse	10-31
Appendix 10C: Screening and Examining Adolescent Clients for STIs.....	10-38
Module 11: Family Planning and PMTCT Services for Adolescents	11-1
Session 11.1: Family Planning Counseling for ALHIV	11-2
Session 11.2: PMTCT Counseling for ALHIV.....	11-8
Appendix 11A: Family Planning Screening Questions and Counseling Points.....	11-13
Appendix 11B: Family Planning Considerations for People Living with HIV.....	11-15
Appendix 11C: Survey of Family Planning Methods for Adolescents.....	11-16
Module 12: Community Linkages and Adolescent Involvement	12-1
Session 12.1: The Importance of Facility-Community Linkages	12-2
Session 12.2: Creating a Community Resource Directory	12-5
Session 12.3: Adolescent Participation and Peer Education Programs	12-6
Appendix 12A: Community Resource Directory Template	12-13
Appendix 12B: Template for Adolescent Peer Educator Job Description	12-15
Appendix 12C: Resources for Peer Education Programs and CABs.....	12-16
Module 13: Supporting the Transition to Adult Care	13-1
Session 13.1: Key Considerations for Health Care Transition.....	13-2
Session 13.2: Preparing and Empowering Adolescents to Transition into Adult Care.....	13-4
Appendix 13A: Transition Checklist for Health Workers	13-9
Appendix 13B: Transition Resources for Health Workers and ALHIV	13-11
Module 14: Monitoring, Evaluation, and Quality Improvement	14-1
Session 14.1: Monitoring, Evaluation, and Data Collection	14-2
Session 14.2: Quality Improvement and Supportive Supervision.....	14-12
Appendix 14A: Adolescent Standards of Care	14-17

Module 15: Supervised Clinical Practicum	15-1
Session 15.1: Practicum Planning and Preparation	15-2
Session 15.2: Supervised Clinical Practicum and Debrief	15-3
Appendix 15A: Tips on Mentoring and Coaching with Preceptors	15-5
Appendix 15B: Practicum Checklist.....	15-7
Module 16: Action Planning, Course Evaluation, and Closure	16-1
Session 16.1: Site-Specific Adolescent HIV Care and Treatment Implementation and Action Planning	16-2
Session 16.2: Reflection on Training Objectives and Concerns, Expectations, and Strengths	16-5
Session 16.3: Post-Test, Training Evaluation, and Closing.....	16-6
Appendix 16A: Adolescent HIV Care and Treatment Action Planning and Implementation Template	16-7
Appendix 16B: Post-Test.....	16-13
Appendix 16C: Training Evaluation Form	16-19

Acronyms

3TC	Lamivudine
ABC	Abacavir
ADHD	Attention deficit hyperactivity disorder
AIDS	Acquired immune deficiency syndrome
ALHIV	Adolescent(s) living with HIV
ALT	Alaninaminotransferase, a liver enzyme
ANC	Antenatal care
ART	Antiretroviral therapy
ARV	Antiretroviral
ATV/r	Atazanavir/ritonavir
AZT	Zidovudine
BMI	Body mass index
CAB	Client/consumer/community advisory board
CD4	T-lymphocyte CD4 cell count
CHUB	Centre Hospitalier Universitaire de Butare
CHUK	Centre Hospitalier Universitaire de Kigali
COCs	Combined oral contraceptives
CTX	Cotrimoxazole
d4T	Stavudine
ddI	Didanosine
DOT	Directly observed therapy
ECP	Emergency contraceptive pills
EFV	Efavirenz
ETV	Etravirine
FTC	Emtricitabine
HBsAg	Hepatitis B surface antigen
HIV	Human immunodeficiency virus
HPV	Human papillomavirus
IMAI	Integrated Management of Adolescent and Adult Illness
INH	Isoniazid
IPT	Isoniazid preventive therapy
IRIS	Immune reconstitution inflammatory syndrome
IUD	Intra-uterine device
LAM	Lactational amenorrhea method
LFT	Liver function test
LPV/r	Lopinavir/ritonavir
M&E	Monitoring and evaluation
MDR TB	Multi-drug resistant tuberculosis
MTCT	Mother-to-child transmission (of HIV)
NGO	Non-governmental organization
NNRTI	Non-nucleoside reverse transcriptase inhibitor
NRTI	Nucleoside reverse transcriptase inhibitor
NVP	Nevirapine
OI	Opportunistic infection
PEP	Post-exposure prophylaxis
PI	Protease inhibitor
PITC	Provider-initiated HIV testing and counseling
PLHIV	Person (or people) living with HIV
PMTCT	Prevention of mother-to-child transmission (of HIV)
POPs	Progestin-only oral contraceptive pills
QA	Quality assurance
QI	Quality improvement
sdNVP	Single-dose nevirapine

SGBV	Sexual and gender-based violence
SMS	Short message service
SOCs	Standards of care
SOP	Standard operating procedure
SQV/r	Saquinavir/ritonavir
SRH	Sexual and reproductive health
STI	Sexually transmitted infection
TB	Tuberculosis
TDF	Tenofovir
TST	Tuberculin skin test
TWG	Technical Working Group
VCT	Voluntary counseling and testing
UNAIDS	Joint United Nations Program on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization
XDR TB	Extremely drug-resistant tuberculosis