



CREATING AN ENABLING ENVIRONMENT

- EXCERPT FROM

PEDIATRIC HIV TREATMENT TOOLKIT: A PRACTICAL GUIDE TO THE IMPLEMENTATION OF THE 2009 WORLD HEALTH ORGANIZATION PEDIATRIC HIV TREATMENT RECOMMENDATIONS



SEPTEMBER 2010

This publication was produced by the AIDS Support and Technical Assistance Resources (AIDSTAR-One) Project, Sector 1, Task Order 1, USAID Contract # GHH-I-00-07-00059-00, funded January 31, 2008.

AIDS Support and Technical Assistance Resources Project

The AIDS Support and Technical Assistance Resources (AIDSTAR-One) project is funded by the U.S. Agency for International Development under contract no. GHH-I-00-07-00059-00, funded January 31, 2008. AIDSTAR-One is implemented by John Snow, Inc., in collaboration with Broad Reach Healthcare, Encompass, LLC, International Center for Research on Women, MAP International, Mothers 2 Mothers, Social and Scientific Systems, Inc., University of Alabama at Birmingham, the White Ribbon Alliance for Safe Motherhood, and World Education. The project provides technical assistance services to the Office of HIV/AIDS and USG country teams in PEPFAR non-focus countries in knowledge management, technical leadership, program sustainability, strategic planning and program implementation support.

Acknowledgements

The AIDSTAR-One team wishes to thank Maggie Brewinski, Shaffiq Essajee, Robert Ferris, Shyami DeSilva, Christine Henneberg, Troy Jacobs, Tom Minior, B. Ryan Phelps and George Siberry for their guidance in the development of this toolkit.

Please Note

This excerpt contains the "Creating an Enabling Environment" section from the publication: *Pediatric HIV Treatment Toolkit: A Practical Guide to the Implementation of the 2009 World Health Organization Pediatric HIV Treatment Recommendations*

To download a copy of the complete publication, please visit:

http://www.aidstar-one.com/focus_areas/treatment/resources/pediatric_HIV_treatment_toolkit

AIDSTAR-One

John Snow, Inc. 1616 Fort Myer Drive, 11th Floor Arlington, VA 22209 USA Phone: 703-528-7474 Fax: 703-528-7480 E-mail: aidstarone-info@jsi.com Internet: aidstar-one.com

CREATING AN ENABLING ENVIRONMENT

It is critical to establish an environment that facilitates implementation and integration of the latest WHO pediatric HIV treatment recommendations. Crucial elements of the environment include public and program policy, costing and financing, quality assurance, sociocultural implications, and the legal framework within which the program will operate. The following section describes these environmental issues in greater detail and provides a framework for how to use information from preimplementation assessment exercises to ensure that identified strengths are optimally utilized and relevant shortcomings are appropriately addressed.

POLICY AND REGULATIONS

Under the assumption that national governments have approved adoption of the new WHO recommendations, data from the situational analysis and program assessment should indicate which program policies, protocols, and regulations are in need of modification. Program planners and implementers must make preliminary decisions on where infant HIV testing will be performed and which pediatric regimens will be offered. In addition, it must be determined:

- How the current program policies and protocols on infant testing and treatment support/hinder implementation of the WHO HIV pediatric recommendations, including related policies on PMTCT, MCH, and VCT.
- Which agencies, departments, and persons have the authority and responsibility to enact the policy changes necessary for successful implementation.
- Which mechanism will disseminate and implement policy changes.
- Which policies or regulatory requirements will be used for selection, approval, registration, and use of new laboratory testing technologies and pediatric ARV formulations.

Obtaining this information will require close consultation with key stakeholders from health, social services, and other relevant government departments (e.g., laboratory services, pharmaceutical services, social welfare department, etc.), as well as careful review of program reports and government documents. Based on this information, program-level bottlenecks related to implementation should be clearly identified. For example, bottlenecks that program planners may strive to overcome in the implementation of the WHO pediatric recommendations may include the following:

• Insufficient infrastructure for diagnosis and treatment of infants and children living with HIV, resulting in gaps in coverage and late diagnosis (e.g., urgent need to scale-up laboratory capacity and utilize innovative strategies, including dried blood spot [DBS] testing)

- Operational barriers such as the lengthy turnaround time between drawing blood samples and reporting results
- Late initiation of infant HIV treatment due to poor access to EID or through loss to follow-up (LTF) of exposed infants
- Difficulty retaining children in the continuum of care after diagnosis and treatment initiation
- Lack of availability of appropriate pediatric ARV formulations and other essential drugs
- Lack of HCWs trained in pediatric HIV treatment and support according to the WHO recommendations, including clinical management of pediatric HIV and the use of pediatric diagnostic technologies, such as DBS testing.

Once key bottlenecks are identified, they must be prioritized to identify those that are most critical to overcome in order to implement the recommendations and achieve a long-term reduction in infant mortality. Tool 13, from the Campaign to End Pediatric HIV/AIDS (CEPA), contains a four-metric system to identify those bottlenecks that are both critical to overcome for successful implementation and also feasible in the context of the national HIV treatment framework. After individual programmatic bottlenecks are identified and prioritized, it is important to determine the mechanisms for addressing these issues for successful implementation of the WHO recommendations (Box 3). Resources 9 to 13 are available to assist program planners in the scale-up of HIV diagnosis, care, and treatment for children exposed to HIV within the context of broader child survival and HIV programs.

Box 3. CEPA, Priority Technologies to Address Major Bottlenecks, Kenya 2009

<u>Background</u>: The Kenyan CEPA country team identified a number of high-priority bottlenecks to EID and EIT including long turnaround time (2–6 weeks) for deoxyribonucleic acid (DNA) polymerase chain reaction (PCR) testing of DBSs. Local facilities used paper-based tracking of laboratory samples and test results, requiring transportation of results via courier services or conventional mail.

Intervention:

- Key informants in Kenya have reported on early efforts to implement a national email-based reporting system for EID results.
- Central PCR laboratories send test results via email to regional or subregional distribution locations, where designated personnel print and distribute results to the peripheral facilities that provide testing.
- Limited internet access has so far prevented larger scale-up, but options like general packet radio service modems, which can transmit email and other data through short message service (SMS) texting networks, create the possibility of electronic results reporting at any facility with cellular network access.

Results and lessons learned:

- Given the rapid progression of HIV infection in infants and the short window in which children living with HIV must be started on treatment, governments, programs, and partners should make every effort to decrease the amount of time it takes to test DBS samples and return results.
- If designed appropriately, electronic results reporting systems of this kind could have enormous impact beyond EID programs, as they would enable rapid reporting of a wide range of other laboratory information, such as CD4 counts or tuberculosis (TB) cultures.

TOOLS AND RESOURCES



Tool 13: On the Road to Developing a CEPA National-Level Advocacy Action Plan, **CEPA (2009).** This guide was developed to assist country teams in the development of strong national-level advocacy action plans to advance the CEPA. http://aidsalliance.3cdn.net/3ceccf6de7fd6541bc_0em6byj93.pdf



Resource 7: Scale up of HIV-Related Prevention, Diagnosis, Care and Treatment for Infants and Children: A Programming Framework, UNICEF and WHO (2008). This framework is designed to assist national health managers and implementing partners in

resource-constrained settings with a high HIV burden to scale-up HIV prevention, diagnosis, care, and treatment for children who are exposed to or who have HIV within the context of broader child survival and HIV programs.

Full guide: http://www.unicef.org/aids/files/OMS_PAEDS_Programming_Frameworks_WEB.pdf

Condensed guide:

http://www.unicef.org/aids/files/Condensed_Guide_Prog_Framework_(final3).pdf

Slide set:

http://www.unicef.org/aids/images/Paeds_Programming_Framework_Slides_Aug_28_2009.ppt



Resource 8: Diagnosis of HIV Infection in Infants: A Comprehensive Implementation and Clinical Manual, ICAP and Columbia University Mailman School of Public Health (2007). This manual provides guidance for designing and

implementing infant diagnosis programs at ICAP-supported programs. The manual is intended to provide guidance at the site level for nurses, physicians, counselors, and other health care providers caring for children exposed to HIV; in addition, it targets HIV program managers, health planners, laboratory technicians, and organizations responsible for program design, implementation, and M&E. http://www.columbia-icap.org/resources/peds/files/Infantdx050307.pdf



Resource 9: Handbook on Paediatric AIDS in Africa, African Network for the Care of Children Affected by HIV/AIDS (2006). This handbook is intended to provide a simple, accessible, and practical resource for health professionals involved in preventing

infection and caring for children infected and affected by HIV. The primary targets are medical students and their lecturers, nurses, clinicians, community health workers (CHWs), and other service providers in resource-limited settings where there is a significant HIV burden. The handbook may be adapted by users in various countries to meet their specific needs. http://www.searchitech.org/pdf/p06-db/db-50966.pdf



Resource 10: Co-trimoxazole Prophylaxis for HIV-exposed and HIV-infected Infants and Children: Practical Approaches to Implementation and Scale Up, UNICEF and WHO (2009). This document provides a brief review of evidence

supporting the use of co-trimoxazole prophylaxis in children and summarizes common barriers to implementation. It proposes specific actions and strategies needed for scaling up co-trimoxazole prophylaxis. <u>http://www.unicef.org/aids/files/CotrimoxazoleGuide_2009.pdf</u>



Resource 11: Taking Every Opportunity: Ensuring Infant Access to Early HIV Diagnosis, Care and Treatment, BASICS and USAID (2008). A presentation by USAID and BASICS containing background on the epidemic, findings from the field, and

recommended actions to ensure access to early HIV diagnosis, care, and treatment. http://www.basics.org/documents/Taking-Every-Opportunity_Pediatric-HIV.pdf

BUILDING AND MAINTAINING POLITICAL PARTNERSHIPS

Even in countries that have adopted EID and EIT into national guidelines, significant support is necessary to ensure site-level practice changes. Some infrastructure barriers can be overcome by a political and financial commitment by both donor and implementing national governments to make the necessary changes. For example, the creation of a national antenatal seroprevalence surveillance system may help to identify infants in need of testing early on. In addition, the capacity of national reference laboratories may need to be expanded to handle infant testing and result dissemination. This level of commitment will be underscored by an accurate understanding of the nature of the epidemic and its impact on country development.

Information regarding the following should be described and, when needed, collected and analyzed:

- The current scope and urgency of national/regional and local pediatric HIV and projections about its likely future course without intervention
- The impact of the epidemic on health as well as the social and economic well-being of the nation or region in question
- The proven WHO diagnostic and treatment interventions that reduce infant mortality and improve the lives of those who are either infected or affected by HIV as cited in the WHO recommendations and other sources
- The current bottlenecks that would need to be addressed in order to successfully implement the new WHO recommendations for pediatric HIV testing and treatment.

Using Tools 14 to 17, this information should be presented to key political gatekeepers who have influence and decision-making capacity to change local service delivery (Box 4). It is important to know which level(s) of government and agencies are appropriate for partnership based on their responsibility for public health policies and resources (i.e., national, regional, district, or local level partnership or a combination).

Box 4. Use of the AIDS Impact Model (AIM) in the Fight Against AIDS in Kenya, **POLICY Project (Tool 14)**

Background: The Kenyan National AIDS/Sexually Transmitted Infection (STI) Control Program (NASCOP) implemented the AIM activity with technical assistance from the RAPID IV and POLICY Projects of USAID. The purpose of the AIM activity in Kenya was to increase awareness and knowledge about the AIDS epidemic in order to build a broad consensus in support of effective AIDS interventions. One of their main objectives was to secure financial support for key activities surrounding care and treatment.

Intervention:

- Initial target audience included the most influential leaders from the public, private, NGO, • and community sectors.
- NASCOP trained presenters, including a number of consultants, and provided them with equipment, materials, booklets on "AIDS in Kenya," travel support, and a small allowance.
- A formal program of reporting for the hundreds of presentations that were required to reach • the target audiences was established.
- A one-page report format that included information on the presenter, the audience, questions • that were raised, and topics that were discussed was developed.

Results and lessons learned:

- Booklets produced using the AIM were later published in the national newspaper and called • to the attention of the president.
- Budget allocations by the government increased markedly with the support of ministries • (other than the MOH), partly as a result of AIM presentations and training for those ministries.
- High levels of political commitment from all sectors were secured allowing for successful • implementation of HIV testing and counseling programs throughout the country.

TOOLS AND RESOURCES



Tool 14: The AIDS Impact Model (AIM), USAID POLICY Project (2000). AIM is a computer program and information dissemination tool with an objective to build political support for HIV programs. AIM and the associated activities are designed to analyze the HIV situation in a country, produce accurate information about the likely course and impact of the epidemic, package that information in a media presentation, and reach out to leaders at all levels of

society. http://www.policyproject.com/pubs/bookgreen.pdf



Tool 15: HIV Advocacy from the Ground Up: A Toolkit for Strengthening Local Responses, Asia Pacific Council of AIDS Service Organizations (2005). This toolkit has been developed for HIV-related NGOs and CBOs working on the ground directly with most affected communities. Operating at the frontline of HIV responses, the experiences and

knowledge of these organizations are critical in the development of policy and programs that reflect community needs and concerns. This resource will provide CBOs and NGOs with the necessary knowledge and skills to effectively influence policymakers at the local, national, and regional levels. <u>http://www.hivpolicy.org/Library/HPP001526.pdf</u>



Tool 16: Advocacy in Action: A Toolkit to Support NGOs and CBOs responding to HIV/AIDS, International HIV/AIDS Alliance (2002). This toolkit aims to support NGOs and CBOs in their advocacy efforts in the field of HIV by providing useful

information on advocacy, including advice on building practical advocacy skills such as analyzing legislation, lobbying, and writing persuasive educational dramatic presentations. <u>http://www.comminit.com/redirect.cgi?r=http%3A%2F%2Fwww.aidsalliance.org%2Fincludes%2</u> <u>FPublication%2Fadv0602_Advocacy_toolkit_eng.pdf</u>



Tool 17: HIV/AIDS Toolkit: Building Political Commitment, USAID POLICY Project (2000). The toolkit contains six modules to assist activists interested in increasing political commitment at international, national, and local levels for effective HIV policies

and programs. The toolkit reviews political commitment, its importance, and describes actions to build political commitment as a key step in combating HIV in sub-Saharan Africa by reviewing approaches that have proven to be effective. <u>http://www.policyproject.com/pubs/bookorange.pdf</u>

INVOLVING A RANGE OF STAKEHOLDERS AT ALL LEVELS OF SOCIETY

National leaders include not only those in politics and government but also leaders from the civil and private sector, including business, education, CBOs, FBOs, and NGOs. These stakeholders are an important part of change. Their support for the implementation of the new treatment protocols will contribute to increased momentum in the acceptance of the new recommendations, as well as to the establishment of the requisite enabling environment. For example, an advocacy campaign by these sectors and organizations may be helpful in establishing protocols for identifying infants exposed to HIV who are not seen by health care providers prior to six weeks of age. Likewise, engaging the community at large, including PLWH, is critical to ensure acceptance of and access to new and existing pediatric HIV services and is discussed more fully in the "Information, Education, and Counseling and Community Promotion" section.

The assessment of community resources performed in the planning period may help to ensure access to all services by identifying potential partners to provide the community-based components of care (Box 5). The partners selected should be intimately familiar with the community's circumstances and needs and be well accepted by community members. Tool 18 can be used to identify the community support needed in the implementation of the recommendations as well as to perform a comprehensive assessment of local CBOs and NGOs.

Box 5. Implementation of a Comprehensive Program to Improve Adherence to HIV Care and Treatment for a Pediatric Population in Kenya

<u>Background</u>: Ensuring adherence to HIV care and treatment amongst the pediatric population has been a great challenge to health programs. Care of children mainly relies on the abilities of the caregivers who more often may not be the parents. To improve adherence and follow-up, Eastern Deanery AIDS Relief Program, an indigenous FBO that provides integrated HIV/tuberculosis (TB) prevention and care in the eastern slums of Nairobi, adopted a community approach to HIV care and treatment.

Intervention:

- All patients seeking treatment are linked to a CHW for follow-up and continuum of care.
- CHWs (including those living with HIV) are selected and nominated by their communities for intense training over a 6- to 8-month period.
- CHWs who are deemed able are appointed as *Muangalizi* (kiswahili for the one who cares) for children. Monitoring tasks include three home visits per week, assessment of nutritional status, pill counts, and assessment of physical health and emotional health; they also remind primary caregivers to accompany children to the clinic, refer children for HIV testing, and bring children to the clinic when the caregiver is unavailable or unable.

Results and lessons learned:

- After one year, ART enrollment increased by 75 percent, patient retention increased from 82 to 90 percent, fewer patients died, and 89 percent of caregivers were retained in care (compared with 76 percent before Muangalizi).
- Engaging the local communities improves service delivery and treatment outcomes for care and treatment for adult and pediatric populations.
- Patients receiving care alongside other members of the family are more likely to remain in care.
- Muangalizi improved pediatric enrollment and retention rates as well as caregiver retention rates.

(Owiso et al. 2009)

TOOLS AND RESOURCES



Tool 18: Child Health in the Community - "Community IMCI": Briefing Package for Facilitators, WHO (2004). This briefing package proposes a process for bringing principal partners together for planning and implementation at the national, intermediary,

district, and community levels. This process will enable development of coherent strategic and operational plans at various levels; facilitate the sharing of experiences, resources, and expertise among projects and geographical areas; and help ensure consistency. The process is best carried out with the assistance of a facilitator.

http://www.who.int/child_adolescent_health/documents/9241591951/en/



Tool 19: Building Political Commitment at Subnational Levels, Policy Project (2008). This component of the Policy Project toolkit describes different approaches for enhancing the participation of all sectors, including the local community.

http://www.policyproject.com/pubs/bookred.pdf



Tool 20: Tool No. 5 Criteria for Choosing Community Services, Baylor International (2008). A list of specific criteria to consider when choosing community-based partners for assistance in service delivery, community outreach, and education. http://bayloraids.org/toolkit/tools/Tool No 5.pdf



Tool 21: New Initiative to Train India's People Living with HIV on AIDS Advocacy in the Workplace, International Labour Organization and the India Network of People living with HIV/AIDS (2009). A unique training video and handbook package

aimed at guiding those living with the virus in AIDS advocacy in the workplace. http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2009/20091007 ILO India.asp

COSTING AND FINANCING

When planning for the implementation of the WHO recommendations, it is essential to have accurate cost estimates for each of the program modifications to determine if there is sufficient funding to both implement and sustain the proposed programmatic changes. Management Sciences for Health (MSH) has developed cost modeling framework (Tool 22) based on the following components:

- Setting out quantified, time-bound measurable goals and objectives
 - Program implementers should consider a phased approach when implementing the WHO recommendations, enabling rapid expansion and coverage of new pediatric services among vulnerable and high-risk populations.
- Describing and quantifying the activities needed to achieve the goals and objectives
 - Careful consideration should be given to:
 - The expected demand of testing and treatment services (i.e., number of sites).
 - Community-based activities required to support adherence and retention.
 - Related programs (PMTCT, VCT, etc.) that need strengthening to support new pediatric services.
- Showing the resources required to carry out the activities
 - Careful consideration should be given to:
 - On- or off-site laboratory infrastructure and transport.
 - Cost, storage, and distribution of new pediatric formulations.
 - HCW recruitment, training, and retention.
 - IEC materials and activities to increase demand for new services.

- Calculating the costs of the resources and the unit cost per patient
 - Particular attention should be focused on testing strategies including DBS collection as these collection and testing materials are not currently available in kits and must be purchased separately (Box 6 and Tool 38).
- Showing the sources of funding and estimating financing gaps
 - Programs must ensure multiple sources of funding for procurement of ARV drugs and HIV test kits as well as a long-term plan for sustainability of financing for new commodity procurement to support scale-up.
- Producing a detailed budget.

Box 6. Costing Exercise on EID using PCR of DBS, Botswana

<u>Background</u>: To accurately estimate the cost of testing infants using DBS collection and subsequent PCR, a Botswana team compiled all of the materials involved in the proper collection, drying, and packaging of DBS in a rural clinic.

<u>Intervention</u>: The following materials were identified in the process and individually costed to come up with an annual cost of implementing DBS PCR for EID:

- Collection of DBSs from infants for PCR testing: gloves, blood collection card (filter paper), lancet (2 mm) (the Botswana study used a self-springing lancet), 70 percent spirit or alcohol, gauze or cotton wool, and lab forms
- DBS samples: large drying rack and a clean, dry, protected area
- Packaging DBS: glassine paper, special sealable plastic bag (10 samples per bag), desiccant packets (1 per sample), humidity card (1 per bag), and a large mailing envelope (1 bag and 10 lab forms per envelope)
- Processing of DBS: Roche Amplicor HIV DNA PCR kit

Results and lessons learned:

- The total cost per test in Botswana's national reference laboratory is \$19.60 (including \$8.00 for the PCR kit), and it is estimated that the ongoing yearly cost of testing Botswana's 13,300 infants who are exposed to HIV will be approximately \$300,000.
- At a 7 percent HIV transmission rate, this represents \$321 per infant diagnosed with HIV or \$24 per infant demonstrated to be uninfected.
- Estimate includes the cost of test kits, laboratory and clinic consumable products, technician time, machine maintenance, and repeat testing after weaning for infants exposed to HIV who are breastfed.

(Creek et al. 2008)

TOOLS AND RESOURCES

The following tools and resources are available for those program implementers who would like additional information on costing and financing of HIV programs and can be adapted for components specific to pediatric programs.



Tool 22: The Planning, Costing and Budgeting Framework, MSH (2007). This is an Excel spreadsheet workbook designed to allow users to clearly identify the linkages between all elements of a plan-the activities, strategies, objectives, and goals, and the

budget that would be required to achieve these goals and objectives. The workbook consists of an example plan and a blank template plan.

http://erc.msh.org/toolkit/toolkitfiles/file/PCB Workbook.xls

The framework is also accompanied by a user's manual that explains the layout of the spreadsheet and provides instructions on how to use it. http://erc.msh.org/toolkit/toolkitfiles/file/PCB Manual2.pdf



Tool 23: Design and Application of a Costing Framework to Improve Planning and Management of HIV/AIDS Programs (With Case Study), Abt Associates (2000). This is a validated activity-based costing (ABC) methodology, including a standardized list

of activities by major intervention, a list of "activity lines," a standardized cost classification system, a set of cost drivers to trace indirect costs to activity centers, and a program management agenda that can be addressed with cost information generated by ABC.

http://www.abtassociates.com/reports/sir29fin.pdf



Tool 24: Financial Management Assessment Tool, MSH (2000). This tool allows managers to assess the current capacity of their organizations, to manage their finances, and identify steps that they can take to improve that capacity. The tool includes an

instrument that one can use for collecting and summarizing technical information, and a process for applying the instrument. <u>http://erc.msh.org/toolkit/Tool.cfm?lang=1&CID=3&TID=134</u>



Resource 12: Chapter 16: "Guidelines for Assessing the Economic and Financial Costs of HIV/AIDS Prevention and Care Programs", Evaluating Programs for HIV Prevention and Care, FHI (2006). This chapter provides guidelines for assessing the

economic and financial costs of HIV/AIDS interventions. In turn, policymakers will use this information to assure that fully informed decisions are made regarding the cost-effective use of limited resources for HIV/AIDS care and prevention.

http://www.fhi.org/NR/rdonlyres/ez7svgsmatlnljiupck35ipxkbfwqr43tmidspsesufm2ptudeudeiithe i2ufzwfbcsebjiilt4ca/31776textR1enhv.pdf



Resource 13: Logistics Fact Sheets: ARV Drugs, USAID | DELIVER PROJECT (2008). This resource provides information on brand names, manufacturers,

strength/form, packaging and shipping information, shelf life, storage conditions, and prices for commonly used ARVs.

http://deliver.jsi.com/dlvr content/resources/allpubs/factsheets/LogiFactShee ARV Comp.pdf



Resource 14: Logistics Fact Sheets: HIV Test Kits, USAID | DELIVER PROJECT (2008). This resource includes information critical to the selection, forecasting, procurement, and inventory management of 16 brands of HIV tests.

ENSURING QUALITY

To ensure the quality of the enhanced pediatric HIV testing and treatment services, all national protocols must be standardized, required tasks must be supported through training and supervision, and performance of HCWs must be measured according to these standards. Improvements can then be made so that the highest quality of care possible is provided. A quality measurement and improvement scheme should be developed for any new pediatric services delivered through implementation of the recommendations and should be integrated into current quality assurance efforts.

DEVELOPING STANDARD OPERATING PROCEDURES

The WHO recommendations and current guidelines should be used to update and expand existing standards for pediatric HIV diagnosis, care, and treatment. In order to be considered valid, credible, and able to be surveyed, standards should clearly identify the performance/service compliance expected; should be specific, measurable, and time-bound; and should permit a valid measuring process (Tool 25). Standard operating procedures (SOPs) can then be developed from the agreed on standards. SOPs describe processes and provide specific instructions to maximize pediatric HIV service delivery at health facilities in accordance with national guidelines. They will serve to guide clinicians in testing for HIV and providing ART to infants and children living with HIV as well as in evaluating performance, thereby serving as a quality assurance tool for management (Tool 26 and Resource 17).

Treating infants and children living with HIV with ART is complex, given the changes in dosing as the child develops, the dependence of the child on other caregivers, and the rapid evolution of scientific evidence. SOPs are "working" documents that must be updated regularly to incorporate new or revised procedures to ensure quality pediatric HIV service delivery. SOPs are intended for all health facility staff, including medical doctors, registered clinical officers, nurses, counselors, health facility management, receptionists, and maintenance staff.

TOOLS AND RESOURCES



Tool 25: Standards of Care for HIV-Exposed and Infected Infants and Children, WHO and UNICEF (2008). This poster outlines the standards of care presented in the 2008 Scale up of HIV-Related Prevention, Diagnosis, Care and Treatment for Infants and Children: A Programming Framework (Resource 9).

http://www.unicef.org/aids/files/StandardsofCareChildren Final.pdf



Tool 26: Standards for Quality HIV Care: A Tool for Quality Assessment, Improvement, and Accreditation, WHO (2004). This publication and the proposed standards are intended for WHO member states and their authorizing bodies in developing

their own framework of accreditation as a guiding principle to improve the quality of HIV care at all levels of health care facilities of the country, with a special focus on ART. http://www.who.int/entity/hiv/pub/prev_care/en/standardsquality.pdf



Resource 15: Defining Quality, The Quality Assurance Project (2009). The project provides technical support in applying modern quality assurance strategies on a large scale as an integral component of the system of health care at the national, regional, or local

levels. Major areas of assistance include development of quality standards, improving compliance with standards, quality improvement (QI), quality monitoring, accreditation and other regulatory strategies, and redesign of systems of care. <u>http://www.qaproject.org/methods/resdefin.html</u>

Resource 16: HIVQUAL International, U.S. Health Resources and Services Administration (2009). The project works with national governments to implement a systematic strategy to build capacity to measure and improve the quality of HIV care for

adults and children. The website also provides access to additional QI resources including links to the U.S.-based National Quality Center, which offers access to a range of online and downloadable resources for training and implementation of quality measurement and improvement. http://www.hivqual.org/

PROVIDING APPROPRIATE TRAINING AND SUPPORTIVE SUPERVISION FOR ALL HEALTH CARE WORKERS

Once SOPs are developed and updated for all aspects of pediatric HIV care, all individuals that will be implementing these procedures must be fully trained and receive ongoing supportive supervision. HCWs must be able to understand all aspects of the expected performances/services according to the SOPs and have a clear idea of the division of labor.

HCWs can be trained with existing pediatric training resources as well as newer resources on infant diagnosis and treatment as they become available (for a full list of available training tools and resources, see the "Human Resources" section). Because the recommendations call for the testing and treatment of very young infants, program implementers must ensure that training and supervision on doing so is strong and consistent. In addition to treatment protocols, laboratory and pharmacy service quality must also be ensured. Training resources for performing DBS collection is available as well as other information regarding laboratory and supply chain quality assurance can be found in the following sections: "Supply Chain and Laboratory," "Supply Chain and Pharmacy," and "Human Resources."

Efforts to integrate preservice training in pediatric care and treatment for HCWs will help in the long-term sustainability of these efforts, including incorporation of updated pediatric HIV curriculum within local medical education. However, in-service continuing medical education will still be required given the rapidly changing nature of the field. Indicators to assess progress in this area should be chosen, including the proportion of HCWs trained and competent in relevant areas as well as geographic coverage of these workers and the targeted services. These might include:

- Percent of targeted health workers trained in DBS sample collection and percent of sites with adequate staffing
- Percent of targeted HCWs trained in recognition of HIV illness among infants and children and percent of sites with adequate staffing.

STRENGTHEN THE EXISTING QUALITY MANAGEMENT PROGRAM

All new and existing program efforts should be integrated into any ongoing performance measurement and QI activities and supervision. Program planners should ensure that any existing QI indicators are updated in accordance with the recommendations and that all staff and supervisors are notified of any changes and additions. New indicators may need to be developed if implementing new services and operating procedures, such as DBS testing and infant testing counseling services. For example, QI indicators may include:

- Percentage of infants exposed to HIV who are linked into follow-up
- Percentage of infants and families exposed to HIV who received appropriate counseling and DNA PCR testing by 6 weeks of age
- Percentage of infants diagnosed as living with HIV in a timely manner (determined by DNA PCR)
- Percentage of families who receive test results
- Number/percentage of infants living with HIV initiated on ART
- Number/percentage of pediatric patients receiving ART
- Percentage of infants (exposed to and living with HIV) LTF.

It is imperative that a strong supervision structure must exist for all components of the health system and delivery of care, including supply chain, laboratory services, psychosocial support, and counseling, as well as clinical care to ensure quality patient care at all levels. Clear and appropriate testing and treatment algorithms supported by the quality management programs should be instituted to ensure that the test results and treatment plans are of the highest quality and being implemented as planned. Laboratory procedures and quality assurance should draw on existing knowledge and practices. For example, performing DNA PCR on a second disc from the same DBS sample has been shown to confirm the initial result and reduce error as well as retesting a subset of all negative samples (see the "Supply Chain and Pharmacy" section). Similarly, all components of the counseling process should be reinforced through in-service training and counseling aids and measured through exit and follow-up interviews (see Box 7, below).

Box 7. Improving Quality in a Decentralized Pediatric HIV Care and Treatment Program: The ICAP Experience in Rwanda

<u>Background</u>: Ensuring high quality clinical services is a challenge to the decentralization of pediatric HIV care and treatment in resource-limited settings. ICAP designed the Clinical Systems Mentorship (CSM) as an approach to QI including three steps: 1) supporting implementation of a model of care (MOC) for HIV using a standardized tool; 2) evaluating the quality of existing services based on available site data and improving on the standards of care (SOC); 3) and maintaining high quality of the SOC over time. In collaboration with district health teams, ICAP trained and mentored site staff to implement a pediatric HIV MOC and routinely evaluated program performance using predefined pediatric SOC indicators. They implemented CSM at 13 sites including two university teaching hospitals (UTHs), nine district hospitals (DHs), and two HCs in Rwanda.

Intervention:

- Site staff randomly selected a sample of 10 to 20 percent of charts from pediatric patients in care to assess SOC indicators.
- Each indicator was compared to a threshold score of 80 percent and poorly performed (≤ 80 percent) indicators were further investigated through root causes analysis, followed by mentorship of site staff to implement a specific action plan to address them.
- We report on trends of specific SOC indicators and impact on routine program outcomes • (enrollment into care, ART initiation, and LTF).

Results and lessons learned:

- Between September 2007 and September 2008, at UTHs, DHs, and HCs respectively, the proportion of children who had WHO staging increased from 83 percent, 12 percent, and 76 percent to 100 percent, 97 percent, and 95 percent.
- CD4 assessment rate was 95 percent at UTHs and increased from 46 percent and 58 percent • to 85 percent and 89 percent at DHs and HCs, respectively.
- Routine program outcomes showed the LTF rate decreasing from 14 percent to 7 percent (p = 0.003); child enrollment and ART initiation rates increased over time in all settings: from 41 percent, 40 percent, and 20 percent to 69 percent, 85 percent, and 57 percent, but were significantly higher at UTHs and DHs than at HCs (p < 0.001).
- The CSM approach contributed to improve quality of pediatric HIV services at selected health facilities. Performance improvement was higher at UTHs and DHs than at HCs.
- Further poor performance investigation and staff mentoring reaching all levels of the health • system will better improve quality of services for children.

(Tene et al. 2008)

TOOLS AND RESOURCES

The following tools are available to assist program managers in designing interventions to increase adherence to standards as well as other QI activities.



Tool 27: Quality Academy Online, The National Quality Center (2009). This is an online, modular learning program designed to increase understanding of QI in HIV care that features 20 content-rich tutorials, which are accessible at all times on any Internetconnected computer. http://nationalqualitycenter.org/index.cfm/5847/8860



Tool 28: Helping Healthcare Providers Perform According to Standards, Quality Assurance Project (2004). This paper examines the principles for designing interventions to increase adherence to standards. It describes the main approaches and interventions that

have helped providers meet clinical and administrative standards and summarizes the findings of studies evaluating the effectiveness of those interventions.

http://www.qaproject.org/pubs/PDFs/helphcpro3.pdf



Tool 29: How Can Self-Assessment Improve the Quality of Healthcare?, Quality

Assurance Project (2001). Many health care providers in developing countries work without supervision. This paper reviews several studies of various kinds of self-assessment interventions and can help policymakers decide what kind of self-assessment program to implement and how to do so. http://www.gaproject.org/pubs/PDFs/selfassess402.pdf



Tool 30: Quality Assurance Measures for Voluntary Counseling and Testing Services: Counselor Quality Assurance Tool, WHO (2006). These documents provide means and measures for assessing staff performance, client satisfaction, and adequacy of

both counseling and testing (CT) protocols. The checklists/forms included are Approaches for Assessing Staff Competency, Counselor Skills, Client Satisfaction and Counseling Protocol and Laboratory Testing Adequacy; Counselor Quality Assurance Tool; VCT Site Instrument; Counselor Reflection Form; and the VCT Client Exit Survey Form.

http://www.who.int/hiv/topics/vct/toolkit/components/service/en/index5.html

SOCIOCULTURAL IMPLICATIONS AND COMMUNITY ENGAGEMENT

In many resource-limited settings, knowledge among the general population of the prevention and treatment of pediatric HIV is limited and sometimes inaccurate or distorted by local beliefs and myths. Those living with HIV are subject to stigma and discrimination and may be afraid to seek medical care for themselves and their children. Other barriers to access may include patient-related factors, such as depression, and health system-related factors, such as distance. For those caregivers and children who overcome these barriers and enter into care, maintaining high levels of adherence to treatment and care remains a challenge due to uncoordinated HIV services among family members.

IDENTIFYING AND ADDRESSING BARRIERS TO ACCESS FOR PEDIATRIC HIV SERVICES

Research in resource-limited settings has shown that there are a number of barriers to accessing critical treatment and care services, many of which may affect the willingness and ability of caregivers to permit pediatric HIV testing and treatment (Box 8). Barriers to testing and treatment must be identified for each setting and unique targeted strategies employed to overcome these challenges to access. A number of strategies have been used or recommended, including psychosocial assessment and treatment, peer counseling and education through home visits, mobile clinics, transport reimbursement, and other incentives such as nutritional support (see Resources 19 and 20). Many of the fear and stigma-related barriers can be addressed through community mobilization and involvement of PLWH.

Box 8. Sociocultural Insights from an EID Stakeholder Meeting on Pediatric HIV, Iringa Region of Tanzania (Resource 7)

<u>Background</u>: In 2006, the BASICS project assessed the status of pediatric HIV treatment and care services in three regions in Tanzania. The objective of the assessment was to find missed opportunities for identification or initiation into care and treatment of children exposed to or living with HIV, with the goal of increasing pediatric access to HIV treatment.

Intervention:

- Thirty-five district and regional medical officers, HCWs from local hospitals, NGOs, and community members including mothers with children living with HIV attended a stakeholder meeting to discuss pediatric HIV care and treatment in the Iringa region of Tanzania.
- The meeting objective was to elicit insights into common barriers to access of pediatric HIV services experienced by families with infants exposed to HIV.

<u>Results and lessons learned</u>: Community members cited a number of barriers to women not taking an infant for testing, whether the baby was sick or well. These included:

- *Personal barriers,* such as lack of money for transport or medication, economic dependency of women on men and thus fear of marital rejection, or depression and despair
- *Knowledge-related barriers,* including a belief that children cannot get HIV, that healthy children do not need care, and that traditional medicines are effective in treating HIV, as well as not understanding the importance of learning the HIV status of a child or not wanting to know their status
- *Fear-/stigma-related barriers,* including fear of a husband's reaction to an infant being diagnosed with HIV, of exposing her own HIV status to her husband, of what will happen in the future, or of her test result, as well as fear of exposure to the community
- *Facility-related barriers,* including distance to the facility or the condescending or judgmental attitude of HCWs.

These findings indicated several important lessons for EID program managers:

- Programs must devote adequate resources to community education and mobilization around the issues of infants and children exposed to HIV.
- Unique strategies must be employed to help families overcome barriers, such as the use of CHWs and peer educators trained to engage families and provide psychosocial support and education to those in need.

MOBILIZING THE COMMUNITY AND INVOLVING PEOPLE LIVING WITH HIV

Mobilizing the community to access the enhanced pediatric HIV services, prior to implementation of the new guidelines as well as on an ongoing basis after implementation, is crucial to attaining the defined goals (see Tools 31 and 32). Objectives of community mobilization include the following:

- Raising awareness and fostering commitment to the provision of basic HIV prevention, care, and treatment services for children
- Strengthening community capacity by facilitating dialogue around newborn care practices including infant HIV testing and initiation of ART according to the WHO recommendations
- Addressing underlying causes of inequitable access and care as a result of physical, social, cultural, and political factors that stigmatize and discriminate against and marginalize women and minority groups.

Community members living with HIV are an important part of advocacy for better management of HIV-related issues and problems. Though many of them may not be in key decision-making positions, their empathy and personal experiences with the disease gives them the ability to influence caregivers of children living with HIV, as well as public officials. PLWH have been shown to effectively provide education, adherence counseling, and psychosocial support to patients living with HIV, including mothers and their infants. Program implementers should support the creation and strengthening of PLWH organizations to better address community needs, knowledge, and access to pediatric HIV services.

Program implementers should work with local advocacy organizations and journalists to develop targeted campaigns and education materials for all stakeholders, including radio messages, community events (such as dramas), as well as door-to-door campaigns to emphasize the importance of early testing and treatment of infants and children (Box 9).

Box 9. HIV Awareness Campaigns by the Entebbe Women Association (EWA) in Gulu, Uganda

<u>Background</u>: With the help of the World Association of Christian Communication, EWA carried out HIV sensitization sessions designed to increase HIV awareness by highlighting issues surrounding stigma, the care and support of PLWH, and the community's role in HIV prevention. EWA hoped to encourage PLWH to adopt and maintain positive living practices, increase the disclosure of HIV status among sexual partners, and improve community involvement in HIV services.

Intervention: Interventions included the following:

- Drama and music sessions highlighting issues surrounding stigmatization and support of PLWH
- Training and advocacy for PLWH in positive living, positive prevention, and drug adherence
- Radio programs focusing on reducing stigma and increasing care and support of PLWH.

Lessons learned:

- An increase in the number of referral cases for integrated HIV support through advocacy
- An increase in testing and disclosure rates
- Requests for additional information through radio calls and letters were also observed.

TOOLS AND RESOURCES



Tool 31: The String Game, UNICEF (2009). This activity was created to educate low literacy community members and patients on the routes of HIV transmission. Educators carry a stand-up display to the clients' homes. Cardboard cut-out figures of men, women, and children are applied to the board and connected by strings to indicate particular modes of transmission. http://bayloraids.org/toolkit/tools/Tool No 12.pdf



Tool 32: Secure the Future Manual: Seven Steps to Involve the Community in HIV/AIDS Treatment Support Programmes, Bristol-Myers Squibb (2009). The purpose of this manual is to guide any group in how to integrate community mobilization

and supportive services provided by CBOs (including FBOs and NGOs) to patients in their homes and communities. http://www.bms.com/documents/STF/manual/print.pdf



Resource 17: "If you build it, will they come?" Kenya Healthy Start Pediatric HIV Study: A Diagnostic Study Investigating Barriers to HIV Treatment and Care Among Children, Horizons Program (2008). This study aimed to examine barriers to

uptake of pediatric HIV care and treatment services, including community perceptions and service quality, to derive lessons for increasing uptake of existing services. http://www.popcouncil.org/pdfs/horizons/Kenya PediatricHIVTreatment.pdf



Resource 18: A Chance for Children: Overcoming Barriers to Pediatric HIV Care and Treatment Services, USAID and BASICS (2009). This poster reviews the common barriers to pediatric HIV care and treatment services and proven strategies to overcome

these barriers in resource-limited settings, with particular emphasis on experiences in Rwanda. http://www.basics.org/documents/pdf/Pediatric HIV A Chance for Children.pdf



Resource 19: Demystifying Community Mobilization: An Effective Strategy to Improve Maternal and Newborn Health, USAID (2009). This document describes the use of community mobilization as a primary strategy to reduce maternal and newborn mortality in communities, while building civil society capacity to achieve and sustain further positive

health and community development results.

http://www.comminit.com/redirect.cgi?m=7e32243c5974bcbb8ae3e08a1b0377dc



Resource 20: The Great Involvement of People Living with HIV/AIDS (GIPA), UNAIDS (2007). A brief detailing actions for governments, organization of PLWH, wider civil society and private sector, and international partners to involve PLWH in obtaining universal access. http://data.unaids.org/pub/Report/2007/JC1299-PolicyBrief-GIPA en.pdf



Resource 21: Involving People Living with HIV: Support to PLWH Organizations in Cameroon, Gesellschaft fur Technische Zusammenarbeit (GTZ) (2007). This is a report describing establishment of the Cameroon Network of PLWH organizations,

RéCAP+, which coordinates the activities of its member organizations, aims at building their institutional capacities, and aims at ensuring the representation of PLWH in political decisionmaking bodies at local and national levels. http://www.gtz.de/de/dokumente/en-produktblattplwh-2008.pdf

ADOPTING A FAMILY-CENTERED MODEL OF CARE

Families affected by HIV have multiple needs, and when services are not coordinated, care can become more complicated, costly, and fractured. By contrast, family-centered care provides comprehensive care in the same facility for parents, caregivers, and children living with and affected by HIV, at the same time and by the same staff. It includes treatment, management of opportunistic infections, palliative care, nutrition support, and child protection and prevention programs. Any new or enhanced pediatric care and treatment services should be integrated into a family-centered model to increase uptake of services and adherence to care and treatment (Box 10). Family-centered approaches include referring parents of HIV-positive infants to CT services for themselves and coordinating routine appointments, counseling sessions, pharmacy pickups, and laboratory testing for families in which the caregivers and one or more children are HIV-positive.

Family-care case managers can be appointed and trained to assess, support, and coordinate HIV and primary care as well as psychosocial needs for children and families, including linkage with community-based services, in order to reduce the burden on the public health care system. Child HBC teams can support case managers in providing follow-up care in the home for the whole family, referring them to the health facility when necessary through established referral systems between facilities and from the community (see Box 16).

Box 10. Promoting a Family-Centered Approach in Scaling-Up Care and Treatment Services for Children in Rwanda

<u>Background</u>: IntraHealth's HIV Clinical Services Program (HCSP) in Rwanda supports HIV service integration. Children's HIV testing rates are often low due to the lack of a children's testing program and providers' discomfort delivering HIV testing results to children. HCSP sought to scale-up care and treatment services via a family-centered approach.

Intervention:

- In 14 HCs, HCSP-trained providers in a family-centered CT approach targeting families of women identified as living with HIV during ANC.
- CT sessions were held on weekends and holidays and all families in the area were invited so as not to draw attention to or stigmatize the target population.
- Children were invited through youth groups to ensure confidentiality.

Results and lessons learned:

- At the end of the first year of (September 2008) there was a seven-fold increase in children tested, to more than 22,000.
- In rural areas, there was a doubling of numbers of children tested.
- Before, children accounted for only 9 percent of all HIV-tested individuals in HCSPsupported sites. With the new approach, the number increased to 30 percent (16,494).
- Of the 1,371 clients living with HIV identified, 134 (10 percent) were children.
- Services for the entire family are thus provided in a single visit, reducing costs and facilitating care and treatment.
- Challenges included the follow-up of identified students living with HIV when children returned to school; identifying information for parents as well as their role in compliance and follow-up of infected children; and parent fears that children cannot cope with their positive status or that children will inform the community that their parents infected them.

(Ngendahimana et al. 2009)

RESOURCES

Resource 22: Family-centered Models of Care and Support for Orphans and Other Vulnerable Children Affected by HIV/AIDS, Joint Learning Initiative on Children and HIV/AIDS (JLICA) (2010). This literature review provides an overview of family-centered support models for children and families affected by HIV.

http://www.jlica.org/userfiles/file/Wakhwaya%20JLICA%20LG1%20Paper%20Brief.pdf



Resource 23: Expanding Access to Services and Protecting Human Rights, JLICA (2010). This report provides a synthesis of the lessons learned and recommendations of Joint Learning Initiative on Children and HIV/AIDS's "Expanding Access to Services and

Protecting Human Rights" group. http://www.jlica.org/userfiles/file/JLICA_LG3_FINAL(1).pdf



Resource 24: Embracing a Family-centred Response to the HIV/AIDS Epidemic for the Elimination of Pediatric AIDS. DeGennaroa, V., and P. Zeitz (2009). This paper reviews the arguments for family-centered pediatric HIV treatment, including

strengthening the general health care system's ability to respond quickly to illnesses in the population and concludes that family-centered programs should be the gold-standard for prevention and treatment of HIV/AIDS. <u>http://aidsalliance.3cdn.net/3dcceac2a703f320d7_orm6bxifw.pdf</u>

LEGAL FRAMEWORK

It should be established early on whether testing of infants will be opt-in, opt-out, or mandatory according to national legislation and international legal instruments, declarations, and guidelines. Implementation of planned activities should be adapted accordingly. Because no major international agencies are advocating mandatory testing for infants and children, issues surrounding informed consent should be clarified and standardized (see Resource 27).

ASSESSING CURRENT LEGISLATION ON HIV TESTING

In light of the need for infants and children to have earlier access to treatment, care, support, and prevention, UNAIDS and WHO are supporting a major expansion of access to HIV CT through the scaling up of client-initiated and provider-initiated CT services using an opt-out approach. With an opt-out approach, an HIV test will be performed routinely unless it is specifically declined. In high HIV prevalence settings, this approach is preferable as it rapidly expands the scope of people who can access prevention (Box 11).

All testing, whether client- or provider-initiated, should be conducted under the conditions of the "Three Cs": involve informed consent, be confidential, and include counseling. The 2004 UNAIDS/WHO *Policy Statement on HIV Testing* recommends that traditional VCT be supplemented by provider-initiated testing in all health settings in generalized HIV epidemics, and in selected health facilities (such ANC clinics) in areas with low or concentrated HIV epidemics.

Box 11. Universal HIV Testing of Infants at Immunization Clinics: An Approach for EID in High HIV Prevalence Settings in South Africa

<u>Background</u>: In the South African province of KwaZulu Natal, 39 percent of women receiving ANC are living with HIV. To try and increase the detection of HIV infection in infants, investigators undertook a study to see how feasible and acceptable opt-out HIV testing was at infant immunization clinics to achieve early diagnosis of HIV and referral for HIV treatment and care services.

<u>Intervention</u>: Mothers attending three immunization clinics with infants aged 6, 10, and 14 weeks were offered opt-out tests by trained counselors. Blood samples were collected by heel prick onto filter paper. DBSs were tested for HIV antibodies and, if present, were tested for HIV DNA by PCR. Testing at the immunization clinics allowed both mothers and infants to be linked into ART programs. Exit interviews were requested of all mothers irrespective of whether they had agreed to infant testing or not.

<u>Results and lessons learned</u>: A total of 646 mothers of infants attending the immunization clinics were offered opt-out HIV tests by the counselors. The median age of the infants was a little under eight weeks. Findings included the following:

- Most (584, 90 percent) mothers consented to their infant being tested for HIV.
- Of those 584 mothers, only 332 (57 percent) returned for the result.
- Among women who reported being HIV-negative, 7 percent of their infants were found to be infected.
- Most mothers (78 percent) reported that they were comfortable with the offer of an opt-out HIV test for their infant, 5 percent of mothers said that the offer frightened them, and 2 percent said that it caused anxiety.
- Only 2 percent of mothers refused the offer of an HIV test because they needed more time to decide.
- The main reasons for accepting a test were to confirm the HIV status of the infant (77 percent) and to gain access to ART (55 percent).
- Over a quarter of women also said that the test result would help inform their infant feeding practices.
- Screening of all infants at immunization clinics is acceptable and feasible as a means for early identification of infants living with HIV and referral for ART.

(Rollins et al. 2009)

ADDRESSING ISSUES OF CONSENT FOR INFANT TESTING

Protocols for acquiring written consent or documentation of verbal consent from parent or guardian, consistent with general requirements for consent for diagnosis and care of minors, should be established for births that take place at the health care facility and at patients' homes. Documentation of at-home births will require maintaining strong linkages with traditional birth attendants (TBAs) as well as other CHWs to properly document and refer new mothers and their babies for testing at the nearest facility. In pediatric wards with high HIV prevalence and among children with TB, universal diagnostic HIV testing may be appropriate. If the parent or guardian is unable to give consent, appropriate protocols must be established in line with national legislation.

These efforts, however well-intentioned, may raise major concerns among caregivers around issues of confidentiality and informed consent. For a mother, the HIV test on her infant amounts to disclosure of her own status. Counselors and medical staff have the important task of ensuring that proper consent is being sought and that accidental disclosure of a woman's HIV status to her partner, relatives, or other community members is avoided. CHWs and other staff need to explain to mothers/caregivers the implications of refusing a test for their child. However, they must do so without undue pressure, rather aiming to educate the mother/caregiver of the benefits of HIV testing and the implications of a positive and negative test result so that he/she is able to make an informed decision and to provide appropriate support systems (see Resource 28).

A counseling script for explaining infant diagnostic testing to parents or caregivers is available in Tool 50.

RESOURCES



Resource 25: UNAIDS/WHO Policy Statement on HIV Testing, UNAIDs and WHO (2004). The cornerstones of HIV testing scale-up must include improved protection from stigma and discrimination as well as assured access to integrated prevention,

treatment, and care services. The conditions under which people undergo HIV testing must be anchored in a human rights approach that protects their human rights and pays due respect to ethical principles. <u>http://www.who.int/entity/hiv/pub/vct/en/hivtestingpolicy04.pdf</u>



Resource 26: Guidance on Provider-Initiated HIV Testing and Counseling in Health Facilities, WHO and UNAIDS (2007). This document responds to growing need at the country level for basic operational guidance on provider-initiated HIV CT in

health facilities. It is intended for a wide audience including policymakers, HIV program planners and coordinators, health care providers, civil society groups, and NGOs providing HIV services. http://whqlibdoc.who.int/publications/2007/9789241595568_eng.pdf