Improving Retention, Adherence & Psychosocial Support within PMTCT Services

A Toolkit for Health Workers

ICAP
International Center for AIDS Care and Treatment Programs
MAILMAN SCHOOL OF PUBLIC HEALTH
Columbia University

Website: www.columbia-icap.org • *Email:* icap@columbia.edu • *tel:* +1 212-342-0505 • *fax:* +1 212-342-1824

Foreword and Acknowledgements

Over the last several decades, HIV infection has ravaged families and communities throughout many parts of the world. Despite noteworthy scientific advances and increased access to prevention and treatment services in HIV high prevalence settings, it is estimated that worldwide approximately 1,000 children are born each day with HIV infection. The vast majority of these infections can be attributed to vertical transmission, acquired during pregnancy, delivery, or through breastfeeding. Without proper treatment, more than half of these children will die before their second birthday. Similarly, many of their mothers continue to suffer the consequences of untreated HIV infection and succumb to an early death.

In Central Harlem, New York City, where I began my work more than 25 years ago, I witnessed the extraordinary success of efforts to prevent mother-to-child transmission. In the early days of the epidemic, the hospital wards were filled with infants and children living with HIV, many too ill to be cared for at home, others orphaned or abandoned. Over time, however, the hospital wards slowly emptied and we stopped attending funerals as fewer children were being born with HIV infection and those who became infected were effectively treated, no longer succumbing to the disease. Instead, we spent our time in busy clinics treating families, celebrating birthdays and holidays, and planning weekend outings and summer camps as successful treatment and prevention efforts enabled many children and families to lead long, healthy lives. A series of scientific discoveries throughout the 1990s provided the foundation on which we built effective prevention of mother-to-child transmission (PMTCT) programs. Women were tested for HIV during pregnancy and routinely received antiretroviral treatments for their own health and to prevent transmission to their unborn child. By the turn of the century, mother-to-child transmission rates were reported as low as 1-2%, down from 25-30%, in countries where resources for prevention and treatment were routinely available. In my clinic in Central Harlem, like many other clinics in Europe and North America, many of the children we cared for at the start of the epidemic are now transitioning into adulthood and starting families of their own.

Similar success has been difficult to achieve in many parts of the world where HIV is more prevalent and resources more constrained. Many factors have contributed to this failure to more effectively prevent new pediatric infections. Among others, there has been limited geographic expansion of PMTCT programs, an over-reliance on the use of short-course prophylaxis regimens, a failure to recognize and effectively address the health needs of the pregnant woman who requires treatment, and until recently, few feasible and safe options to prevent transmission during breastfeeding. Furthermore, health workers caring for women and children in clinics and hospitals often find themselves poorly prepared and supported to effectively implement PMTCT, a complex series of interventions that start during pregnancy, continue throughout breastfeeding, and include the mother, child, and oftentimes partner and family members.

The year 2010 marks the beginning of a new era for PMTCT. International leadership is championing the health of women and children throughout the world, with special attention to those affected by HIV. UN agencies, national governments, and implementing partners have launched an MTCT elimination campaign aimed to lower transmission rates to less than 5% worldwide. In addition, the 2010 revision of WHO guidelines denotes an important turning point in approach to PMTCT, emphasizing the need to initiate antiretroviral treatment for eligible pregnant and postpartum women, and recommending more potent regimens for prevention during pregnancy, as well as antiretroviral prophylaxis to the mother or baby throughout breastfeeding. If these guidelines are well implemented,

rates of new infections in children should drop dramatically in the years ahead. In addition, we can expect to see significant improvements in maternal health outcomes.

At the forefront of the epidemic are the health workers tasked with translating these guidelines into effective interventions in the field. In the HIV clinic in Central Harlem, NY, as well as the PMTCT clinic in Maseru, Lesotho, the nurses, midwives, counselors, and peer educators form the bridge to good health for the community. And, in this case, health workers in the maternal and child clinics will be the ones to help women and their partners effectively engage in PMTCT and HIV care and treatment services. What these frontline health workers understand and what they communicate to their clients will dramatically impact the health outcomes of millions of women, children, and families.

This PMTCT Toolkit was developed in an effort to support health workers in this daunting task. It aims to provide a simplified, step-by-step approach to the many components of PMTCT care, with a particular emphasis on retention, adherence, and psychosocial support. It should enable health workers to systematically provide key information to their clients as they progress through pregnancy, delivery, breastfeeding, and planning for future pregnancies. It should enable health workers to effectively communicate important health messages to their clients and facilitate effective engagement in care. This work is built on two basics concepts: parents will go to extraordinary lengths to protect their children, and health workers are deeply committed to helping families stay safe and healthy. This Toolkit offers health workers and families a means towards more effective PMTCT services and healthier lives for women, children, and families living with HIV.

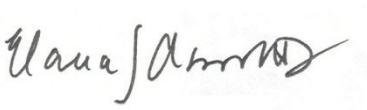
I have had the privilege of working with countless talented individuals committed to improving the health of women, children, and families living with HIV. The PMTCT Toolkit brings together the collective experience of hundreds of people who have worked in this area and who have willingly shared their learning and insights. The Toolkit is presented as a set of generic tools that can be easily adapted by Ministries of Health, health care facilities, and other organizations seeking to improve the quality and outcomes of PMTCT services. I am hopeful that the availability of these tools reflecting our collective learning and experiences will further efforts to eliminate new pediatric infections, and contribute to the good health of families infected with and affected by HIV throughout the world.

I would like to express my appreciation and gratitude to all of the individuals who contributed a significant amount of their time and effort to the development of this Toolkit. Special thanks go to Tayla Colton, independent consultant, for her technical support, expertise, and inspired and informed approach to material development; Leah Westra, ICAP Project Officer, for coordination and editing of the materials; Sara Riese, ICAP PMTCT Program Officer, Fatima Tsiouris, ICAP Associate Program Director for PMTCT, and Xoliswa Keke, ICAP-South Africa Technical Advisor-Care and Support, for their thoughtful contributions throughout the development process; Anne Schoeneborn, ICAP Project Assistant, for her superb drafting and editing skills; Erin Dowling, independent consultant, for layout and production of the materials; Petra Röhr-Rouendaal, artist, for her beautiful illustrations; and Cristiane Costa, ICAP Southern Africa Region Program Director, for bringing everyone together to create this important and excellent product. Special thanks to Peter Sasowsky, independent film producer, for contributing his time, expertise, and creativity to the production of the video, to the ICAP South Africa staff, and to the cast who so eagerly offered their time, energy, and insights to help spread the important messages of PMTCT. Also, a note of thanks to three nurses from Central Harlem, Maxine Frere, Monica DiGrado, and Jacquelyn Brinney, who so skillfully and lovingly cared for countless children and families living with HIV. I admire the talent and vision of each of these individuals and am inspired by their commitment to improving the health and wellbeing of women, children, and families affected by HIV.

This work would not have been possible without the support of the MTCT-Plus Initiative. The MTCT-Plus Initiative was the first multi-country, family-centered HIV care and treatment program and it supported services in 14 centers in 9 countries in Sub-Saharan Africa and Thailand. The Initiative is recognized as a leader in family-focused HIV care and in addressing the special needs of pregnant and postpartum women and their children. Funding for the MTCT-Plus Initiative was provided by the Bill & 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 Lucile Packard Foundation, the Rockefeller Foundation, the Starr Foundation, and the U.S. Agency for International Development.

The MTCT-Plus Initiative was the first program providing the foundation for the formation of ICAP, the International Center for AIDS Care and Treatment Programs. ICAP is an important partner in the global effort to expand access to quality PMTCT and HIV care and treatment services. ICAP, in collaboration with national and local governments and Ministries of Health, supports the design, development, and implementation of a diverse range of initiatives providing HIV prevention, care, and treatment services in resource-limited settings. ICAP endeavors to build sustainable programs that address the ongoing clinical and psychosocial concerns and needs of PLHIV, as well as their partners, families, and caregivers. ICAP programs are funded by a variety of U.S. government and private sources, including the U.S. Centers for Disease Control and Prevention (CDC) under the President's Emergency Plan for AIDS Relief (PEPFAR), the U.S. Agency for International Development (USAID), the Department of Defense, the National Institutes of Health,

I am hopeful that this Toolkit will help individuals, agencies, governments, and organizations in their efforts to eliminate new pediatric infections and to keep women and their families healthy and safe.



Elaine J. Abrams, MD
Director, MTCT-Plus Initiative
Senior Director for Research
Professor of Pediatrics & Epidemiology
ICAP, Columbia University