

Introduction

New York State (NYS) has made tremendous strides towards the elimination of mother-to-child transmission (MTCT) of HIV. A comprehensive public health program for preventing MTCT in NYS evolved over decades, encompassing interventions at multiple levels. These interventions have maximized the benefits of advances in prevention, diagnosis and treatment of HIV infection. Coordinated efforts of a broad array of stakeholders - - health and human service providers, public health agencies, individuals, families and communities - - have been crucial to this success.

Achieving and sustaining elimination of MTCT in NYS requires continuous, focused efforts. To foster ongoing coordination, the "New York State Strategic Plan for Elimination of Mother-to-Child Transmission of HIV" was developed in 2011. The "Strategic Plan" outlined a comprehensive approach to decrease the incidence of HIV among women of childbearing age, ensure quality care for pregnant women who are at risk for or living with HIV, and prevent transmission of HIV to exposed infants.

This "User Guide" is a resource for implementation of the "Strategic Plan". It provides further information about the strategies contained in the "Strategic Plan" and presents examples of action steps for each strategy. For ease of use, the "User Guide" mirrors the organization of the "Strategic Plan". It is organized around four cross-cutting issue areas: 1) Health and Wellness of Women and Children, 2) Clinical Issues, 3) Work Force Issues, and 4) Systems Development and Coordination.

The "Strategic Plan" and "User Guide" provide a flexible approach for stakeholders to align their efforts in support of elimination of MTCT. Stakeholders are encouraged to review the goals, strategies and possible action steps for each issue area, identify those that are applicable to their settings and incorporate as many as possible into their activities. Some action steps are relatively straightforward and easily completed. Others will take longer to put into place, requiring collaboration with many partners.

We hope that the "Strategic Plan" and "User Guide" are useful. The action steps provided in the "User Guide" are examples and not all inclusive. In order for us to understand how the "Strategic Plan" and "User Guide" are put into action and if/how they may be improved, we invite you to comment. We welcome suggestions for other action steps that can be highlighted as examples. We also invite you to share "success stories" that illustrate your successful approaches to elimination of MTCT. Please address any questions, comments or suggestions to the Perinatal HIV Prevention Program at: phpp@health.state.ny.us Please be sure that what you submit contains no information that could be used to identify specific clients or patients.

Thank you for your ongoing efforts to eliminate mother-to-child HIV transmission in New York State!

Focus area: Health and Wellness of Women and Children Goal: Women of childbearing age are empowered and supported to prevent mother-to-child transmission of HIV. Possible Action Steps Strategy Background Rationale 1.1 Ensure that all women of 25% of Americans living with HIV do Knowledge of HIV status empowers Encourage HIV testing for all women of childbearing age women to seek health care and prevents childbearing age know their HIV in all health care settings and appropriate communitynot know their status. • Women who know their HIV status are status. risk of new infections of mother-to-child based settings. • Retest pregnant women for HIV in the third trimester. transmission. more likely to seek health care and less likely to transmit HIV. 1.2 Provide access to HIV prevention Lack of preconception health information and Access to prevention education Disseminate information on HIV prevention, including risk and preconception health information, HIV prevention strategies leads to increased interventions and supplies is essential to reduction and perinatal management. • Distribute supplies and materials to prevent acquisition messages and supplies (e.g., male risk of acquisition and transmission of HIV. prevent HIV acquisition and transmission. and female condoms, sterile injection and transmission of HIV. Make formula available to HIV-positive women in order to equipment, formula for HIV-exposed infants). avoid postpartum transmission to exposed infants via breastfeeding. Comprehensive perinatal care is critical to • Provide outreach to pregnant women who are not 1.3 Recruit, engage and retain all Without treatment, risk of mother-topregnant women in prenatal and decrease risk of mother-to-child engaged in care and link them to HIV primary care and child transmission is approximately transmission of HIV as well as assure the primary care, and HIV-positive prenatal care. Implement strategies to sustain engagement in care (e.g., 25%; with appropriate treatment, pregnant and postpartum women in well-being of the pregnant woman. transmission risk is reduced to HIV care as well. less than 2%. • Retention in care improves treatment cultural and linguistic competence, transportation assistance). adherence and medical outcomes. 1.4 Engage and retain HIV-exposed Continuity of care provides optimal Conduct discharge planning with parents and/or other A variety of social and economic variants may and HIV-positive children in HIV care impede access to and continuity of care for both medical outcomes and improves quality of caregivers to identify and alleviate barriers to care and women and their infants after delivery. life. improve retention. • Supply parents and/or other caregivers with medications and formula at discharge.. Provide referrals for social support and needed services. Link the infants to pediatric HIV specialty care for appropriate treatment. 1.5 Identify and address barriers that Many women and children are not likely to Barriers impede and interrupt consistent Validate family experiences. may lead to limited or no care for receive health care if substance use, mental care and treatment. This leads to Assess potential barriers to care. health, domestic violence and immigration Develop action plans to address barriers. women and children. negative health outcomes. Monitor progress of the plan to reassess and modify, as issues are not identified and addressed. needed. • Maintain ongoing communication regarding issues

related to access to care

Goal: Women of childbearing age are empowered and supported to prevent mother-to-child transmission of HIV.			
Strategy	Background	Rationale	Possible Action Steps
	Perinatally-infected young people have endured stringent medical regimens throughout their lives. An adolescent developmental milestone is the assertion of independence. Nonadherence to medication and risk-taking may ensue.	special support and guidance to address their developmental needs and to sustain healthy behaviors and optimal medical outcomes.	 Offer options and support to address patient challenges. Offer specialized programs to adolescents with cognitive deficits and to those with other special needs. Develop long and short-term goals. Provide peer led support as well as individual and group activities. Plan for the transition from a pediatric provider to an adult provider.
1.7 Involve both behaviorally- and perinatally-infected young people in primary and secondary activities for the prevention of HIV and other sexually transmitted infections.	Feelings of invulnerability may lead to risky behavior among young people.	Knowledge and application of prevention measures will diminish risk.	 Provide prevention education in a manner that motivates young people to act responsibly with others and to take nacessary steps to protect themselves. Emphasize individualized harm reduction. Provide self-esteem building strategies. Encourage screening for sexually transmitted infections, hepatitis and other diseases, as appropriate.
1.8 Educate women and their families regarding the stigma and discrimination that may surround an HIV-positive diagnosis; provide counseling and support.	Stigma and discrimination continue to have a substantial role in sustaining the HIV epidemic.	Preventing stigma and discrimination is necessary to provide an appropriate environment for people living with HIV/AIDS to seek HIV testing, disclose their status and seek care.	Inform women about their rights. Intervene or identify an appropriate intervention if rights have been violated. Explore implications of disclosure of their HIV status with women and families and provide support as they disclose. Promote partner services as a practicable option. Advocate for programs and policies that prevent HIV-related stigma and discrimination.

Focus area: Clinical Issues				
Goal: Highest quality care for high risk and HIV-positive women and their HIV-exposed or HIV-positive children.				
Strategy	Background	Rationale	Possible Action Steps	
access to current standards and	Advances in HIV-related knowledge, medical technology and clinical care are evolving rapidly.	Expert-developed guidelines and recommendations focused on HIV-positive pregnant and/or postpartum women, and HIV-exposed and HIV-positive children help ensure optimal prevention, care and treatment.	Support the continued development and dissemination of clinical guidelines for women and children. Promote the Perinatal HIV Hotline and the Pediatric HIV Clinician Warmline to practitioners. Publicize webinars and webcasts on the care of pregnant women and their children. Disseminate information on educational training opportunities.	
2.2 Respond to both medical and psychosocial complexities of high risk and HIV-positive pregnant and postpartum women.	Many high risk and HIV-positive pregnant and postpartum women have multiple chronic medical conditions and co-existing psychosocial stressors, such as mental health issues, substance use, and unstable housing.	and psychosocial issues strengthen the	Provide initial and ongoing comprehensive assessments for women, including medical and social histories. Design and implement action plans to address identified medical conditions and psychosocial barriers. Initiate referrals to medical, mental health and addiction medicine specialists, as needed. Optimize appropriate referrals to HIV primary care by mental health and substance use treatment providers.	
2.3 Integrate service models that are inclusive of medical co-morbidities, mental health and substance use treatment services for high risk and HIV-positive pregnant and postpartum women.	Systems of medical, mental health, and substance use treatment services may not always result in the coordinated provision of needed care and services.	Integration of these multiple systems is necessary in order to eliminate barriers and facilitate accessible, comprehensive and consistent care.	Identify and address regulatory issues to facilitate provision of health care, substance use treatment, and mental health services in one location. Ensure reimbursement structures support co-location of mental health, substance use and medical services. Provide mental health and/or substance use services at medical care sites serving high risk and HIV-positive pregnant and postpartum women. Implement integrated models that are client-and family-centered.	
management as a standard of care for high risk and HIV-positive pregnant and postpartum women and their children.	High risk and HIV-positive women and their children often have extensive, complex medical and psychosocial conditions and they must interact with multiple service systems.	Coordination of care by an interdisciplinary team will facilitate access to, and receipt of, all needed services, as well as foster retention in care.	Include women as members of their interdisciplinary teams. Include both medical and community providers in the interdisciplinary teams. Identify team leaders who are responsible for development and modification of the care plan and ongoing assessment.	
2.5 Co-manage the care of HIV-positive pregnant and postpartum women and their HIV-exposed or HIV-positive children across disciplines and subspecialties.	HIV-positive women and their HIV-exposed or positive children may obtain health care from multiple providers and subspecialties with varying levels of expertise related to HIV.	Co-management builds on each discipline's scope of practice and expertise. Sharing knowledge promotes optimal care.	 Identify health care team members. Clarify respective roles of all team members. Identify frequency and means of communication among interdisciplinary team members. Expand care teams to include all necessary disciplines and subspecialties. 	

Focus area: Clinical Issues Goal: Highest quality care for high risk and HIV-positive women and their HIV-exposed or HIV-positive children. **Background Possible Action Steps** Strategy Rationale Educate providers on how to access and properly use 2.6 Maximize appropriate access to A streamlined process for consent and release Exchange of information helps eliminate health information through use of of confidential health information is essential for barriers to needed care and services DOH form-2557, "Authorization for Release of Medical while maintaining compliance with state timely access to care and continuity of care. existing consent and authorization for Information and Confidentiality HIV Related Information", release of health information forms and federal laws and regulations (e.g., and DOH form 5032. "Authorization for Release of Health Health Insurance Portability and and electronic medical records. Information (Including Alcohol/Drug Treatment and Mental Accountability Act (HIPAA)). Health Information) and Confidential HIV/AIDS - related Information "Consider incorporating such language into Information". existing consent or release of information forms. 2.7 Increase mental health and Mental health and substance use assessments Integration of mental health and Inform providers how to access and use mental health substance use assessments for high facilitate identification of issues and referral to substance use assessment skills within and substance use assessment forms. • Encourage use of standardized assessment forms that risk and HIV-positive pregnant and necessary services. routine, ongoing care can help identify postpartum women, with provision of new or recurring issues that need to be have been proven effective in the conduct of mental health mental health and substance use addressed. and substance use assessments. • Emphasize that comprehensive mental health and treatment services if indicated. substance use assessments should be performed at the initial visit and at least annually thereafter. • Review at each visit social context with women who have complex psychosocial issues. Inform providers of mental health and substance use treatment services in their catchment area. Disparities, stigma, and discrimination Recommend that clinical and non-clinical staff receive 2.8 Seek to eliminate health Health disparities, stigma, and discrimination continue to be experienced by people living with impede many persons living with HIV disparities, stigma and discrimination initial and ongoing training on HIV/AIDS and confidentiality. • Engage professionals in the community to address from disclosing their HIV status, seeking in clinical and community settings. HIV/AIDS. medical care, adhering to treatment and stigma and discrimination of people living with HIV/AIDS. • Educate funders on the needs of diverse populations and implementing measures to prevent transmission to others. the ongoing need to address stigma, disparities and discrimination. Train staff to understand and be responsive to cultural differences and beliefs related to health care.

Focus area: Work Force Issues				
Goal: Enhanced work force capacity to care for women of childbearing age at risk for, or living with HIV, and their children.				
Strategy	Background	Rationale	Possible Action Steps	
3.1 Expand work force capacity to provide mental health services for high risk and HIV-positive pregnant or postpartum women.	among high risk and HIV-positive women necessitates availability of comprehensive mental health services. There are fewer providers than needed and insufficient capacity to meet the mental health needs of high risk and HIV-positive women.	a paucity of community mental health	Provide mental health providers with training in core competencies for trauma informed care, patient-centered care and culturally sensitive service delivery. Include information on self-help, community support and social services in initial and ongoing provider education. Create reimbursement strategies necessary to support and encourage provider involvement. Offer incentives, such as loan forgiveness for practicing providers, including nurses and psychiatric social workers.	
3.2 Increase work force capacity to provide substance use treatment for high risk and HIV-positive pregnant or postpartum women.	among high risk and HIV-positive women necessitates availability of comprehensive substance use services. There is insufficient capacity to meet the substance use needs of	HIV-positive pregnant women assessed for substance use needs and provided care, if indicated, will have improved treatment adherence outcomes. A paucity of providers are available for low threshold services for the broad spectrum of substance use issues.	Provide substance use providers with training in core competencies for trauma informed care, patient-centered care and culturally sensitive service delivery. Include information on self-help, community support and social services in initial and ongoing provider education. Create reimbursement strategies necessary to support and encourage provider involvement. Offer incentives, such as loan forgiveness for practicing providers, including nurses and licensed social workers.	
3.3 Maintain clinical expertise and work force capacity for optimal medical care of HIV-positive pregnant or postpartum women and their HIV-exposed or HIV-positive children.		The complexity of the treatment and care of people living with HIV/AIDS demands clinicians with training and expertise in managing HIV/AIDS.	Integrate HIV care in medical residency programs for internal medicine and family practice. Use new and emerging technologies to maximize access to clinical education. Provide notline access to experts for clinicians in the field. Use telemedicine to enhance knowledge of clinical staff. Link providers with experienced clinicians who are willing to serve as mentors. Enable professional staff to participate in continuing education opportunities (e.g. pertinent trainings to provide updates on new programs and research). Allow time to participate in professional staff continuing education opportunities.	

Focus area: Work Force Issues				
Goal: Enhanced work force capacity to care for women of childbearing age at risk for, or living with HIV, and their children.				
Strategy	Background	Rationale	Possible Action Steps	
3.4 Support the use of peers for recruitment into care, outreach to those lost to care and assistance to individuals in navigating care and services.	The peer model for outreach, recruitment and linkage to care is a proven effective intervention.	Utilizing peers improves engagement in care and allows the provision of medical, social and supportive services.	Develop and expand peer programs to navigate high risk and HIV-positive women to care and services. Develop and expand education and training for peers to build skills and enable successful interventions. Recognize and address burn out among peers in order to retain them as resources. Promote the role of peers to other members of the care team.	
3.5 Prepare professional staff for offsite activities that complement on-site care (e.g., adherence support, postpartum and exposed infant care).	Individuals who have complex care needs benefit from coordination and collaboration between hospital-based and community-based providers. Hospital policies and demands on professional staff may preclude opportunities to conduct off-site activities related to the individuals' care and services.	Comprehensive off-site care and services can facilitate better patient outcomes.	Identify the situations in which off-site care would benefit the patient. Clarify roles between hospital-based and community-based providers. Enable hospital-based staff to join community-based providers when beneficial to the patient's care.	
3.6 Promote the use of social workers and case managers as valued and necessary members of the interdisciplinary team.	that influence adherence and treatment outcomes.	Interdisciplinary team approaches to care enhance patient outcomes and sustain continuity in care.	Promote the role of social workers and case managers in interdisciplinary teams. Implement procedures for routine, active communication between other practitioners and social workers and case managers. Identify and disseminate "best practices" that illustrate the unique contributions of social workers and case managers. Recognize the roles of social workers and case managers when designing public health initiatives, as appropriate.	
3.7 Build and retain a diverse work force able to address the needs of high risk and HIV-positive women and their families in a culturally competent, non-judgmental manner.	disproportionately effects communities of color. Sustaining a diverse work force will facilitate	with providers who share their racial and ethnic background, as well as those who	Seek to hire staff that share commonalities with the population served. Encourage staff to establish positive helping relationships with patients. Train staff in cultural competencies and values clarification.	

Focus area: Work Force Issues Goal: Enhanced work force capacity to care for women of childbearing age at risk for, or living with HIV, and their children.				
Strategy	Background	Rationale	Possible Action Steps	
3.8 Maintain a public health work force to provide leadership and support for activities related to prevention of mother-to-child HIV transmission.	transmissions of HIV has resulted in an inaccurate assumption that the issue is resolved and there is no longer need for vigilance or	a resurgence of perinatal transmission of HIV is likely.	Sustain emphasis on monitoring programs and services to prevent mother-to-child transmission of HIV. Continue to collect, evaluate and disseminate data that provide insights into mother-to-child transmission of HIV eldentify opportunities to cross-train state and local staff on issues pertaining to HIV/AIDS (e.g., sexually transmitted infections, hepatitis, tuberculosis, public health disease surveillance, infection control, continuous quality improvement). Disseminate public health "best practices" and achievements, including in areas pertaining to HIV/AIDS. Develop and monitor initiatives to attract and retain a diverse and well-trained public health work force.	

Focus area: Systems Development and Coordination

	ets the needs of high risk and HIV-posi		
Strategy	Background	Rationale	Possible Action Steps
4.1 Optimize coordination and collaboration among public health, nealth and human service, housing, mental health and substance use providers, and the criminal justice system for high risk and HIV-positive pregnant and postpartum women and heir children.	High risk clients often move among care delivery systems and from place to place geographically. Many women have needs which are beyond the capacity of one provider or service system.	Agencies which coordinate and collaborate in an effort to improve client outcomes benefit both their clients and the communities that they serve.	Identify opportunities to offer multiple services at one location. Mobilize communities with a focus on building relationships among entities serving pregnant and postpartum women and their children. Optimize ongoing communication among agencies and organizations. Increase awareness of resources in each catchment area. Develop and disseminate resource directories.
4.2 Maintain effective coordination and collaboration among state and ocal governmental agencies and nongovernmental organizations for prevention of mother-to-child HIV ransmission.	Complex systems with multiple layers of agencies and organizations are involved in the prevention of mother-to-child transmission of HIV.	Coordination and collaboration are essential to increase effectiveness and efficiency of systems and to decrease duplication of efforts.	Clarify specific roles and responsibilities of agencies and organizations. Develop processes and mechanisms to enhance communication among agencies and organizations. Foster better understandings of shared goals and missions. Share knowledge and resources among organizations. Seek out opportunities for collaboration.
develop and maintain adequate esources for prevention of mother-to-child transmission of HIV and to provide necessary support for HIV-positive women, children and adolescents.	No single agency or system can provide all resources needed by high risk and HIV-positive women, adolescents, and children. Each agency or system has the responsibility to ensure their respective services are available to meet the needs for those services.	and other supportive services have a greater chance of remaining in care. They are also more likely to receive the medical	Understand the needs of high risk and HIV-positive women and their children. Conduct community needs assessments to identify needs and available resources. Become familiar with services provided by agencies in the same catchment area. Understand the importance of each agency's role, responsibilities and services in caring for HIV-positive women, children and adolescents and preventing mother-to-child transmission. Be aware of funding opportunities and apply for those that are applicable. Make best use of existing resources, and advocate for needed resources. Maintain a system of referrals with other agencies and organizations.

Focus area: Systems Development and Coordination

Goal: An environment that meets the needs of high risk and HIV-positive women and their HIV-exposed or HIV-positive children. Strategy Background Rationale Possible Action Steps				
Strategy	9		Educate private and public insurers about the needs of	
4.4 Advance changes in health insurance programs to facilitate streamlined access to support adequate health care for high risk pregnant women and their children.	substantial roles in ensuring access to medical, mental health and substance use services for women and children. Lack of health insurance remains a barrier for many high risk women and	Adequate health care coverage for high risk pregnant women and their newborns increases their ability to remain in preventive and primary care. Health insurance programs also provide access	high risk and HIV-positive women and their children. Advocate for coverage of the full range of needed	
			services. • Monitor the NYS Medicaid Redesign process in relation	
	their children in receiving timely services. Public insurance programs, such as Medicaid	to other needed services (e.g., mental health services, substance use	to streamlined Medicaid eligibility processes and	
	and ADAP, fill critical roles in ensuring access	treatment).	comprehensive maternal and inter-conception care. • Ensure that emerging models of integrated care	
	to care.		coordination, such as health homes, consider the needs of high risk mothers and their children. • Advocate for high risk pregnant women and their	
			children to obtain timely and comprehensive health insurance through the Affordable Care Act and Ryan White re-authorization.	
4.5 Clarify and address policy and operational issues for placement in shelters and housing, mental health programs and substance use treatment for high risk pregnant women and women with children.	adequately address the special needs of high risk women and their children. This presents	Policy and procedures that address the	 Understand current policies and procedures pertaining 	
		needs of high risk women and their children will increase their chances of	to placement of women in shelters, housing, mental	
		accessing services and remaining in care.	health and residential substance use treatment	
			programs. Identify policies and operations that are barriers for	
			meeting the needs of high risk women. • Develop strategies to eliminate identified barriers. • Implement and monitor strategies to eliminate barriers	
			and assess effectiveness.	
4.6 Inform policy makers and elected		Raising awareness of issues helps	Identify and educate state and congressional elected	
officials about issues that contribute to mother-to-child transmission of HIV and unmet needs. Enlist the active involvement and support of federal	infrastructures for services needed by high risk women and their children. Many nationa guidance and strong focus of key participar	ensure a focused response to the needs of high risk women and their children. Many national organizations that provide guidance and recommendations with a	officials so that they are informed about issues of women, children, adolescents and mother-to-child transmission of HIV. • Attend public forums and seek out opportunities to inform	
agencies and national organizations on issues related to the care of high		strong focus on women and children are key participants in the development of	program planning and priority setting. Work with the local chapters of state and national	
risk pregnant women and their children.		relevant national policies.	organizations that champion issues of high risk women and their children.	

Focus area: Systems Development and Coordination			
Goal: An environment that meets the needs of high risk and HIV-positive women and their HIV-exposed or HIV-positive children.			
4.7 Be aware of and advocate for national, state and local policy changes that would enhance quality of care and promote HIV prevention outcomes.	Both national and state level health care reform is underway, with goals for improving access to service, quality of care, and cost containment.	services for high risk and HIV-positive women and their children will prevent mother-to-child transmission and help ensure quality care and effective prevention outcomes.	Stay informed about changes in national and state health care reform. Participate in national and state stakeholder meetings. Offer guidance and best practices about caring for high risk pregnant women and their children. Be proactive about providing comments on any relevant state or federal proposed policy and/or regulatory initiatives. Enlist active support of stakeholders willing to participate in coordinated efforts to promote policy changes related to HIV/AIDS issues.
4.8 Provide a policy and regulatory environment that supports activities necessary for sustained elimination of MTCT.	relevant issues is necessary to sustain an	transmission of HIV, policy and regulatory activities must continue to be developed and maintained to ensure that the needs of high risk women and their children are addressed.	Identify and respond to changing issues as the perinatal HIV epidemic evolves. Review and revise regulations and policies, as needed, to sustain elimination of mother-to-child transmission of HIV. Anticipate the potential impact of proposed policy and regulatory initiatives and tailor them, as needed, to sustain elimination of mother-to-child transmission of HIV.

www.health.ny.gov/diseases/AIDS/EMTCT

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