

POPULATION FACT SHEET: AUGUST 2012

INFANTS AND CHILDREN

In the United States, almost all new HIV/AIDS cases diagnosed in children under age 13 result from perinatal transmission of HIV. Although new HIV infections among infants have dropped dramatically since the introduction of zidovudine-based regimen testing recommendations in 1995, perinatal transmission continues to occur, often when HIV-positive pregnant women do not receive appropriate prenatal care, or routine antenatal HIV testing to diagnose women who may be unaware of an HIV infection. Transmission may occur during gestation (in utero), during labor and delivery (intrapartum), during breastfeeding, and less frequently in instances of caregivers chewing food to make it softer and easier for children to eat (pre-mastication).

SURVEILLANCE

- In 2010, an estimated 219 HIV cases occurred among children under the age of 13; of these, 164 were perinatal. That same year, 23 AIDS cases were diagnosed in children under age 13.^{1,2*}
- An estimated 9,898 cumulative AIDS diagnoses have been among children. Of those cases, approximately 91 percent resulted from perinatal transmission.³
- Perinatal HIV transmission has declined significantly in the United States with the aid of antiretroviral (ARV) treatment. Nevertheless, perinatal infections continue to occur:

* Unless otherwise noted, HIV estimates and diagnoses are gleaned from data provided by 46 U.S. States (Hawaii, Maryland, Massachusetts, and Vermont are not included) and 5 U.S. dependent areas (American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, and the U.S. Virgin Islands).

U.S. dependent areas, however, are not included in reference to HIV among specific racial and ethnic groups, since the U.S. Census Bureau does not collect demographic information from all dependent areas.

AIDS surveillance data are based on reports submitted by all 50 States, the District of Columbia, and 6 U.S. dependent areas (American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, Republic of Palau, and the U.S. Virgin Islands).

85 percent of diagnoses of perinatal HIV infection among children under age 13 years were in Blacks or African-Americans (69 percent) or Hispanics/Latinos (16 percent).⁴

CRITICAL ISSUES

When zidovudine is administered appropriately, the risk of passing HIV from mother to child is less than 2 percent.^{5,6} Access to early prenatal care for pregnant women is therefore critical for reducing HIV infections in infants.

Today, most HIV-infected infants are born to women who receive inadequate prenatal care. Interventions, such as routine HIV screening of pregnant women, use of ARV drugs for treatment and prophylaxis, avoidance of breastfeeding, and use of elective cesarean delivery when appropriate, have lowered the number of estimated AIDS cases.⁷

Children with HIV/AIDS face an array of difficult issues, including stigma. Unlike adults, school-age children often have no choice about disclosing their HIV status to others. As a result, children often must grapple with adult issues associated with living with a chronic illness, especially an illness that is stigmatized by society. Children lack the maturity to effectively manage these issues on their own.^{8,9}

Caregivers of young children may attempt to protect them from anticipated stigma by postponing telling them about the diagnosis. This decision may be motivated by the caregiver's fear that the child, unaware of the social repercussions of disclosure, will inappropriately reveal the diagnosis. This may, however, lead to an atmosphere of secrecy and still result in feelings of internalized stigma. As children grow into adolescents, it becomes imperative that they be told their HIV status so they can make healthful—and informed—life choices.¹⁰

Due to the development of more effective antiretrovirals during the last 20 years, people infected with HIV during childhood are able to live longer, healthier lives. Many have



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grown into young adults and deal with the normal challenges of their peers not living with HIV/AIDS. Children and adolescents, however, are at greater risk for psychosocial complications related to HIV infection such as mental illness, and are likely to experience body image concerns resulting from delayed development, chronic dermatologic conditions, or fat redistribution.¹¹

HIGHLIGHTS OF THE HIV/AIDS BUREAU'S RESPONSE

Care for HIV-positive infants and children is most successful when provided in the context of care for the entire family. Most caregivers are also HIV positive, and they must take care of their own health needs to meet the needs of their children. Services that respond to the myriad problems commonly seen in families with an HIV-positive family member—including comorbidities, poverty, lack of transportation, and poor housing—are essential.

All Ryan White HIV/AIDS Program Parts serve children and their families, and Part D Programs specifically focus on this population. Services include perinatal and pediatric specialty care, support services, and linkages to research and clinical trials. In 2010, 11,355 infants and children (2 percent of all clients) were served by the Program.*

* U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB). 2010 *Ryan White HIV/AIDS Program Services Report*.

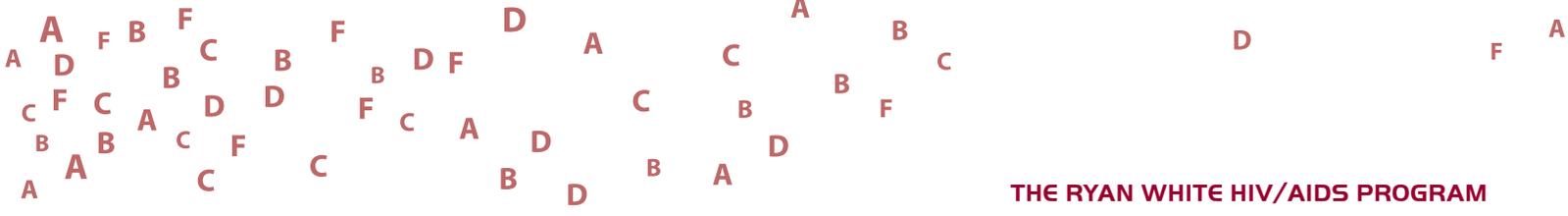
The Health Resources and Services Administration (HRSA) HIV/AIDS Bureau has supported innovative research to bolster and develop community-based health-care networks that reduce barriers to early HIV identification and ensure entry to high-quality primary health care among children living with and impacted by HIV/AIDS. HRSA currently is gleaning best practices from these and other programs concerning the engagement of hard-to-reach populations into care for inclusion in an upcoming training manual, curriculum, and webinar.

HRSA also provides comprehensive training to clinicians and other providers delivering HIV services, ensuring that underserved communities have access to standard care. Additional support to increase the capacity of grantees and providers delivering care to racial and ethnic minority children infected and affected by HIV is accessible through the Minority AIDS Initiative.

In addition, HRSA has engaged in community consultations and collaborations with national agencies addressing HIV infected and affected children, including the National Minority AIDS Council and HealthHIV. It has produced a publication of studies and findings on the search for increasingly effective means for reaching underserved populations. Examples include *From Isolation to Transformation: A CARE Act Guide to Supporting Men Caring for Children Living with HIV/AIDS*, a tool for fathers and other men caring for children and youth living with HIV/AIDS (www.aids-alliance.org/resources/publications/isolationtransformation.pdf) and the June 2007 and June 2012 issues of *HRSA CAREAction* (<http://hab.hrsa.gov/deliver-hivaidscares/careactionnewsletter.html>).

NOTES

- U.S. Centers for Disease Control and Prevention (CDC). *HIV Surveillance Report, 2010*. Vol. 22, Table 1b. Available at: www.cdc.gov/hiv/topics/surveillance/resources/reports. Accessed March 15, 2012.
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- Baylor International Pediatric AIDS Initiative at Texas Children's Hospital (BIPAI). *HIV curriculum: prevention of mother-to-child transmission of HIV/AIDS*. 2011. <http://www.bipai.org/HIV-curriculum/>.
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⁸ Brown LK and Lourie KJ. Children and adolescents living with HIV and AIDS: a review. *J Child Psychol Psychiatry*. 2000;41:81–96.

⁹ Maleea K, Tassiopoulo K, Huoc Y, et al. Mental health functioning among children and adolescents with perinatal HIV infection and perinatal HIV exposure. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*. 2011;23(12):1533–1544.

¹⁰ Baylor International Pediatric AIDS Initiative at Texas Children’s Hospital (BIPAI). *HIV curriculum: psychosocial aspects of HIV/AIDS: children and adolescents*. 2011. www.bipai.org/HIV-curriculum/.

¹¹ Nachman S, Chernoff M, Williams P, et al. Human immunodeficiency virus disease severity, psychiatric symptoms, and functional outcomes in perinatally infected youth. *Archives of Pediatrics and Adolescent Medicine*. February 2012.