

Supporting Students Living With, Affected by, or at Risk for HIV

NASP is committed to ensuring that all schools are equipped to meet the unique needs of students living with human immunodeficiency virus (HIV) and to contribute to broader HIV prevention efforts. Physical and mental health, social–emotional functioning, and academic functioning are closely linked, and schools play an important role in promoting the well-being of students living with HIV and those who have family members living with HIV. Applying established best practices (Chenneville, 2014), NASP supports the use of multitiered services to address issues associated with HIV within school settings along a continuum of preventive care. This involves high-quality primary prevention efforts for all students, targeted prevention for students who are at risk for acquiring HIV, and intensive individualized interventions for students who are directly affected by HIV. Multitiered services to address HIV-related issues will help to create a school culture sensitive to the unique issues facing students living with HIV and will contribute to public health efforts to end the HIV pandemic.

RATIONALE AND CONSIDERATIONS

HIV is a virus that attacks the human immune system and is spread through bodily fluids. Without treatment, HIV impairs the body’s ability to fight off infections which may lead to the development of acquired immune deficiency syndrome (AIDS) and death (Centers for Disease Control and Prevention [CDC], 2017). Currently, there is no cure for HIV although highly effective medications (e.g., antiretroviral therapy) have been developed that help people with HIV live longer and healthier lives.

Prevalence of HIV Among Youth

Approximately 1.1 million people are estimated to be living with HIV in the United States (CDC, 2017). In 2016, approximately one fifth (21%) of new HIV diagnoses in the United States occurred among 13- to 24-year-olds (CDC, 2017). HIV affects men and women across demographic backgrounds, sexual orientations, and gender identities. Gay, bisexual, and other men who have sex with men currently have the highest HIV risk, accounting for approximately 70% of all new U.S. infections (CDC, 2018). Significant racial and ethnic disparities also exist, with Black/African American and Hispanic/Latinx communities disproportionately affected (44% and 25% of new cases, respectively; CDC, 2018) and particularly high rates of infection among African American women, including African American heterosexual women, who account for more HIV/AIDS diagnoses than women of any other race or ethnicity (2019). Coordinated public health efforts have resulted in a significant decrease in mother-to-child HIV transmission during pregnancy, delivery, or through breastfeeding, yet cases persist, with the CDC (2018) reporting a total of 2,322 children under the age of 13 living with HIV in the United States. Further, an estimated 60,300 youth ages 13–24 currently are living with HIV in the United States (CDC, 2017). HIV infection among youth most often results from behavioral transmission, through unprotected sexual activity or injection drug use (i.e., needle sharing). Although perinatal and behavioral transmission of HIV are highly preventable with medical and behavioral interventions, no single

approach can eliminate the HIV epidemic on its own. Given the prevalence of HIV among youth, it is important for school psychologists to understand the impact of HIV on academic and social–emotional functioning, as well as the legal and ethical implications associated with HIV. School psychologists should also understand the ways in which HIV disproportionately affects individuals from minority backgrounds, including sexual, gender, racial, and ethnic minority groups.

Academic Considerations

Because of effective treatment options, most youth living with HIV can achieve good to excellent health and are therefore increasingly present in school settings. Nonetheless, students living with HIV are at risk for academic deficits (e.g., in reading comprehension and/or mathematical reasoning) associated with the neuropsychological effects of suboptimally treated HIV, such as short-term memory difficulties, attention deficits, expressive and receptive language disorders, and visual–spatial ability problems (Phillips et al., 2016). Further, students living with HIV may experience high rates of absenteeism due to the side effects of medication and clinic visits. These effects on learning and academic functioning often result in the need for accommodations and special education services. It is important to recognize that academic deficits may also be affected by social, economic, and environmental factors associated with HIV, including poverty, stigma, discrimination, and homophobia.

Stigma

Stigma and discrimination associated with HIV are widespread and may have long-lasting negative effects on children and families. Stigma and fear of inadvertent disclosure of one’s HIV status are associated with negative outcomes, including reduced treatment adherence (Katz et al., 2013) and depression (Tanney, Naar-King, & MacDonnel, 2012). Components of successful stigma-reducing interventions include providing HIV education, teaching coping skills, and fostering contact with other youth living with HIV for social support and normalization of their experience (Harper et al., 2014). Stigma experiences may change throughout development, and youth living with HIV may experience shame and worry about sexual activity. A small but growing number of HIV stigma reduction programs for general audiences are available (Mak, Mo, Ma, & Lam, 2017). These programs seek to improve attitudes and behaviors toward people living with HIV and could be adapted for school settings.

Disclosure

Disclosure of HIV status can be a multifaceted and sensitive topic. For youth with perinatally acquired HIV, caregivers may be hesitant to disclose to the child their HIV status for fear of the child’s reaction (e.g., blame, anger, sadness) or because they believe the child is too young to fully understand the implications (Vranda, Subbukrishna, Ramakrishna, & Veena, 2017). However, research has identified multiple psychological (Krauss et al., 2013) and physical (Ferris et al., 2007) health benefits associated with planned disclosure. The American Academy of Pediatrics (Committee of Pediatric AIDS, 1999) and World Health Organization (2011) recommend disclosing HIV status to children with consideration of their cognitive and psychological maturity. School psychologists, mental health professionals, and healthcare providers can assist caregivers in informing the child about their HIV status using a process-oriented approach that emphasizes positive adjustment to, and coping with, a chronic health condition (Pinzon-Iregui, Beck-Sague, & Malow, 2013). Disclosure is also an issue for youth living with HIV who are sexually active or use injection drugs. In these cases, disclosure concerns are best addressed in consultation with healthcare providers and with recognition that most states have specific laws regarding HIV disclosure to sexual and needle-sharing partners.

Medication Adherence

One of the most effective treatments for HIV is antiretroviral therapy. To be maximally beneficial, treatment adherence is critically important for youth living with HIV, although often difficult to achieve. If a student's HIV status has been shared with the school, efforts should be made to involve a school nurse in adherence monitoring and support. Poor adherence may be caused by many factors including problems with memory and time management, issues with the medication regimen itself, and socioemotional concerns (e.g., concerns about inadvertent disclosure, depression). Given their training in problem solving, progress monitoring, and collaborative consultation, school psychologists can provide support with identifying causes of nonadherence and developing interventions to improve medication adherence. Previous research has shown that pediatricians perceive collaboration with school personnel to be beneficial, especially for improving patient outcomes, cross-disciplinary problem solving, and assessment of patient progress across settings (Bradley-Klug, Sundman, Nadeau, Cunningham, & Ogg, 2010).

Legal and Ethical Considerations

School psychologists should be aware of important legal and ethical considerations, particularly surrounding disclosure of a student's HIV status within and outside of school. NASP's (2010) *Principles for Professional Ethics* outlines privacy and confidentiality standards. Depending upon jurisdiction, school records that contain information about a student's or family member's HIV status may be protected by state and federal laws as well as by the U.S. Department of Education. These laws include the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which confers privacy protections for individual health information and medical records, as well as the Family Educational Rights and Privacy Act (FERPA), which safeguards the privacy of educational records. School personnel must know that inadvertent disclosure, as well as bullying and harassment based on HIV status, is a violation of state and federal laws. However, it is important to note that HIPAA and FERPA may not apply to the sharing of individual health information with state public health agencies, which frequently require mandatory HIV reporting. Confidentiality issues may arise when laws are unclear or when state and federal laws appear in conflict. In such instances, school psychologists and administrators may wish to seek the advice of legal counsel to ensure compliance.

All individuals living with HIV are legally protected against discrimination under Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 (ADA). Some students with HIV may require accommodations under Section 504. In addition, many students living with HIV receive additional protections and services through the Individuals with Disabilities Education Act (IDEA), most commonly by meeting eligibility criteria for Other Health Impairment (OHI).

School psychologists should be aware of any HIV-specific criminal laws within their jurisdiction that impose criminal penalties on individuals living with HIV who knowingly engage in certain behaviors (e.g., sexual activity, needle sharing) without prior disclosure of their HIV-positive status (Lehman et al., 2014). Despite a lack of evidence that such laws prevent new cases of HIV (Sweeney et al., 2017), criminalization laws remain widespread and are associated with high rates of stigmatization. They also fail to consider major advances in the treatment of HIV, including the availability of pre- and postexposure prophylaxis and the discovery that individuals who achieve undetectable levels of HIV through adherence to antiretroviral therapy have effectively no risk of transmitting the virus to others.

Considerations for Serving Diverse Populations

HIV disproportionately affects ethnic, racial, gender, and sexual minorities; people who use substances; and individuals who face many social stressors (e.g., limited access to healthcare, unstable housing, trauma histories; CDC, 2018). Thus, it is critical that school psychologists who work with students living with or at risk for acquiring HIV are attuned to issues of cultural and contextual diversity, demonstrate a diversity-minded orientation, and demonstrate respect and empathy. NASP has a library of resources to build skills for working with marginalized youth and advocating for social justice (see <https://www.nasponline.org/resources-and-publications>).

THE ROLE OF THE SCHOOL PSYCHOLOGIST

NASP supports the use of established best practices for addressing HIV in the school setting using multitiered services along a continuum of preventive care (Chenneville, 2014).

Tier 1: Universal Interventions

Tier 1 focuses on universal interventions for all students. At this tier, NASP recommends that school psychologists support schools by advocating for comprehensive sexuality education, providing HIV-related professional development for teachers and staff, and helping to build home–school–community infrastructure for HIV prevention efforts.

Tier 2: Targeted Interventions for At-Risk Students

Tier 2 focuses on targeted interventions for at-risk students. At this tier, NASP recommends that school psychologists help identify and provide HIV prevention support services to students at risk for HIV including youth who are sexually active, pregnant youth, youth who use substances, and youth from sexual and gender minority backgrounds. In addition, school psychologists are encouraged to advocate for HIV testing programs by promoting school-based HIV testing services or by linking students to community agencies that provide free HIV testing. It may be necessary to inform and/or involve parents and caregivers at this tier.

Tier 3: Intensive, Individualized Interventions

Tier 3 focuses on intensive, individualized interventions. At this tier, NASP recommends that school psychologists help develop intensive, individualized interventions for students living with or affected by HIV based on comprehensive assessment and evaluation, collaborative problem solving, and principles of child advocacy. The primary goal of individualized interventions is to improve the physical, social–emotional, and academic functioning of students living with or affected by HIV. It may be necessary to inform and/or involve parents and caregivers at this tier depending on the circumstances and taking into account state laws and ethical guidelines. Secondary prevention (i.e., preventing transmission of HIV to others) also is a goal of tailored interventions. To achieve these goals, NASP recommends that school psychologists:

- Work to recognize their own biases and develop a relationship with students living with HIV, keeping a nonjudgmental and genuine attitude.
- Use a biopsychosocial model to conceptualize cases by considering the interaction among biological/medical factors, psychological factors, and cultural/social factors.

- Participate in intervention development, delivery, and monitoring to ensure that the academic, social–emotional, and behavioral needs of students living with HIV are met, and, when indicated, conduct comprehensive psychoeducational evaluations to generate recommendations regarding a need for educational programs or accommodations.
- Educate parents about the importance of HIV disclosure, generally, and how to disclose HIV status to children in a manner that is congruent with the child’s cognitive and psychological maturity.
- Assist students in making HIV disclosures to others, if desired, including sexual and/or needle sharing partners.
- Help students cope with the internalized stigma resulting from living with HIV.
- Support the provision of developmentally appropriate, accurate education about sexual and reproductive health, including risks for transmitting HIV to others.
- Work with medical providers to provide education, self-monitoring, motivational interviewing, problem solving, and cognitive–behavioral techniques to improve medication adherence.
- Provide training to teachers and staff to create a safe environment for students living with HIV.

SUMMARY

NASP supports a comprehensive approach to meeting the needs of students living with HIV and their families, including implementing developmentally appropriate HIV prevention in schools as well as providing direct academic and social–emotional services to students living with HIV. NASP believes school psychologists must be at the forefront of prevention efforts to reduce the risk of HIV transmission, address psychosocial needs of students and families affected by HIV, and foster full inclusion in the community. Finally, NASP believes school psychologists should recognize the strengths and limitations of their knowledge and training. They should seek information about community-based resources and agencies and be ready and willing to collaborate across disciplines, including with medical providers, in order to promote health and well-being for all students living with HIV.

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RESOURCES

CDC National Prevention Information Network: <http://www.cdcnpin.org/scripts/hiv/index.asp>
 Provides recent news and publications about HIV/AIDS prevention, as well as current CDC guidelines and recommendations for the detection, treatment, and care of HIV/AIDS.

Center for HIV Law & Policy: <https://hivlawandpolicy.org>

Provides information about and resources related to federal and state-specific laws regarding confidentiality and disclosure of HIV status.

Chenneville, T. (Ed.). (2017). *A Clinical Guide to Pediatric HIV: Bridging the Gaps Between Research and Practice*. Cham, Switzerland: Springer International Publishing.

This edited book provides a comprehensive overview of topics related to HIV prevention and interventions for children and youth.

Chenneville, T. (2014). Best practices in responding to HIV in the school setting. In P. L. Harrison & A. Thomas (Eds.), *Best practices in school psychology: Systems-level services* (pp. 1389–1402). Bethesda, MD: National Association of School Psychologists.

Sexuality Information and Education Council of the United States (SIECUS): <http://www.siecus.org>

Professionals interested in school-based health education are encouraged to consult this website.

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