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A PRACTITIONERS BULLETIN

How do you deal with HIV/AIDS at your school?

By Linda Dawson

Since 1998, the Illinois Department of Public Health and local health departments have been responsible for notifying building principals when a child who attends their school has been diagnosed with AIDS or as having HIV-positive status. While an initial push was made to educate principals about Section 697.400 of the state's HIV/AIDS Confidentiality and Testing Code, turnover in those positions may have led to new principals who are not fully aware of their responsibilities.

Who should they tell? When should they tell? What does "as necessary" really mean? Are schools subject to the same privacy regulations as medical personnel? In light of these questions, it should be obvious that principals, now more than ever, need to be well-versed in what they *can* or *should not* do when they are notified that someone in their school is dealing with HIV/AIDS.

Those questions and the issue of principals needing well-informed training surfaced during a 2005 conference in Portland, Oregon. The conference was sponsored by the National School

Boards Association (NSBA) and the Chief Council of State School Officers (CCSSO) through a cooperative agreement with the U.S. Centers for Disease Control and Prevention, Division of Adolescent and School Health (CDC/

implement, and evaluate effective education strategies, policies and programs addressing HIV prevention, and other serious health issues affecting youth." Following the conference, NSBA and CCSSO worked with the state teams,

"Students who test positive for HIV or who have AIDS . . . continue to have a right to public education."

DASH). It brought together leadership teams from 16 states and the District of Columbia in a fledgling organization known as the *Leadership Network for Healthy Students & Healthy Schools*.

Each team was headed by representatives from that state's NSBA and CCSSO member organizations. Some teams included school board members; others invited representatives from the public health sector. Illinois team members were Linda Dawson, director of editorial services with the Illinois Association of School Boards; Glenn Steinhausen, principal education consultant with the Illinois State Board of Education; and André Rawls, HIV/AIDS section chief with the Illinois Department of Public Health.

According to the letter of invitation, the goal of the Network was "to foster collaborative efforts to formulate, adopt,

through telephone conference calls and a listserv, to help further progress toward goals and needs identified at the conference.

Illinois' identified goals involved work with school principals around the Principal Notification Act, as well as enlarging the Leadership Network to encompass other education and health care organizations. While ISBE and IDPH supported a repeal of the Act, IASB's position in opposition to a repeal led the state team to focus its initial work on educating principals about the Act, as well as other issues involving HIV and AIDS.

Why the need?

Since the first case of AIDS was diagnosed in the late 1970s, the number of cases of HIV, AIDS and other sexually transmitted diseases among young

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people have increased, making it more likely that a school might have students affected by these conditions.

The National Association of State Boards of Education (NASBE) prefaced its 2001 guide, *Someone at School has AIDS*, with the following:

“Every state and school district needs policies that address serious issues raised by HIV infection. Sound policies provide essential guidance to educators; reassurance to families, students, and school staff members; legal protection for schools; and support for people with the virus.”

Students who test positive for HIV or who have AIDS also continue to have a right to a public education. But the numbers of those affected continue to grow.

In the 2001, the NASBE guide reported statistics from the Centers for Disease Control and Prevention that 3,664 children under the age of 13 were currently living with AIDS as of June 30, 2000, although it was not known how many of these children attended school.

Also in cumulative statistics through June 2000, 3,865 young people between the ages of 13 and 19 had been diagnosed with AIDS. An additional 1,911 children under 13 and 5,263 between 13 and 19 had been diagnosed as HIV-positive, but had not progressed to full-blown AIDS cases.

At that time, Illinois was among a group of four states that did not count cases of HIV infection for children under 13, which means the total might have been higher.

Since then, the numbers have grown. As of December, 31, 2005, approximately 13,955 people in Illinois are reported by the Illinois Department of Health statistics as “living with HIV,” and an additional 15,461 in the state are “living with AIDS.”

Even more troubling in the statistics is the over-representation of African Americans in the numbers. According to the CDC, African-Americans make up 12 percent of the population nationwide, but represent almost 37

percent of all AIDS cases. The statistics are worse in Illinois, where 52 percent of those living with HIV/AIDS are African American.

Worse than that, the Washington, D.C.-based group Advocates for Youth reports that, through 2001, “African Americans and Latinas accounted for 84 percent of cumulative AIDS cases among women ages 13 to 19 and 78 percent of cases among women ages 20 to 24.” Advocates for Youth provides information, training, and strategic assistance to youth-serving organizations, policy makers, youth activists, and the media in the United States and the developing world.

The numbers were nearly as bad for males in those two ethnic groups, the organization reported. “Through 2001, African Americans and Latinos accounted for 62 percent of cumulative AIDS cases among men ages 13 to 19 and 60 percent of cases among men ages 20 to 24.”

Why should these statistics concern education leaders? According to a CCSSO School Health Project publication, education leaders and policymakers need to be knowledgeable about the issues confronting the nation’s young people ... and one of these issues is HIV/AIDS.

HIV (Human Immunodeficiency Virus) is the virus that causes AIDS (Acquired Immunodeficiency Syndrome). The virus weakens the immune system. Individuals with a weakened immune system have a harder time fighting off infections. As many as 950,000 Americans may be infected with HIV, one quarter of whom are unaware of their infection (CDC, 2005).

Since the beginning of the HIV/AIDS epidemic, there has been a significant demographic shift in the populations affected by the disease. What was once thought to be a disease that primarily affected white gay men is now known to be one that shows

no discrimination with regard to sexual orientation, ethnicity, gender, or age. School-aged youth continue to engage in behaviors that put them at risk for HIV at significant rates.

The virus that causes HIV/AIDS is transmitted almost exclusively by behavior that school-aged youth can modify. Educational programs that reduce and prevent risky health behaviors are effective in preventing the spread of HIV/AIDS. Comprehensive school health education, which establishes a foundation for understanding the relationships between personal behavior and health, provides schools with an appropriate and effective means of educating school-aged youth about HIV/AIDS.

The overall number of HIV-positive school-age youth is relatively low compared to other age groups. But it is important to keep in mind that it is possible for a number of years to pass from the time of infection to the time an individual is diagnosed with HIV. A delay in diagnosis can occur for a number of reasons, including the absence of symptoms or symptoms that are not recognized; therefore, it is very likely that many 20- to 24-year-olds diagnosed with HIV contracted it between the ages of 13 and 19.

In Illinois, of those who are living with HIV, 29 percent (4,110) are under the age of 30. That means the oldest in the group would have been 11-year-olds ... or approximately fifth-graders ... when the Principal Notification Act was passed.

Other statistics show that 47 percent of high school students reported they had had sexual intercourse on the *Youth Risk Behaviors Surveillance 2003* report and, of those, only 63 percent used a condom. These statistics taken together also point to the need for health

HIV cannot be transmitted through casual contact, which means it is **not** risky to:

- Shake or hold hands
- Hug
- Kiss
- Share toys
- Share offices, classrooms, or locker rooms
- Share kitchens, bathrooms, or laundry rooms
- Use public drinking fountains, toilet seats, and doorknobs
- Swim in public pools
- Eat food prepared or served by a person with HIV infection

education and preventative programs that extend over multiple school years, according to the CCSSO.

What does the Act say?

The Principal Notification Act, Section 697.460 of the Administrative Code, is fairly straight-forward. It reads, in part:

- Whenever a child of school age is reported to the Department (of Public Health) or to a local health department as having been diagnosed as having AIDS or as having been shown to have been exposed to Human Immune Deficiency Virus (HIV) (or any other identified causative agent of AIDS) ... such department shall give prompt (within three working days) and confidential notice of the identity of the child to the principal of the school in which the child is enrolled. If the child is enrolled in a public school, the principal shall disclose the identity of the child to the superintendent of the school district in which the child resides.*
- Upon receipt of such notice, the principal may, as necessary, such as when a student needs medical*

attention or must take medication during school attendance, or when the student's clinical condition necessitates other such services, disclose the identity of an infected child to the school nurse at that school, the classroom teachers in whose classes the child is enrolled, and those persons who, pursuant to Federal or state law, are required to decide the placement or educational program of the child. In addition, the principal may inform such other persons as may be necessary in the opinion of the principal that an infected child is enrolled at that school so long as the child's identity is not revealed. (Section 2a of the Communicable Disease Prevention Act [410 ILCS 315/2a])

- No person to whom the child's identity is disclosed may disclose such information to any other person except as permitted by law (Sections 9 and 10 of the AIDS Confidentiality Act).*

This may seem to be contradictory and in some instances becomes a judgment call on the part of the principal. However, those who work in a school

setting are supposed to use “universal precautions” when dealing with any body fluid, according to the Occupational Safety and Health Administration (OSHA) “Rules on Blood-borne Pathogens,” which also were adopted by the Illinois Department of Labor.

“Blood-borne Pathogens” are defined as “pathogenic microorganisms that are present in human blood and can cause disease in humans. These pathogens include, but are not limited to the hepatitis B virus (HBV) and the human immunodeficiency virus (HIV).

“Universal precautions” is an approach to infection control. “According to the concept, “all human blood and certain human body fluids are treated as if known to be infectious for HIV, HBV, and other blood-borne pathogens,” whether a student’s status is known or not.

These definitions are contained in a memorandum of the rules by the Illinois State Board of Education, dated February 5, 1993. The rules require schools to:

- develop a written exposure control plan;
- provide annual in-service education programs for all employees;
- offer, at no charge, hepatitis B vaccine to employees who may be occupationally exposed;
- provide hand washing facilities;
- provide employees with protective clothing such as gloves, gowns, etc.;
- provide for safe disposal of contaminated waste such as blood-tinged materials and sharps;
- provide post-exposure evaluation and follow-up;
- and keep records of staff training and immunizations, waste disposal, blood exposures, etc.

If *all* school employees are following universal precautions for all incidents when they come into contact with body fluids ... such as cuts on the playground or in the gymnasium ... then the list of those on the principal’s “need to know” list could be very short.

What about HIPAA?

Under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), doctors, nurses, pharmacies, hospitals, clinics, nursing homes, and many other health care providers must follow certain guidelines designed to protect a patient's privacy, to give patients access to their medical records and to prevent medical information from being used and shared against a patient's wishes.

This would seem to preclude information from reaching a principal in the first place if a student were diagnosed with HIV/AIDS. However, under limited circumstances, the law allows previously accepted disclosure practices to continue. Among a list of permitted circumstances is "public health needs," which would cover the release of information about HIV/AIDS status.

While HIPAA has established new safeguards for the release of patient information, the rules also state that "covered entities may continue to use their professional judgment to decide whether to make such disclosures based on their own policies and ethical practices."

What can be done?

According to a 2003 revised edition of "Management of Chronic Infectious Diseases in Schoolchildren," distributed by ISBE and IDPH, those organizations, along with the Illinois General Assembly, "place a high priority on the need to prevent the spread of infectious diseases in schools."

The Management document contains "reasonable and practical guidelines for school personnel to follow when working with children who have infectious diseases." The document urges local school district to develop their own policies and procedures related to infectious diseases. Among those guidelines are:

- All children in Illinois, including those with chronic infectious diseases have a right to a free public education.

- The school should respect the right to privacy of the individual. ... The law permits school administrators to inform such other persons as may be necessary that an infected child is enrolled at that school, so long as the child's identity is not revealed. In all cases, knowledge that a student has an infectious disease should be confined to those persons with a direct need to know (e.g. principal, superintendent, school nurse, and student's teacher) or as prescribed by law. Those persons who are informed of the identity of an infected child must be provided with information concerning any precautions that may be necessary and should be made aware of confidentiality requirements.
- Students known to have chronic infectious diseases should be individually evaluated in order to determine if their behavior or physical condition poses a high risk of spread of disease.
- As a consequence of the evaluation, there should be a specific plan for the education of the student.
- In most cases, students with chronic infectious diseases should be allowed to attend school in a regular classroom environment or curricular offerings.
- Under certain circumstances, it may be necessary to provide the student with an alternative school program or to remove the student from the school setting for a period of time. (e.g. changes in condition that require removal from a regular program; on-going risk because of open sores or demonstrated behaviors)
- The length of time that a student with a chronic infectious disease should be kept out of school should be determined on a case-by-case basis, depending on the recommendations of the student's physician, local health officials, and the school's infectious disease review team.
- Each student should have the right to due process.
- The maintenance of confidentiality is of the utmost importance in the case of students who have a chronic infectious disease.
- In some instances, students who have an immune deficiency may need to be removed from the classroom for their own protection, for example, if there is an outbreak of a contagious disease.
- Individual health conditions permitting, a student who is removed from the school should be provided with a continuing education program until it is determined that the student can be safely returned to the classroom.
- The school nurse should routinely monitor all students identified as having infectious diseases.
- Universal precautions should always be used for clean up after any student who has an accident or injury at school. Blood or other body fluids (saliva, vomitus, feces, urine) emanating from any student, including ones known to have infectious diseases, must be treated cautiously.

Policies and administrative procedures based on these guidelines should be discussed and implemented by the school board. If your district does not have such policies and procedures in place, it would be appropriate for school officials to convene a task force to assist the board in developing such policies.

The management guidelines indicate such a task force should include "the school administrator, the school medical advisor, the school nurse, and representatives of the school board, local health department, teaching staff, PTA or PTO, custodial staff, food service staff, etc." Other community members with an interest may also be included.

In addition, sample policies are available from the Illinois Association

of School Boards.

Once these policies and administrative procedures are written, they should be available to the public, including distribution to all parents and school staff in the district.

Although not mentioned in the guidelines above, the district may want to consider additional policy work around the issue of continuing education for all staff to increase their working knowledge of information provided in these documents as well as professional development so that teachers might work more effectively with students in the area of health education for HIV/AIDS.

“The success of schools in gaining support for HIV and other prevention programs depends largely on understanding the community and its beliefs,” stated another CCSSO health project report, “What Education Leaders Should Know About Forming Partnerships to Prevent Sexual-Risk Behaviors in School-Aged Youth.” “Community support can be obtained by encouraging parents to take an active role in their children’s health education as part of their involvement with all facets of their children’s education.”

The report goes on to state that collaboration among a number of parent and community groups “can help build broad-based support for school health programs, especially when they address topics that can be emotionally charged, such as HIV prevention.”

In that same collaborative vein, IASB, ISBE and IDPH are in the development stages of a CD-Rom or Web-based program that would provide principals with necessary updates on HIV/AIDS information, as specified by Principal Notification Act provisions.

While work toward this goal is going forward, the Network itself has been abandoned by NSBA and CCSSO due to a change in funding priorities. The Illinois team will continue its efforts at least through the Illinois Principals Association conference in October and the IASB/IASA/IASBO conference in November.

Confidentiality checklist

Protecting client confidentiality on your premises:

- Are names visible on the outside of student files?
- Where are your open files during the day?
- Where are they after office hours?
- Where are closed files?
- Where is your outgoing mail?
- Where is your incoming and outgoing mail?
- Where are your printer and your fax machine?
- Do you have a shredder? What do you use it for?
- Where do you talk to students/parents in private?
- Do you use sign-in sheets that can be seen by other students/parents?
- What’s your policy when a friend or family member accompanies a student to the office?
- How are phone calls announced?
- Where do you leave phone message slips?
- What efforts do you take to maintain privacy in your waiting area?
- Can students/parents in your waiting area hear your receptionist on the phone?
- Can students/parents in your waiting area hear conversations in offices or hear staff on the phone in their offices?
- How do you protect student information on your computer?
- How do you protect student information on your network?
- Who has access to HIV information at your school?

Protecting client confidentiality beyond your premises:

- What are your procedures for releasing student information to other entities?
- What are your procedures for obtaining information from other schools your students have attended?
- Do you have staff who are mandatory reporters (i.e. to DCFS)? How do you communicate that to students/parents?
- What’s your policy on leaving messages on answering machines?
- Do you have a policy on unscheduled interactions with students/parents in public?
- What are your policies and procedures about using student photographs, stories, thank you notes, or names in your publications?

General:

- Are your confidentiality policies written?
- How are they communicated to new staff? To volunteers? To board members?
- What and how do you tell parents about your confidentiality policies?
- How do you respond when confidentiality has been breached?

– Adapted from guidelines developed by AIDS
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Illinois Principals Association

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Resources

Advocates for Youth, "Youth of Color — At Disproportionate Risk of Negative Sexual Health Outcomes," *Transitions*, Volume 15, No. 3, January 2004

Joint Committee on Administrative Rules, Administrative Code, Title 77: Public Health, Chapter I: Department of Public Health, Subchapter k: Communicable Disease Control and Immunizations, Part 697 HIV/AIDS Confidentiality and Testing Code, Section 697.400 Notification of School Principals.

"Management of Chronic Infectious Diseases in Schoolchildren," Illinois State Board of Education and Illinois Department of Public Health, Revised Edition, 2003

"Overview of HIV/AIDS in Illinois," PowerPoint presentation by André W. Rawls, Illinois Department of Public Health

"Protecting the Privacy of Patients' Health Information," fact sheet, United States

Department of Health & Human Services, <http://www.hhs.gov/news/facts/privacy.html>

Someone at School has AIDS, National Association of State Boards of Education, 2001 Edition

"What Education Leaders Should Know About HIV and AIDS," School Health Project, Council of Chief State School Officers, 2005

"What Education Leaders Should Know About HIV and AIDS and School-Aged Youth," School Health Project, Council of Chief State School Officers, 2005

"What Education Leaders Should Know About Forming Partnerships to Prevent Sexual-Risk Behaviors in School-Aged Youth," School Health Project, Council of Chief State School Officers, 2005



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