Schoolhouse Stigma

"How was school?" may be a hard question for kids with HIV.

March 4, 2010 By Rachel Rabkin Pechman

Fearful parents barred HIV-positive children from attending school last summer in An Nhon Tay, Vietnam. Real Health wondered: Could that happen here?

Sadly, it does. "Even though [Americans] seem to understand that HIV/AIDS is not the death sentence it used to be, it still carries stigma," says Khadijah Tribble, of Pediatric AIDS/HIV Care Inc. (PAHC), in Washington, DC.

In a PAHC survey, 95 percent of respondents said they wouldn't treat someone differently if he or she were HIV positive. But only 62 percent said they would feel comfortable letting their children play with HIV-positive youngsters. The result? Most parents choose not to disclose their child's HIV to the school (medical privacy laws make it voluntary). "I can count on one hand how many families have disclosed," says Lorri Connelly, a nurse case manager at Southern New Jersey Regional Family HIV Treatment Center.

When parents do disclose to a school nurse or principal, the picture isn't bad, says Richard Rutstein, MD, of the Children's Hospital of Philadelphia: "In most cases with my patients, there have been very few instances where things did not go well."

When children 9 and older disclose to friends, however, "it's gone all different ways," adds Gail Burack, PhD, clinical assistant professor of pediatrics at the UMDNJ-Robert Wood Johnson Medical School in New Brunswick, New Jersey. "[Some suffered] no negative consequence, but others [met with] a lot of prejudice."

Because many HIV-positive children in urban areas lost a parent to HIV/AIDS, to them it still feels like a secret to guard closely. In that case, "disclosing HIV status is the last thing kids and parents want to do," says Tribble, whose group serves mainly urban-area kids.

"We hope we're moving toward a more tolerant community," Tribble adds. But until families disclose their children's HIV status, it's hard to know what level of tolerance they'll encounter. And, as Connelly points out, "It's a high price to pay to find out."

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