

Testimony of Linda S. Coon
FCAN Project Director
House Bill 90
Illinois House of Representatives
Human Services Committee
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Thank you for the opportunity to provide testimony to the House Human Services Committee regarding House Bill 90.

My name is Linda Coon, and I am the Project Director for FCAN, the Families' and Children's AIDS Network. I am also an attorney, and serve as the Legal Services Director for FCAN's Family Options Program. In this capacity, I have represented hundreds of HIV-positive parents in the Cook County metropolitan area regarding issues that have impacted their children. Our program also provides case consultation and technical assistance to families and service providers downstate on a host of issues that impact children and families.

I have authored or co-authored many of Illinois' legal permanency reforms in recent years, including our standby guardianship, short-term guardianship, and standby adoption laws. In addition, I am the past Chair of the Chicago Bar Association's Adoption Law Committee, and currently serve as Chairperson of the committee's Legislative Subcommittee. I also serve on the Illinois State Bar Association's Child Law Committee, and chair its Legislative Subcommittee.

FCAN was organized in 1985 to address the unique needs of HIV-affected families in Illinois. In addition to legal services, FCAN supports families through social work and psychological services. Through support groups and retreats for families, FCAN has worked with HIV positive children, teens and adults for many years. We have been operating statewide family retreats and summer camps since 1995. We have worked with families – some for many years – that have grown up in FCAN programs. The population of HIV-positive teens is large and growing, and we have created new support groups and retreats for positive teens as a result. In addition, we provide expert consultation for families and HIV service providers around disclosure of HIV status to family members, schools, and others.

House Bill 90 is a bill that will make long overdue changes to the Illinois Communicable Disease Prevention Act. The current law, approved in 1987 by the General Assembly, requires the Illinois Department of Public Health or local health departments to report the name of an HIV-positive child to the child's school principal. The principal may then notify others in the school.

The current law was written at a time when not enough was known about HIV transmission. When the law was written in 1987, it was believed that special precautions needed to be taken with respect to HIV-positive children in school. Over time, we have learned that simple universal precautions will prevent the spread of any blood borne disease among students. Thus, Illinois changed its state regulations in 1994 to require that school personnel take these precautions.

We have also come to know that the Communicable Disease Prevention Act needed repealing. We are grateful to Representative Ford for introducing this long-needed measure.

The current law has had a negative impact on our children and youth. In preparing for this testimony, I looked back through my files for some older and newer examples. One older example occurred twelve years ago. I received a call from a respite care provider regarding a family participating in her program. The caller was concerned about the family's only child – a third grader, whose mother had recently died of AIDS. The child learned of her own HIV status on the playground at school from a teacher. The sharing of the child's HIV status was most likely not intentional, but this information needed to be shared only by the child's father and the child's doctor – not others. And it could have resulted in legal action against the school, since the Illinois AIDS Confidentiality Act prohibits disclosure or re-disclosure of an individual's HIV status.

A newer example is best illustrated through a recent letter from an HIV Teen Support Group. I spoke to this group of positive teenagers about the bill last spring, and they asked if they could write a letter to this committee. The following is an excerpt from their letter:

“There were two sisters in the same school. One sister was thirteen and in the eighth grade the other was seven and in the third grade. The seven-year-old told her friend about her secret. Her friend told her mother, and the mother she demanded some answers from the school.

The principal didn't simply address the concerns related to the students being positive. He wrongly informed the entire school community there were two positive students in attendance.

The older sister was horrified that she might be found out so she devised a plan to remain invisible, which was brilliant. She began asking other students at school if they knew the names of the students that had HIV...but because of stress and fear of being discovered, she ultimately dropped out of school...This student had posed no risk to others, but she had to suffer the consequences of her HIV information being shared. A student's confidential health information should remain with the physician, child and the parents.

Whether people believe it or not, when the confidential trust of privacy is broken, a high rate of emotional distress can occur for a HIV + child. When the student's trust is broken it leads to thoughts of fear, suicide, anger, and even public humiliation and victimization, by both peers and the community at large. School officials' knowledge of students' HIV/AIDS status is frequently misused by sharing this private information with others. When a student's status is exposed he/she is often ostracized by others. Being ostracized can cause students to lose interest in school, and makes them feel like the personification of a disease...Teens don't get tested because they can't be sure their privacy will be protected.”

Through FCAN's work with positive teens, we are aware that the current law can - and does - deter teens from being tested. They don't want their HIV status to be public knowledge at school. Not being tested keeps some teens from receiving the treatment that they need, and risks further spread of HIV.

We hope that you will support HB 90. Your support will not only help protect the privacy of students with HIV. It will facilitate more treatment for those who need it, and more prevention of HIV disease. Thank you.

Linda S. Coon
Project Director