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Re. Emergency Proposed Rulemaking: Confidentiality Protocols for Victims of Domestic Violence and Endangered Individuals, ID No. DFS-41-13-00008-EP

Dear Sir/Madam:

I commend you on the important step forward that the proposed regulation takes, and I thank you for the opportunity to comment on the regulation. HIV Law Project believes that all people deserve the same rights, including the right to live with dignity and respect, the right to be treated as equal members of society, and the right to have their basic human needs fulfilled. These fundamental rights are elusive for many people living with HIV/AIDS. Through innovative legal services and advocacy programs, HIV Law Project fights for the rights of the most underserved people living with HIV/AIDS.

### **Young People Access Sensitive Health Services, and a Breach in Confidentiality Results in Serious Harm**

While the proposed regulation and underlying law may have been largely driven by an understanding that current insurance practices harmed or threatened to harm survivors of intimate partner violence, the regulation should be broadly construed to cover minors and young people who fear danger that might flow from release of confidential health information to their parent/policy holders.

Minors in New York may, under certain circumstances, consent to their own confidential healthcare. More specifically, they may consent to contraceptive care, prenatal care, testing and treatment for sexually transmitted infections (STIs), and HIV testing. Minors can also consent to HIV treatment in those cases where, in the physician's judgment, disclosure would not be in the minor's best interest.<sup>1</sup> These state-granted rights stem from an understanding that privacy and confidentiality are essential in sensitive situations to preserving minors' safety. A breach of this

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<sup>1</sup> N.Y. PUB. HEALTH LAW §2782(4)(e)(2)(A).



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confidentiality is a *per se* harm, but the consequences from such a breach, which can include abuse, neglect, even homelessness, can be truly devastating. Just as disclosure of a survivor's location endangers her health and welfare, disclosure of a young person's confidential, HIV-related information threatens his health and safety. It is, therefore, not only logical but imperative that the regulation's protections explicitly include endangered minors and other young dependents when they are receiving confidential services to which they have the right to consent.

### **The HIV Epidemic and Young People**

In 2009, the CDC estimated that young people aged 13-29 accounted for 39% of new HIV infections, though they comprise only 21% of the U.S. population.<sup>2</sup> At the same time, youth are less likely to know their HIV status than adults. While an estimated 20% of adults living with HIV/AIDS are unaware of their status<sup>3</sup>, astoundingly an estimated 60% of adolescents living with HIV/AIDS are unaware of their infection.<sup>4</sup> Young men who have sex with men (MSM), especially those from racial minorities, are most at risk. Between 2006 and 2009, the incidence of HIV among young black MSM increased by 48%.<sup>5</sup>

In order to connect minors to HIV care and keep them in care, state law and regulation must provide a guarantee of confidentiality in those situations where minors have the right to consent to their own care; this regulation provides just that opportunity. When confidential care is uncertain, adolescents may be deterred from going to the doctor and fail to seek the treatment they need.<sup>6</sup> In a study of 950 adolescent girls seeking treatment at 33 Planned Parenthood clinics, 59% said they would delay treatment for HIV and other sexually transmitted infections (STI's) if their parents were informed that they were seeking treatment.<sup>7</sup> Disclosure in the case of young people living with HIV is similarly threatening. Young people with HIV rightly fear the stigma that remains strongly associated with HIV, and in many cases too they fear the related

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<sup>2</sup> Centers for Disease Control and Prevention, "HIV among Youth," (2011), <http://www.cdc.gov/hiv/youth/>.

<sup>3</sup> Centers for Disease Control and Prevention, "HIV Surveillance—United States, 1981-2008," *Morbidity and Mortality Weekly Report (MMWR)*. 60:21 (2011): 689-693.

<sup>4</sup> Centers for Disease Control and Prevention, "Vital Signs: HIV Infection, Testing, and Risk Behaviors Among Youths — United States" *Morbidity and Mortality Weekly Report (MMWR)* 61:47 (November 30, 2012); 971-976, [http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6147a5.htm?s\\_cid=mm6147a5\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6147a5.htm?s_cid=mm6147a5_w)

<sup>5</sup> Centers for Disease Control and Prevention, "HIV among Youth," (2011), <http://www.cdc.gov/hiv/youth/>.

<sup>6</sup> Rachel Benson Gold, "Unintended Consequences: How Insurance Processes Inadvertently Abrogate Patient Confidentiality," *Guttmacher Policy Review* 12:4 (2009): 14.

<sup>7</sup> Diane M. Reddy et al., "Effect of Mandatory Parental Notification on Adolescent Girls' Use of Sexual Health Care Services," *JAMA* 288:6 (2002): 710-714.



involuntary disclosure of their sexual orientation. These highly charged disclosures can trigger not just unwanted but explicitly dangerous behavior by parents, guardians, family and community. Accordingly, confidentiality must be strictly maintained, both to assure young people that they may safely enter care, and to ensure their safety once they've taken the affirmative step of doing so.

### **Confidentiality by Insurers is Central to the Health and Safety of Young People Living with HIV**

Insurance practices threaten to breach confidentiality, and young people appreciate this danger. Explanations of Benefits (EOB's), which are sent routinely by insurers to policyholders in order to protect against fraud, itemize services rendered for all covered individuals. Knowledge of this practice, and fear of this indirect disclosure to their parent(s) forces some insured young people living with HIV to seek coverage of care and treatment through the AIDS Drug Assistance Program (ADAP), a public insurance program for people living with HIV/AIDS, straining already tight state resources.<sup>8</sup> Others may choose to forego treatment altogether rather than trigger disclosure to their parents via EOB. This challenge to confidentiality impacts not just minors but all those young people, now up to age 26, who receive coverage through their parent(s)' health insurance.

The proposed regulation provides an opportunity to ensure that young people may receive the confidential care they need in those situations where they perceive that they could be endangered by disclosure. Section 244.2(d) provides that "Covered individual means an individual covered under a policy issued by a health insurer who could be endangered by the disclosure of all or part of claim related information by the health insurer." This section should be broadly construed to include minors and other young people who would be endangered by an unwanted disclosure of their health information to their parent(s) or guardian. This broad construction should be made explicit in 244.2(d), so that insurers are not left to parse the regulatory meaning, and young people who fear the harms that might flow from disclosure, and their healthcare providers and advocates know with certainty that the proposed regulation offers them a source of protection.

In conclusion, because confidentiality is essential to the health and safety of young people as they access certain sensitive health services, and because a violation of this confidentiality may pose a true danger to some young people, the proposed regulation should make explicit that young people are covered individuals within the meaning of the regulation.

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<sup>8</sup> Rachel Benson Gold, "Unintended Consequences: How Insurance Processes Inadvertently Abrogate Patient Confidentiality," *Guttmacher Policy Review* 12:4 (2009): 14-15.



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I thank you very much for your attention to these concerns, and I look forward to working with you. Please feel free to contact me at 347.473.7490 with any questions or to discuss further.

Best,

Alison Yager  
Supervising Attorney, HIV Policy