



January 19, 2017

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NYS Department of Health
Bureau of House Counsel, Reg. Affairs Unit
Room 2438
ESP Tower Building
Albany, NY 12237

RE: Proposed Rule Making Amendment Section 23.1 and 23.2 of Title 10 NYCRR RE: Expansion of Minor Consent for HIV Treatment Access and Prevention

To whom it may concern:

Community Healthcare Network (CHN) writes in support of the proposed rulemaking amendment published by the New York State Department of Health on December 14, 2016 regarding **expansion of minor consent for HIV treatment access and prevention.**

CHN is a not-for-profit organization providing access to affordable, culturally competent, and comprehensive community-based primary care, behavioral health and social services for 85,000 underserved individuals throughout New York City. CHN serves 8,000 to 9,000 young people a year between the ages of nine and 18, and it is crucial for theirs, and others, safety and well-being to be able to access HIV treatment without parental consent. Furthermore, allowing minors to receive treatment safely and confidentially, without parental involvement, will continue to encourage testing as well as increase HIV awareness and education.

CHN is pleased that these regulations have been put forth and offers its full support, including recommendations to augment the rule as outlined below.

New York State Recognition of the Importance of Confidentiality

In New York State, minors already can consent on their own to the provision of reproductive and sexual health care, including medical treatment to diagnose, prevent, and manage sexually transmitted infections.¹ We support enabling minors to be able to consent on their own to HIV treatment and prevention.

New York Public Health Law § 2305(2) provides that a health care provider “may diagnose, treat or prescribe for a person under the age of twenty-one years without the consent or knowledge of the parents or guardian of said person, where such person is infected with a sexually transmissible

¹ New York Public Health Law uses the term “sexually transmitted disease.” To reflect current medical terminology these comments use the term “sexually transmitted infection” (STI) except where referring specifically to language found in a statute or bill. For purposes of these comments, these terms carry the same meaning.

disease, or has been exposed to infection with a sexually transmissible disease.” This section is consistent with New York State public policy that seeks to encourage access to services related to reproductive and sexual health by keeping those services confidential. Under New York’s Public Health Law, minors can consent on their own to abortion services and other health care related to pregnancy without parental consent.² These statutes reflect recognition of the importance, from a public health perspective, of providing minors with unimpeded access to these critical services, and further, are grounded in data that support the critical connection between confidentiality and improved access to care. Indeed, many minors will not seek sexual health care services if confidentiality is compromised.³ And in some circumstances, parental involvement results in harm to individual minors.⁴ These same concerns apply equally in the case of HIV treatment, including preventive HIV treatment. Minors may fear that their parents will find out they have received HIV treatment or prevention (and/or that they have received other confidential services related to reproductive and sexual health), and that they will suffer harmful consequences due to their parents’ discovery that they are or will soon become sexually active. Minors should not be deterred from receiving this potentially life-saving treatment because of such fears.

Prevention, Treatment, and Care Coordination

Data support the critical importance of access to HIV prevention and treatment for young people. According to the U.S. Centers for Disease Control and Prevention (CDC), in 2014, 22% of new

² See N.Y. Pub. Health Law §§ 2504, 2305 (McKinney 2006).

³ Studies have clearly shown that teens will simply not seek sexual health care services if their confidentiality is not assured. In a nationwide survey of students, the most common reason (35%) adolescents gave for failing to obtain needed health care was that they did not want a parent to know. Jonathan D. Klein et al., *Access to Medical Care for Adolescents: Results from the 1997 Commonwealth Fund Survey of the Health of Adolescent Girls*, 25 J. of Adolescent Health 120 (1999). Further, a 2002 study in the *Journal of the American Medical Association* showed that almost half of sexually active teens visiting a family planning clinic would stop using clinic services if their parents were notified that they were seeking birth control, and another 11% reported that they would delay testing or treatment for STIs, including HIV. Notably, though, virtually all (99%) reported that they would continue having sex. D.M. Reddy et al., *Effect of Mandatory Parental Notification on Adolescent Girls’ Use of Sexual Health Care Services*, 288 JAMA 710 (2002); see also Carol A. Ford et al., *Influence of Physician Confidentiality Assurances on Adolescents’ Willingness to Disclose Information and Seek Future Health Care*, 278(12) JAMA 1029-34 (Sept. 1997) (finding that assurances of confidentiality increased adolescents willingness to return for a future visit from 62% to 72%); Tina L. Cheng et al., *Confidentiality in Health Care, a Survey of Knowledge, Perceptions, and Attitudes Among High School Students*, 269(11) JAMA 1404-07 (March 1993) (36% of youth with health concerns they wish to keep private would forgo healthcare if their parents might find out); T.M. Meehan et al., *The Impact of Parental Consent on the HIV Testing of Minors*, 87 Am. J. of Pub. Health 1338 (1997) (finding that the number of adolescents tested for HIV in state-funded HIV testing centers in Connecticut doubled after parental consent requirements were removed, and visits and tests of high-risk minors in particular tripled).

⁴ Minors who do not wish to disclose to their parents that they are, or will soon become, sexually active often have good reasons, and threatening to compromise their confidentiality can have serious consequences. In one study, 30 percent of teens who did not tell a parent that they were pregnant feared physical violence between themselves and their parents (in many cases because it had already occurred) or being forced to leave home. Among minors whose parents found out about the pregnancy without being told by the minor herself, 58 percent reported one or more adverse consequences. Of those, a minimum of 6 percent suffered serious consequences, including physical violence at home, being beaten, or being forced to leave home. Eighteen percent said their parents were forcing them to have an abortion. These consequences were two to four times as common when the parents discovered the pregnancy as when their daughter herself told them. Stanley K. Henshaw and Kathryn Kost, *Parental Involvement in Minors’ Abortion Decisions*, 24 Fam. Plan. Persp. 196, 207 (1992).

HIV infections were diagnosed among youth ages 13-24 years old. Most of these newly diagnosed infections occurred among young gay and bisexual males. Young black/African American and Hispanic/Latino gay and bisexual males are especially affected. Youth with HIV are the least likely out of any age group to be linked to care. Addressing HIV in youth requires that we give youth the tools they need to reduce their risk, make healthy decisions, get treatment and care if needed, and communicate effectively with others.⁵

In New York State, more than 30% of new HIV diagnoses in 2014 were among individuals under 24 years of age.⁶ In New York City in 2015, 39% of persons newly diagnosed with HIV were under the age of 29, and persons living with HIV under the age of 24 had the lowest rate of viral load suppression of any group.⁷ Moreover, statewide one in four adolescents is likely to acquire an STI, and this rises to one in two for sexually-active people by age 25, according to the New York State Sexual Health Plan.⁸

Therefore, CHN is in full support of the amendment to add HIV to Group B of the existing list of sexually transmitted diseases (STDs) enabling minors to consent to HIV treatment and prevention without parental consent. We support amending this rule to enable “STD clinics operated by local health departments or providing services through contractual arrangements ... to provide diagnosis, treatment, including preventive services, to person diagnosed or at risk for HIV, either directly or through referral.” Making explicit a requirement for services to include HIV treatment and prevention acknowledges the compelling data mentioned above and addresses not only the risk of HIV infection for young people but also the barriers to HIV treatment and care should they test positive for HIV. In addition, STIs are often a predictor for later HIV infection. We are in favor of the amended regulation, which will allow young people to access pre-exposure prophylaxis (“PrEP”) and post-exposure prophylaxis (“PEP”), just as they can access other reproductive and sexual health-related services, including preventive care for other preventable infections.

To strengthen this rule, we recommend adding “care coordination services as needed” to the list of services that are required to be provided by clinics and local health departments. Care coordinators—and care coordination services—play a vital role in the public health infrastructure of New York State. Care coordination and management integrates and coordinates all primary, acute, behavioral, long-term care health services and social supports to treat the whole person. Expanding the services provided to include “care coordination services as needed” will ensure that the spectrum of young people’s needs is met.

Criminalization

⁵ *HIV Among Youth*, CDC, <https://www.cdc.gov/hiv/group/age/youth/index.html> (last visited Jan. 6, 2017).

⁶ *New York State Epidemiological Profile*, N.Y. Dep’t Health (Sept. 2016), http://www.health.ny.gov/diseases/aids/general/statistics/epi/docs/epi_profile2016.pdf, at 16, figure B9.

⁷ *HIV Surveillance Annual Report, 2015*, N.Y.C. Dep’t Health & Mental Hygiene (Dec. 2016), <https://www1.nyc.gov/assets/doh/downloads/pdf/dires/hiv-surveillance-annualreport-2015.pdf>, at 2, 8.

⁸ *New York State Youth Sexual Health Plan*, N.Y. State Dep’t Health (2016), https://www.health.ny.gov/community/youth/development/docs/nys_youth_sexual_health_plan.pdf at 5.

CHN objects to any criminalization of STIs (including HIV). A growing body of research and analysis has found that HIV criminalization laws magnify stigma and create a fear of persecution and prosecution. This contributes to increased fear of HIV testing among high-risk negatives, and to reluctance to seek and remain linked to HIV prevention and care.⁹

Regrettably, HIV status has been criminalized in New York in the past, and New Yorkers with HIV have been prosecuted under existing State laws for felony charges, including reckless endangerment and aggravated assault charges that have led to incarceration and even civil confinement. (Indeed, in one case HIV infection was treated as a “deadly weapon,” and an HIV-positive man was found guilty of aggravated assault for biting a police officer, despite the fact that HIV cannot be transmitted through saliva.)¹⁰ However, more recent court rulings have shifted away from these findings towards a more informed public health approach.¹¹

We are aware that Article 23 of the New York Public Law includes a provision that a person who is aware that he or she is living with an infectious venereal disease may be guilty of a misdemeanor if they have sexual intercourse with another person. However, we understand that the misdemeanor provision has rarely been invoked regarding any STI, and therefore strongly believe that it should not be a barrier to the adoption of the proposed rule. The significant individual and public health benefits of expanding minors’ access to HIV prevention and treatment far outweigh the risk of an attempt to enforce the misdemeanor provision. We recommend adoption of the proposed rule and urge efforts by government and advocates to fully decriminalize HIV status as rapidly as possible.

Cost

Expanded access to HIV prevention and healthcare under the proposed rule will not only produce better individual and public health HIV outcomes for young New Yorkers, but will also *reduce* overall public costs. Highly effective antiretroviral therapy, taken as treatment or prevention, enables persons with HIV to maintain optimal health and virtually eliminates ongoing HIV transmission. Improved health outcomes for youth living with HIV will reduce the use of avoidable emergency and inpatient care, while the discounted present value of medical costs saved through each avoided new HIV infection has been conservatively estimated at \$229,800 to \$326,500 (in 2012 U.S. dollars).¹² Therefore, while increased access to care for young New Yorkers at highest risk of HIV will likely result in near-term increases in Medicaid and other public spending for HIV prevention and care, this care will generate substantial savings in future public spending that will

⁹ See Sophie E. Patterson et al., *The Impact of Criminalization of HIV Non-Disclosure on the Healthcare Engagement of Women Living With HIV in Canada: A Comprehensive Review of the Evidence*, 18(1) J. Int’l AIDS Soc. 2015: 20572 (Dec. 22, 2015), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4689876/>; Michelle Pentecost, *The Public Health Implications of HIV Criminalization: A Special Issue of Critical Public Health*, Somatosphere (July 27, 2015), <http://somatosphere.net/2015/07/the-public-health-implications-of-hiv-criminalization-a-special-issue-of-critical-public-health.html>.

¹⁰ CENTER FOR HIV LAW & POLICY, POSITIVE JUSTICE PROJECT: STATE AND FEDERAL LAWS AND PROSECUTIONS, VOL. 1, 151-54 (2d. ed. Winter 2015), <http://hivlawandpolicy.org/sites/www.hivlawandpolicy.org/files/HIV%20Crim%20Manual%20%28updated%205.4.15%29.pdf>.

¹¹ *Id.*

¹² B.R. Schackman et al., *The Lifetime Medical Cost Savings from Preventing HIV in the United States*, Med Care 53(4) (April 2015), 293-301, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4359630/>.

more than offset near-term costs, making the proposed rule cost-saving for the State and localities. Even more importantly, greater access to effective treatment will enable young New Yorkers with and at risk of HIV to live long, healthy and productive lives.

Summary

In conclusion, CHN supports the adoption of the proposed rule as a means to give young people access to preventive, treatment and care coordination services and to end the epidemic in New York State.

In 2015, CHN tested over 28,000 New Yorkers for HIV. With each positive diagnosis, CHN provides education, counseling, and treatment at all of our centers and medical mobile vans. In order to end the AIDS epidemic in New York State by 2020, these services must be made accessible to minors without the need for parental consent. Protecting the health and well-being of our youth is a top priority for CHN, and should be for the state as well.

Sincerely,

A handwritten signature in black ink that reads "Robert M. Hayes". The signature is written in a cursive style with a large initial "R" and "H".

Robert M. Hayes
Community Healthcare Network
President and Chief Executive Officer