Thank you to the New York State Assembly Committee on Health and Committee Chair Gottfried for the opportunity to testify today regarding HIV testing, counseling and informed consent. My name is Dr. Adele Webb, and I am the Executive Director of the Association of Nurses in AIDS Care. I practiced as an HIV nurse for XX years, and have been serving as the Executive Director of Association of Nurses in AIDS Care, or ANAC, for the past 6 years. ANAC represents nearly 2,500 HIV nurses, and our membership consists of a diverse group of clinicians, educators, researchers and administrators. Members of ANAC work in clinics, hospitals, prisons, universities, public health departments and various levels of government.

The hallmark of nursing rests in nurses' standard of care for patients. The foundation for nurses' standard of care is the empowerment of patients in matters affecting their health. The Code of Ethics of the American Nurses Association (2005) states that "The nurse strives to provide patients with opportunities to participate in planning care, assures that patients find the plans acceptable and supports the implementation of the plan" (p. 9-10). Nurses facilitate patient education. An important role of a nurse is to act as a health information translator, helping patients to fully understand how to take control of their own healthcare decisions. Nurses facilitate the transfer of medical knowledge to the patient. It is from this perspective that ANAC views the CDC's Revised Recommendations for HIV Testing of Adults, Adolescents and Pregnant Women in Health Care Settings and the issues of HIV testing, counseling and informed consent.

In reference to the CDC Revised Recommendations for HIV Testing of Adults, Adolescents and Pregnant Women in Health Care Settings, ANAC supports the CDC's recommendation to expand voluntary HIV testing in health care settings and feels that routine access to HIV testing is a commendable goal. ANAC, however, believes that the CDC's revised recommendations fall short of laying the groundwork for responsible and patient-centered medical care. The recommendations (2006) state that "CDC recommends that diagnostic HIV testing and opt-out HIV screening be a part of routine clinical care in all health-care settings while also preserving the patient's option to decline HIV testing and ensuring a provider-patient relationship conducive to optimal clinical and preventive care" (p. 8).

ANAC has specific concerns about several of the CDC's revised recommendations, as we feel they may undermine providers' ability to provide "optimal clinical and preventive care" (CDC, 2006, p. 8). First, CDC recommends that "*An HIV screening test may be performed after an individual has been notified that the test will be conducted, unless the person declines (opt-out screening)* (CDC, 2006, p. 2)." Notification to a patient about performing a test can take many forms. All medical care requires consent, and informed consent for HIV testing must involve more than an agreement with, conformity to, compliance with or otherwise failure to reject the plan or proposal of a healthcare provider to perform the test. ANAC believes a patient must be specifically given information that an HIV test is being performed, what an HIV test is, and what HIV test results, whether positive or negative, mean. This need not be arduous, but should not be omitted. The provider should give patients an information sheet that provides key information about an HIV test. Delivery of this information sheet must be documented in the patient's medical record.

At a minimum, this information sheet should include the following information:

- A definition of HIV
- How HIV is transmitted
- How HIV can be prevented
- An explanation of why the patient is being given an HIV test
- A clear explanation of the patient's rights, including a statement that the patient has the right to decline an HIV test
- A definition of an HIV test
- An explanation of HIV test results, whether positive or negative
- A listing of local and national resources for more information about HIV

ANAC has drafted a sample information sheet, and has included it with our written testimony. ANAC feels that CDC's recommendations imply that this transfer of information to patients is a barrier to testing, and ANAC does not agree. Providing such information is not without precedent. The CDC requires that individuals receiving a flu vaccine receive a Vaccine Information Statement created by the CDC. This information statement is entitled "Inactivated Influenza Vaccine – What You Need to Know," and includes sections that explain the reason for getting a flu vaccine, the definition of an inactivated flu vaccine, an explanation of who should get a flu vaccine, symptoms of the flu and basic prevention against the flu. This has not proven to be a barrier to receiving care, and is not a time-consuming or arduous process. Providing a similar information statement about an HIV test would prove no more difficult and would help a provider to ensure that a patient's consent is in fact informed.

A second revision put forth in the CDC's recommendations is that "*Separate written consent for HIV testing should not be required; general consent for medical care should be considered sufficient to encompass consent for HIV testing* (CDC, 2006, p. 2)." The principle of informed consent requires that a patient receives and indicates understanding of the meaning of the medical care being proposed. Requirement for true informed consent for HIV testing should, at a minimum, require the person ordering the test to inquire openly about the patient's individual understanding and misconceptions about an HIV test. A patient must receive an information statement like the one described in this testimony, must have the opportunity to voice questions and concerns and must indicate understanding of the contents of this statement. The provider must document the review of the statement with the patient in the patient's medical record. The statement must be communicated in a way that is culturally competent and take into consideration a patient's language and literacy skills. All necessary accommodations should be made and documented.

I would like to describe a case example that illustrates the importance of informed consent. Upon release of the recommendations, a physician decided to routinely test every patient that the physician saw. The provider thinks that he mentioned that an HIV test was one of the routine tests being performed during the visit, but is not certain that he did so with every patient. One particular patient screened positive for HIV. The physician admits that he never thought this person would test positive and was not prepared to deliver positive results to the patient. As a result, the patient left the physician's office without the knowledge that an HIV test was administered or that the test result was positive. The physician stated that he was reluctant to tell the patient because he himself did not completely understand the test result and did not know what to tell the patient or where he could refer the patient. It is now two weeks after that initial visit, and the patient still does not know the result. In an effort to make HIV testing routine, this provider did not ensure that the patient was given the opportunity to understand or decline an HIV test and clearly did not deliver results at all. A patient's rights must not be undermined because a provider is not comfortable discussing HIV or because a provider does not know how to talk with a patient about positive HIV test results.

CDC has recommended that HIV test results be given to patients in the same manner that other test results are given. It is also the position of ANAC that HIV test results must be delivered confidentially in person so that the patient understands the meaning of the test result, whether positive or negative. There are primary care providers who deliver routine test results by postcard or leave messages on answering machines. To recommend that providers can deliver HIV test results in the same manner that they deliver other routine test results greatly decreases the chance that patients will be confidentially informed and linked into the necessary care and treatment. All persons who receive positive HIV test results should be linked into an appropriate system of care, and the provider should offer the patient information about accessing care and treatment as well as prevention information to avoid further transmission of the virus.

A third revision recommended by the CDC is that "*Prevention counseling should not be required with HIV diagnostic testing or as part of HIV screening programs* (CDC, 2006, p. 2)." This revision implies that prevention counseling is an arduous and time-consuming activity that is a barrier to testing. ANAC believes that HIV testing can and should include prevention counseling. By providing a patient with the information statement described in this testimony, the provider enters into a conversation with the patient about the rationale for and benefits of an HIV test. One cannot talk about the rationale for and benefits of an HIV test without discussing how HIV is transmitted. A responsible discussion about transmission includes information about prevention, which can be readily and easily communicated in the course of client-centered care. ANAC believes that linking voluntary testing, counseling and referral is an appropriate mechanism for helping to diagnose cases of HIV infection in order to provide appropriate and early care for those with HIV infection, as well as prevention messages for both infected and uninfected individuals.

Another of the revisions put forth by the CDC is that "*Persons at high risk for HIV infection should be screened for HIV at least annually* (CDC, 2006, p. 2)." It must be made clear that persons at risk for HIV must be tested when they engage in any form of high risk behavior. Providing an annual minimum benchmark implies that an annual test is adequate for all persons at high risk, and is gravely misleading as a standard of practice. High risk behavior certainly can occur more than once per year. Thus, providers must convey to patients when and why an HIV test is necessary.

ANAC supports the expansion of voluntary routine HIV testing, but is greatly concerned about the implementation of the CDC's revised recommendations in health care settings. Informed consent requires information. Voluntary consent requires the right to decline any test being proposed, including an HIV test. Responsible and patient-centered care requires that providers give patients information about how to stay healthy. Taking HIV prevention counseling out of a medical visit does not prioritize the health or rights of patients. Providers talk to patients about how to prevent getting the flu, about how to prevent heart disease, about how to prevent diabetes. If a provider is to be testing for HIV, then the provider should also be talking to patients about how to prevent HIV.

Thank you, again, for the opportunity to provide this testimony.

References:

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