



ANDREW M. CUOMO
Governor

**Department
of Health**

HIV Advisory Body

HOWARD A. ZUCKER, M.D., J.D.
Commissioner

SALLY DRESLIN, M.S., R.N.
Executive Deputy Commissioner

April 26, 2018

Johanne Morne, Director
New York State Department of Health AIDS Institute
Empire State Plaza, Corning Tower
Albany, NY 12237

Dear Ms. Morne:

The New York State HIV Advisory Body (HAB) writes this letter in support of the AIDS Institute's recent efforts to make the disability community a key population to be addressed within HIV prevention and treatment services. HAB is committed to learning more about the disability community to better determine needs and strategies for inclusion in Ending the Epidemic goals.

There are common misconceptions about the disability community that are based on stigma and stereotypes. Individuals with disabilities face multiple barriers and life experiences that increase risk for HIV, STD and Hepatitis C exposure. These barriers and life experiences include lower employment rates, violent victimization, lack of access to sexual health education, and discrimination in health care settings. Individuals are often perceived as not engaging in risk behaviors, therefore they are not seen as at risk of or in need of sexual health education.

It is reported by the Centers for Disease Control and Prevention (CDC) that thousands of individuals with disabilities are living with HIV in the United States. While the data is not comprehensive, there are clear indicators that HIV seroprevalence rates among this community are higher than among the general population. For example, some experts estimate that the deaf population is eight years behind the hearing population in HIV knowledge and awareness, reflecting a dearth of appropriate HIV information and communication strategies.

A lack of cultural competency among medical and support service providers about the disability community negatively impacts their ability to serve consumers appropriately. As a result, health care providers are less likely to offer services such as HIV, STD and Hepatitis C (HCV) screening to people with disabilities in New York State.

HAB recognizes and supports the following recommendations to address fundamental issues in serving the disability community:

Advocacy training and community involvement

Develop statewide and regional relationships with Independent Living Centers that offer expertise in advocacy for persons with disabilities. Provide education and training opportunities on civil and legal rights for New Yorkers with disabilities; cultural competency and sensitivity trainings for city and state employees, community based organizations, medical and clinical facilities.

Surveillance and needs assessments

Comprehensive needs assessments and surveillance studies are essential to establish the scope of the epidemic. Review of the CDC Behavioral Risk Factor Surveillance System (BRFSS) for responses that address disability among persons living with HIV is also needed.

Technical assistance, provider education, and capacity building

Organizations serving the disability community that lack experience in the HIV/AIDS epidemic should be engaged in HIV prevention and care. Simultaneously, HIV/AIDS service organizations with no experience regarding persons with a disability must be encouraged to address the needs of this underserved population. Continued engagement efforts and the development of guidance documents for HIV providers, community organizations and consumers. Technical assistance, capacity building services, and required cultural competency training should also be provided. Collaboration and partnerships with statewide organizations like the NYS Association of Independent Living and the New York Council on Independent Living must also be considered.

Prevention and treatment materials for persons with disabilities

Educating the public, community-based and HIV/AIDS service organizations, and other organizations charged with creating prevention and treatment materials, is a crucial step toward improving prevention and treatment education among the disability community. The HAB recommends the development of accessible educational workshops/training for persons with a disability, both physical and cognitive, centered on HIV, STD and HCV education, testing/screening access and supportive services.

Outreach to the disability community

Culturally appropriate outreach based on social marketing theory is essential to reach people with disabilities. Any outreach initiative should be implemented in the context of a comprehensive approach addressing HIV, STD and HCV within this population.

HAB supports the importance of identifying data elements to advise on how to make HIV prevention efforts comprehensive to include disabled individuals living with HIV. HAB commends the AIDS Institute, in its pilot program with the University of Rochester, collect data and build relationships with deaf communities. The proposed Public Service Announcement also aligns with HAB's priority to engage and support the disability community in accessing HIV and STD prevention, screening and treatment. These two initiatives are a step forward in addressing the needs of the overall disability community.

We thank you for your support and attention to the disability community. As an advisory body our mission will remain to advocate for the inclusion of all persons with disabilities and to partner with the AIDS Institute to ensure that all communities benefit from ending the epidemic goals.

Sincerely,

Ofelia Barrios, Community Co- Chair
NYS HIV Advisory Body

Vaughn Taylor-Akutagawa, Community Co- Chair
NYS HIV Advisory Body