

EXECUTIVE SUMMARY

Introduction

The HIV/AIDS Bureau at the Massachusetts Department of Public Health engaged the Health and Disability Working Group (HDWG) at the Boston University School of Public Health to conduct an exploratory review of HIV-related services available to individuals with disabilities in the Commonwealth. The purpose of this review was to identify existing HIV-related services and resources for individuals with disabilities, to identify gaps in policies and services, and to develop recommendations to strengthen the continuum of HIV prevention and care for people with disabilities. The specific areas of inquiry included HIV education and prevention services, HIV counseling and testing, and HIV care and treatment. The populations included in this review were adults with serious mental illness, developmental disabilities or mental retardation, physical disabilities, blindness, visual impairments, and deafness or hearing impairments.

The impetus for this review came from a number of sources. The HIV/AIDS Bureau's statewide Consumer Advisory Board recommended this review on behalf of consumers who have encountered questions and concerns from disability providers and fellow consumers. Furthermore, though there is little prevalence data about HIV infection among people with disabilities, certain groups of individuals are at high risk for HIV infection. Finally, the HIV/AIDS Bureau realizes that HIV prevention education messages and treatment may need to be customized in order to accommodate the needs of people with different disabilities.

This summary is based on information collected primarily from interviews with 65 individuals who were selected for their policy-making responsibilities, previous involvement in disability and HIV issues, or their current knowledge of HIV and disability services. In addition, HDWG conducted internet searches, and a review of policies and educational materials.

The individuals interviewed included state agency staff, community-based providers, and consumer advocates. They constituted a convenience sample; therefore, the findings reported below are based upon respondent perceptions, rather than a representative sample of the provider or policy-making constituencies.

Overall Results

Overall, the interview process revealed a lack of focus on HIV prevention or routine service accommodations for individuals with disabilities in the Commonwealth. No benchmark data on HIV prevalence among disability groups was identified. The general perception among those interviewed for this report was that people with disabilities are at low risk for HIV, with the exception of DMH consumers. One key finding of the study was that it was difficult to find individuals with any sophisticated awareness or knowledge of the intersect between disability and HIV.

At the same time, some of the interviewees described certain segments of the disability community as being at high risk for HIV. These populations included:

- Independently living individuals with mental retardation or serious mental illness;
- Persons requiring personal care assistance in activities of daily living from personal care attendants;
- Recently injured young men with spinal cord injuries;
- Young, gay, deaf men; and
- Women with developmental or other disabilities who are victims of sexual assault.

For some of these individuals, social isolation makes them more vulnerable to sexual abuse and victimization. For others, cognitive impairments can impact decisions about sexual activity and substance use. And for others, mobility limitations may pose practical barriers to practicing safe sex or safe injection.

Interviewees also described several issues that underlie the lack of focus given to HIV-related services for people with disabilities. These included:

- Stigma about HIV, which still has a stronghold among a subset of policy-makers, providers, and families/guardians;
- A continuing belief that many persons with disabilities are not sexually active;
- The unknown incidence of HIV--perceived to be low--among most people with disabilities, in the context of other health concerns;
- Lack of consent and confidentiality protocols adequately adapted to disability-specific needs, especially for individuals with cognitive disabilities;
- Lack of resources to address HIV among people with disabilities, including provider inability to meet un-funded state service mandates; and
- Other competing health care needs such as primary and preventive care, or the management of more common chronic conditions such as diabetes and asthma.

Summary of Results by Type of Disability

Specific HIV prevention and treatment issues were also identified for each of the different disability areas.

People with Mental Illness: In general, DMH consumers are presumed sexually active and substance abuse is a known risk factor. However, consumers' knowledge and skills about prevention vary widely, and the prevention services that do exist do not necessarily take into account the wide variation in knowledge and cognitive capacity. Much of the prevention education focuses on universal precautions. Another important issue for this population is the confusion and lack of standardization on obtaining informed consent for HIV counseling and testing. Finally, most interviewees reported that consumers with HIV infection were able to access medical care, but care coordination was often problematic due to the heavy caseloads of case managers.

People with Mental Retardation/Developmental Disabilities: Most providers are more concerned with primary health care access and more common medical conditions such as diabetes or asthma. HIV prevention education for people with mental retardation needs to be

strongly linked with sexuality education, and both need to be tailored to the cognitive abilities of this population. Many providers and policy-makers reported serious barriers in addressing these issues due to prevailing assumptions that people with mental retardation are not sexually active. Several interviewees reported a resistance to education by parents/guardians; however we did not interview families to confirm or deny this perspective. While multiple providers and policy-makers spoke about this resistance, few spoke about the existence of programs to provide training to families. However, we did identify noteworthy organizations providing sexuality training to families (see the Resource Directory) in addition to several prevention education programs and curricula that might be useful for the broader provider community.

People with Physical Disabilities: The links between physical disability and HIV run in both directions: people with physical disabilities may become infected with HIV, and people with HIV may become physically disabled. For people with existing physical disabilities, high-risk behaviors include drug use and unsafe sexual practices. Newly disabled individuals, in particular, may have a previous history of drug use or may begin using drugs to cope with pain and social isolation. Sexual function is another important issue for people with physical disabilities who may not know how, when, or with whom they might have sexual relations. Health care and rehabilitation providers do not commonly address these issues. As a result, people with physical disabilities face challenges with safe-sex negotiation skills, and practical challenges in physically implementing safe sex practices. In addition, because many individuals with physical disabilities see specialists for their medical care, they do not receive the risk assessment screenings that might be provided by a primary care provider. A few model programs that provide these services were identified and are listed in the resource directory.

Independent Living Centers (ILCs), which offer peer support, skills training, and other services to individuals with disabilities, report that they occasionally receive requests for services from individuals with HIV who are physically disabled. While they are very willing to provide these services, they are not well informed about HIV-related resources, and their services are not well known in the HIV community. However, the three ILCs who were interviewed expressed a strong interest in strengthening these linkages.

People who are Deaf/Hard of Hearing: The deaf community is a tight-knit community, and HIV efforts need to be culturally sensitive, addressing the fear and stigma of HIV/AIDS within the community. Communication barriers exist at every step, from prevention education, to counseling and testing, to care and treatment. These barriers are especially amplified for counseling and testing services, because there are no protocols for counseling individuals who are deaf or hard of hearing. HIV counselors reported using written messages in the absence of other tools, interpreters or protocols. When asked about HIV-related services for people with disabilities, the majority of individuals in the interview sample immediately mentioned the HOPE Program at DEAF, Inc. This program has an excellent reputation in serving the deaf community, but program services are limited geographically to the metro-Boston area.

People who are Blind/Visually Impaired: None of the interviewees indicated any awareness of the existence or need for HIV services or service needs for this population. Sexual or drug risk behaviors were denied by interviewees, and they reported no knowledge about HIV/AIDS-related materials in Braille. When questioned further about HIV educational information,

interviewees responded that it was the responsibility of DPH to provide materials and education in Braille. While the incidence of HIV may be low among blind or visually impaired individuals, it is reasonable to expect that many consumers are sexually active, and some may have drug risk behaviors, as is true with the general population.

Summary

Overall, the interview findings indicated both discrete and wide-ranging gaps exist for persons with disabilities in the Commonwealth across the continuum of HIV services, from education and prevention, to counseling and testing, to health care and support services. The study also identified several individuals across the Commonwealth who are knowledgeable about HIV and disability. Many of these leaders and program models have been present since the onset of the epidemic and remain active today. Their dedicated leadership is crucial to bringing into focus, addressing and sustaining involvement in HIV/AIDS services for persons with disabilities.

HIV/AIDS Resource List for People with Disabilities

Despite existing gaps, several worthy program models and unique practices were identified that could serve as the foundation for future work. A listing of HIV/AIDS resources, derived from web searches, literature searches and materials gathered from local interviewees, has been collected and organized by disability type and integrated with Massachusetts-specific resources. This list was prepared as a reference source and general orientation to resources available for further exploration. It is not meant to be comprehensive or exhaustive in nature; rather, we encourage the HIV/AIDS Bureau to build upon this list as new resources come to light.

Recommendations

The following recommendations are presented with acknowledgement of the current fiscal constraints on state agencies and service providers in the Commonwealth. The recommendations span a range from general information dissemination with minimal cost to more resource intensive activities such as the expansion of certain programs or the development of uniform skills-building tools and training.

- *Disseminate Information.* Disseminate the study findings and accompanying models and resource materials as broadly as possible to a range of stakeholders and planning groups including:
 - DPH-funded counseling and testing sites, and prevention/planning groups;
 - Statewide consortia;
 - Other state agencies;
 - The Olmstead initiative planning group;
 - DPH Office of Health and Disability; and
 - Websites [including DPH website].
- *Expand and Promote New Leadership*
 - Develop/promote new leadership through such activities as recognizing ongoing efforts of leaders, including the interviewees who provided critical information for this review
 - Expand Deaf, Inc.'s Hope Program statewide
- *Develop Standardized Protocol*
 - Develop a risk assessment tool for all human service agency populations to identify priority populations and a point of contact at each agency for HIV
 - Develop guidelines for consent and counseling and testing
 - Contract with disability agencies and advocates to develop disability-specific prevention education curricula and materials
 - Work with state agencies to develop consistent monitoring and enforcement of HIV/AIDS contractual provisions with community vendors
- *Foster Collaboration, Referral, and Cross Training*
 - Revive the Executive Office of Health and Human Services inter-agency task force to collaborate and troubleshoot around the needs of people with disabilities in the face of this ever-changing epidemic

- Forge regional relationships/partnerships between the regional AIDS Consortia and the Independent Living Centers to promote cross training and referral relationships
- Work with the Office of Health and Disability and the Substance Abuse Bureau to orient all DPH-contracted providers to the issues of disability and HIV
- *Identify and outreach to vulnerable sub-populations*