

Double Jeopardy: HIV and Disability

RRTC on Drugs and Disability

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Almost fifteen years ago in this country, a new and lethal disease which many physicians believed limited to homosexual men quickly gained the attention of the nation's medical community. This disease was called GRID, an acronym for Gay Related Immune Disorder. However, as early as 1982, it became increasingly clear that no group or class of society was out of the reach of this deadly disease, now known as Acquired Immune Deficiency Syndrome (AIDS).

In 1983, the pathogen that causes AIDS was identified- a fragile but deadly virus which became known as Human Immunodeficiency Virus (HIV). Since that time AIDS and HIV have spread through the North American population. The Centers for Disease Control now estimates that 2.3 million Americans have HIV, with a total of 295,473 AIDS related deaths as of June, 1995.

HIV works primarily by destroying specialized lymphocytes known as T-cells which allow the body to defend against illness and disease. AIDS is the final stage of this immune system destruction, when the body is susceptible to a variety of debilitating diseases such as cancer and pneumonia, as well as fungal and bacterial infections. Another focal point which is now emerging is the risk of HIV infection for people with other disabilities.

From the earliest days of AIDS in our country, many of those affected have been people with disabilities. Of the approximately 450,000 cases of AIDS known in this country, over 20% are known to be individuals with a disability-most frequently substance dependence or hemophilia as the disability of record. However, little data are available on the prevalence of other disabilities among the population of people living with HIV/AIDS. SARDI staff estimate

that perhaps up to one third of individuals with HIV/AIDS in this country have some form of co-existing disability, especially chemical dependency.

HIV risk may be greater with certain disabilities. While little research exists, knowledgeable public health and HIV prevention professionals agree that certain disabilities place individuals at greater risk of contracting HIV. This includes disabilities such as deafness or blindness which cause barriers to traditional HIV education. Developmental and learning disabilities also present unique and largely unaddressed challenges for providing effective HIV prevention education.

Education has been the primary weapon in the war against HIV/AIDS primarily due to the lack of an effective vaccine or cure. These education efforts have increasingly been directed to specific populations based on shared characteristics such as, cultural norms or patterns of risky behavior. Many ethnic and racial groups have access to specialized HIV/AIDS prevention and service organizations, but there is a lack of resources for individuals with disabilities, even though risk patterns and educational needs may be quite unique.

HIV as a disability: People living with HIV/AIDS are increasingly identified as constituents of the disability community. Some disabling conditions associated with HIV include AIDS related dementia, blindness, chronic fatigue, and clinical depression. Also a number of disability related services are particularly effective in serving people living with HIV/AIDS. People living with HIV have seen continuing improvement in their quality of life and overall life span. The past fifteen years have also fostered a greater level of understanding of the nature of HIV/AIDS and thus more effective methods of managing HIV as a long term illness. Medical research has yielded increasingly effective treatment for the opportunistic infections that are the actual causes of death in individuals living with HIV. Today, HIV/AIDS continues to evolve as a

long term debilitating condition, increasingly characterized as a chronic but manageable health condition.

Need for job training and vocational services. One very obvious change in the need for HIV disability services is in the area of job re-training and vocational rehabilitation. People who may experience intermittent chronic fatigue or other medical problems frequently must readjust career goals or professions. Fortunately, vocational rehabilitation services such as Multitasking Systems in New York City are discovering meaningful ways to assist people living with HIV/AIDS. As HIV/AIDS evolves from a non-treatable lethal disease to a chronic condition and long term disability, the necessity of regarding HIV/AIDS as a disability will become even more apparent, especially when it co-exists with other disabilities.

