

- Study the impact and risks of pregnancy and childbirth, and, at the discretion of the applicant, other reproductive health issues affecting women with various physical disabilities;
- Identify the current gaps in research and the information needed by practitioners and consumers regarding gynecologic and reproductive care for women with physical disabilities;
- Identify and evaluate strategies that foster communication and collaboration among the various health care practitioners relevant to pregnancy and childbirth and to other reproductive health issues of women with physical disabilities;
- Identify and evaluate methods to improve education and training for health care providers regarding the medical and psychosexual aspects of disability and reproductive issues;
- Incorporate issues pertinent to culturally diverse populations in addressing issues of pregnancy and childbirth, and, at the discretion of the applicant, other reproductive health issues identified by women with disabilities from minority backgrounds; and
- Disseminate the research findings to health care providers and women with disabilities through the most effective channels, likely to result in maximum impact on practice and training.

Priority 3: HIV/AIDS and Disability

Background

The human immunodeficiency virus (HIV) causes a chronic, progressive immunologic deficiency disease with a spectrum of manifestations. (Atkins, B. J. and Hancock, A. K., *American Rehabilitation*, 1993). The continuum can be seen as four major stages: Acute HIV Disease; Chronic Asymptomatic HIV Disease; Chronic Symptomatic HIV Disease; and Advanced Disease (AIDS). It is known that HIV affects every cultural, social, economic, sexual, racial, and geographic group in this country.

Former Surgeon General C. Everett Koop stated that HIV is expected to impact every household in America in the 1990's." The numbers of people who have AIDS is significant: the Centers for Disease Control and Prevention (CDC), in its HIV/AIDS Surveillance Report, 1994, noted that, as of December, 1993, 361,509 cases of AIDS had been reported in the United States. Of these, 138,223 individuals were known to be living with AIDS. These figures do not include individuals who have been diagnosed as HIV seropositive, but have not yet developed full-blown AIDS; that

number is estimated to exceed one million. Racial and ethnic minority populations have been disproportionately affected by HIV infection and AIDS. In 1992, 47 percent of all reported AIDS cases were among African-Americans and Hispanics although these two groups represent only 21 percent of the entire population (1992 CDC Newsletter). HIV infections are also increasing rapidly among women.

Although HIV disease is chronic, progressive, and, so far, ultimately fatal, the average period of time from onset of infection to death continues to increase, due to improved health care interventions, and is now estimated to be 11.5 years (Whitman-Walker Clinic). Individuals may well begin to live longer at each stage of the disease process. Thus, as the natural course of the disease changes, it will be important to track the changing needs for rehabilitation and community support services. Most "Persons Living with AIDS" (PLWA) aspire to maintain as normal a life as possible during the period of disease and disability and have both the potential and the right to benefit from appropriate service programs. It is extremely critical that culturally sensitive, community integrated service systems to promote rehabilitation, independence, employment, and community integration and to reduce barriers be developed and implemented.

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973, as amended, have very similar definitions of an individual with a disability, and define such an individual, in summary, as one who has a physical or mental impairment that substantially limits his or her ability to perform one or more major life activities, has a record of an impairment that substantially limits a major life activity, or is regarded by an employer or other covered entity as having an impairment that substantially limits a major life activity. This definition includes people with HIV/AIDS.

Individuals with HIV/AIDS may be entitled to income transfer payments and medical assistance; they also may be eligible, depending on specific criteria in the various statutes, for services under a number of public service programs, including vocational rehabilitation and independent living, mental health and drug abuse services, veterans' services, and housing assistance.

There are many allegations that the traditional social service systems, including vocational rehabilitation, are

ill-equipped to respond to the need for services. For example, the 1991 National Survey of Vocational Rehabilitation (VR) and AIDS," distributed to State VR agencies by the American Rehabilitation Association (ARA), concludes that there are numerous barriers to the delivery of rehabilitative services to persons living with HIV/AIDS. These barriers include the fears and anxieties of vocational rehabilitation staff, public stigma associated with HIV/AIDS, confidentiality issues, lack of knowledge about the rehabilitation needs of persons with HIV/AIDS, and the need for more extensive services than those currently available through the vocational rehabilitation system.

Factors in the natural course of the disease, including remissions, exacerbations, compounding, rates of decline, and many other characteristics that are not well understood in terms of their relation to disability and to support services, may affect the suitability of existing service models to meet the needs of PLWA. In addition, there is some indication that the patterns of the disease, and the associated service needs, are different for minority individuals, who are likely to enter the health care service system later in the illness, and for women, for whom not only the support needs but also the natural course of the disease appear to differ (Campbell, et.al., 1989).

Many rehabilitation experts hypothesize that the approaches and techniques that have been developed to address issues regarding other types of disability are relevant to, and will be effective in, addressing issues regarding HIV/AIDS. These approaches include secondary prevention, vocational rehabilitation, job accommodations, barrier removal, peer support, independent living, personal assistance services, public education, integrated model service systems, job sharing, and advocacy.

However, the most effective application of disability and rehabilitative approaches to HIV/AIDS is dependent upon first increasing knowledge about the pattern(s) of disabling consequences typically associated with the disease process; the functional capacities associated with various stages of the disease process; and the duration and intensity of various types of supports needed for this population at different stages of the disease process. Any research designed to address these issues must ensure that findings can be applied cross-gender and to various ethnic and linguistic cultures.

Any project to be funded under this priority is expected to be familiar with,