STATEMENT OF PRINCIPLES: TOWARD A MORE COMPREHENSIVE HIV/AIDS MEDICAL AND SOCIAL MODEL

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A Living History of HIV/AIDS

For over two decades, the world has been waging a war against a virus. Acquired Immune Deficiency Syndrome (AIDS), caused by the Human Immunodeficiency Virus (HIV), has killed over 486,000 people in the United States alone. While the public health community has gained much ground in preventing and treating the virus, there is still no cure. HIV and AIDS still remain a public health crisis. While deaths attributed to AIDS have decreased due to the remarkable advancements in drug therapies and medical care, transmission rates have remained relatively stable for over five years.

Current epidemiological science is teaching us that the people being newly infected are more and more likely to be poor, to be members of a minority community, and have inadequate access to healthcare. Though medications are helping many infected individuals lead healthier and more productive lives, we are only beginning to understand the long-term impact of HIV treatment, as well as the unique interaction of HIV with other diseases, such as hepatitis and diabetes. Scenarios created during the early part of the epidemic predicted that our health infrastructure would crumble under the weight of suffering and dying AIDS patients. Reminiscent of those scenarios, present day systems can barely support the ever-increasing numbers of people living with HIV/AIDS entering these systems with inadequate access to healthcare, especially those for whom private health insurance is entirely out of reach. To fight and win a war against this virus, it is incumbent upon all Americans, especially elected and appointed officials, to provide adequate and appropriate resources. These resources must provide for equitable, continuous, and consistent access to high quality health care and attendant social services at the point of HIV diagnosis regardless of age, race, gender, geography, sexual orientation, or socioeconomic status.

Responding to the HIV/AIDS epidemic of the 1980’s and 1990’s, advocates fought for and won a government response to address the medical and social needs of individuals infected with and affected by HIV/AIDS. The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, named for an infected teenage advocate, was passed in 1990, and reauthorized in 1996 and 2000. The CARE Act is a discretionary program administered by the Department of Health and Human Services, Health Resources and Services Administration. The CARE Act has been successful in bringing access to specialized medical care and social services to low income people living with HIV/AIDS.
Successful in providing client and family centered services, the CARE Act provides a fair amount of local control and a level of flexibility requisite to meet the needs of local, state, and national government agencies and nonprofit sector organizations in providing these crucial services. However, there is a dire need for systemic change. There are significant challenges found in implementation of the CARE Act which need to be addressed so that it can adequately meet the needs of the people it was designed to serve while maintaining fiscal solvency in an environment of shrinking resources and growing need.

The CARE Act is slated for reauthorization again in 2005. This reauthorization provides an opportunity to ensure that we keep steadfast the successful provisions of the CARE Act while ensuring that the legislation, and subsequent policies and programs, improves its ability to keep abreast of the latest medical and technological advancements in providing efficient, accountable, and equitable services for all recipients.

In June of 2004, the Institute of Medicine (IOM) produced a report, mandated by the 2000 Ryan White CARE Act reauthorization, on the public financing structures of HIV/AIDS programs (“Public Financing and Delivery of HIV Care, Securing the Legacy of Ryan White”). The IOM committee charged with developing the report, comprised of experts in program provision and finance, recommended that an entitlement-based financing structure be created that would allow for access to essential service provision to all HIV-positive individuals, from the point of HIV diagnosis, through all acuity levels and stages of disease progression. The IOM report also recommended that the CARE Act be preserved, in part, to meet additional, unique needs of people living with HIV/AIDS. Such a program would provide enormous benefits in lives saved, health maintained, and medical and socioeconomic costs deferred or avoided. The report and its recommendations are supported by The AIDS Institute and should serve as the philosophical basis for the work of advocates and government officials alike; ensuring continuous and equitable access to high quality healthcare from the point of diagnosis of HIV infection for all people in need of public assistance regardless of where they live. The IOM report is instructive in the sense that the proposed system would go far in addressing the current state of quality of HIV/AIDS care and access to that care, while rectifying many of the funding problems related to the discretionary nature of the CARE Act.

To that end, programs that serve people living with HIV/AIDS who are uninsured or underinsured should adhere to the following principles:
All Necessary Medical and Attendant Social Care should:
• Keep current with epidemiologic trends together with medical and technological advancements, given the increasingly chronic nature of HIV/AIDS.
• Provide access to cutting edge clinical trials.
• Recruit and retain competent, specialized, certified, healthcare practitioners as well as social service staff.
• Be made available to all low income people infected with HIV/AIDS, no matter where they reside.
• Be culturally and linguistically appropriate.

Funding/Fiscal/Administrative endeavors should:
• Provide for a seamless system between all publicly and privately funded medical and social service systems.
• Provide for adequate infrastructure, in both physical and human resources.
• Provide for equitable and appropriate reimbursement rates to medical and social service providers.
• Build in fiscal prudence prominently featuring competition.
• Build in cost efficiencies related to purchasing and procurement as well as collective purchasing.
• Address accountability at the client, provider, and administrative levels.
• Equitably distribute resources across geographic regions.
• Utilize HIV data in funding formulas as soon as possible.
• Support expanded HIV testing and counseling in clinical settings so that it may become a part of standard medical screenings.
• Understand that there are ethical considerations related to expanded HIV testing, at any level. New cases will increase the burden on existing, under funded care systems.

Structure/Impact should:
• Reduce disease-related stigma.
• Reduce confounding social factors for people living with HIV/AIDS such as racism, homophobia, and sexism.
• Reduce other socioeconomic and medical confounders such as poverty and homelessness, and medical conditions related to mental health condition, history of substance abuse, hepatitis, tuberculosis, and sexually transmitted diseases.
• Build personal dignity into Quality Management and Continuous Quality Improvement.
• Empower people living with HIV/AIDS to make choices, based on objectively assessed needs, to benefit their medical and social outcomes without creating a dependency system.
• Provide philosophical guidance to service provision systems to focus on preventing disability rather than encouraging physical and mental disability.
• Allow recipients to return to work without losing their healthcare benefits and not force them to choose between health care and dignity of work.
• Provide for meaningful input into health care planning by people living with HIV/AIDS.

Towards Care that is Competent, Consistent and Fair

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In summation, by realistically assessing the programmatic and administrative changes desperately needed in the CARE Act, and contextualizing the CARE Act funded system in the wider government sponsored service provision system; we can avert a deepening public health crisis and the ensuing burden on our public health infrastructure. The ultimate goal of this concerted response is to provide continuous access to quality care beginning at the point of HIV diagnosis so that people living with HIV/AIDS might attain their health, social, and work-related goals.

Optimally, a system designed from the Institute of Medicine’s committee report recommendations would provide enormous benefits in lives saved, health maintained, and medical and socioeconomic costs deferred or avoided. It would also result in significant public health benefits by removing barriers to HIV testing. Finally, it would help to alleviate existing strains on the CARE Act allowing it to fill gaps in care and provide the range of essential support services required to meet the complex challenges created by HIV disease.

Until there is a cure, we must ensure that no person infected with HIV/AIDS suffers needlessly. We must strive to create and maintain a government response to this disease that is competent, consistent, and fair. Human dignity deserves no less.