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Executive Summary

Statewide Needs Assessment Study Of Care and Support Services Access for Floridians Living with HIV Disease & AIDS

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Purpose

The purpose of the Statewide Needs Assessment was to conduct a comprehensive statewide study and analysis of the needs of the infected and affected HIV/AIDS population for the Florida Department of Health, Bureau of HIV/AIDS, using a) existing data and information, and b) supplementary studies in selected areas to provide a representative assessment of communities throughout Florida. The Statewide HIV/AIDS Health Care Needs Assessment was

designed to provide the Florida Department of Health HIV/AIDS service providers and other HIV/AIDS planning entities with information to:

1. Establish resource allocation priorities and to implement positive changes in service delivery,
2. Correct service delivery gaps in various client need categories throughout the state of Florida,
3. Formulate culturally

competent service responses in the form of new or revised programs or initiatives,

4. Identify unmet needs, those service needs of individuals not currently in care as well as those who are in care but whose needs are only partially met or not being met, and
5. Determine major barriers to accessing services.

Other Reports:

Patient Care Epidemiologic Profile

Meta-Evaluation of Area Needs Assessment Reports

Recommended Protocols for Area Needs Assessment Reports

Qualitative Studies of Selected Populations

Secondary Analysis of Selected Studies and Reports

Projections for Cost of HIV/AIDS

Final Report of Statewide Needs Assessment of Health Care

General Conclusions

This Statewide Needs Assessment was composed of a number of studies. Each of these components yielded conclusions. The following conclusions were the most important that emerged from across the various components. For more detailed conclusions, the reader should consult the sections of the Final Report related to each

component and the more detailed reports for each component.

Conclusion: Privacy and Confidentiality

The results of this statewide needs assessment indicate that providing HIV/AIDS health care through known and distinctly identifiable HIV/AIDS clinics pre-

sents a number of problems. It is clear from the findings of many of the needs assessment studies that this process creates a barrier for many PLWHA to accessing care or testing. Linked to the barrier issue, but a problem in

itself, is the violation of the PLWHA's privacy and confi-

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Conclusion: Privacy and Confidentiality

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Confidentiality that occurs when one must enter a clinic, testing center or other types of care that is dedicated to or known to be for HIV/AIDS. This situation presents moral and ethical problems. It may also be violating the spirit of the Health Insurance Portabil-

ity and Accountability Act (HIPAA).

This problem is further discussed in various contexts in a number of sources including areas of this needs assessments, the RARE studies, and the Qualitative Studies of Selected Populations.

Conclusion: Standardized Needs Assessments

The planning areas currently develop their Health Care Needs Assessments using very inconsistent approaches, with varying levels of validity. Because of this inconsistency and, in some cases, lack of documented validity it is difficult to assess how some

areas are providing services to meet the needs. This is particularly relevant to issues identified in the HRSA guidelines. Extensive resources have been used to develop these needs assessments, but, due to their lack of comparability, they have limited value

for compiling a statewide needs assessment. They are also not developed in a way that would support comparisons over time for benchmarking the many key issues.

Conclusion: Importance of Culture and Context

The importance of culture and context is a very central finding of various dimensions of this overall needs assessment. The importance of avoiding the use of stereotypes about people or avoiding the tendency to reduce complex information to "risk factors" as a way to identify these populations was made particularly clear. Emphasizing a simplistic view of marginalized populations results in a continuation of missed "understandings" of

culture and context that could make a difference in the effectiveness of our efforts. Consequently, the assumptions, research methods and best practices employed would be most effective if validated by or informed by an accurate understanding of the specific populations, contexts or individuals of concern (rather than taken from generalized assumptions made about these populations). Briefly, qualitative data collection appears to be critical

to adjust to the continually changing epidemic and the changing populations impacted by the disease. It is imperative that the individuals responsible for the needs assessments acquire training on the many phases of doing qualitative research and the appropriate methods of analyzing the

Conclusion: Program Evaluation

Major programs that provide funding for HIV/AIDS care services have limited evaluations. An evaluation of these programs could include an assessment of all major stakeholder expectations for the programs followed by an assessment of the program's success in meeting those expectations. Stakeholders might include

PLWHA, case managers, care providers, and DOH staff. AICP has surveyed some stakeholders, in particular, the clients of that program. All programs may benefit from systematic data collection with case managers who have critical insights about program implementation. Data from this type of evaluation is critical for more substan-

tive analysis of the relationship of the HIV/AIDS epidemic to the funding and delivery of health care services. A third-party evaluation could also help to increase the credibility of any evaluation results.

Conclusion: Prevention and Care Continuum

Separation of health care and prevention may undermine successful planning and delivery of effective interventions. It may be helpful to conceptualize prevention and care as a continuum rather than distinct aspects of the efforts to stop the epidemic. Recent research has shown that an integrated approach that simultaneously implements complementary processes for primary prevention, secondary prevention and early medical intervention, tertiary care and tertiary prevention may have good potential. These strategies are especially effective when developed collaboratively with clients and community. Using this concept as an organizing construct could significantly impact planning and implementation efforts. Using this construct to organize efforts will require significant additional training for all people involved across the continuum. It will also require that clients and community members become trained in how to participate in collaborative assessments and participatory research.

Conclusion: Integration of Other Services

Substance abuse and mental health services appear to be a major unmet need. Though consumers may be in denial about the need for substance abuse treatment services in particular, it is clear that this, along with mental health interventions, remains a major contributor to the evolving epidemic of HIV/AIDS. Other issues that appear to create barriers for use of these services are accessibility to these services, the lack of integration of these services with HIV/AIDS services, the lack of cultural awareness and sensitivity and the lack of integration with other non-stigmatizing health care services.

Conclusion: Ecological Model for Health Care Planning

There also appears to be a need to plan and deliver health care from an ecological perspective. Approaching individuals or groups from a biomedical perspective, reducing their concerns to a disease model and emphasizing our own expertise does not appear to be the most successful approach to control this evolving epidemic. The multifaceted realities of the lives of people and the complexity created by their situations require more integration of care and more emphasis on client-focused resource decision-making. The studies involving members of the FCPG, the recently incarcerated individuals, migrant workers and young adults all documented how the current system of care and prevention is organized around the experts and the biomedical model, not around the people and communities of concern. Recent recommendations to promote healthy social environments and recommendations for linking the social environment to health from the Task Force on Community Preventive Services would be an organizing construct for greater emphasis on these issues (American Journal of Preventive Medicine: Supplement. Interventions in the Social Environment to Improve Community Health; A Systematic Review. April 2003). Another important resource would be to provide more training in the ecological model and how it is most effectively applied to assess needs, assets and plan change (Brownson 2003).

Conclusion: Geographic Distribution of Funding

Analysis of the data for the different types of HIV/AIDS care services funding shows an imbalance of specific types of funding for the different areas. In addition to population density, these variations are at least partially explained by the demographic makeup of the areas. For example, some areas have higher rates of private insurance than others. In particular, an examination of data from the *Florida Health Insurance Study* indicates that Miami-Dade has one of the highest rates for uninsured (24.6 percent) in the state, compared to the state average of 16.8 percent. This high rate of uninsured, with particularly high rates of uninsured among some racial/ethnic groups, at least partially explains the high rate of ADAP funding in some areas compared to others. Variation in funding should be examined and similar justification provided, or reallocation of funding considered.

INSTITUTE FOR HEALTH, POLICY AND EVALUATION RESEARCH

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