Assessing Primary Medical Care, Mental Health, and Substance Abuse Treatment Systems Serving Persons Living with HIV/AIDS

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Why a “Systems Assessment”?  

In August of 2002, the Chicago Department of Public Health, Division of STD/HIV/AIDS Public Policy and Programs (CDPH), began to work with the evaluation staff at the Midwest AIDS Training and Education Center (MATEC) to undertake an study of the systems of care that surround the HIV/AIDS care network in the Chicago EMA, specifically in the areas of primary medical care, mental health, and substance abuse services. The primary goals of the study were to:

- Describe the degree to which the primary care, mental health, and substance abuse treatment systems interact and collaborate in delivering services to persons living with HIV/AIDS;
- Identify obstacles to effective systems interaction; and
- Recommend modifications to improve system interactions and collaborations.

The scope of this project was intended to go beyond the Title I-funded HIV/AIDS care system to identify and assess care delivery systems (primary medical care, mental health, and substance abuse) that have the capacity to supplement traditional HIV/AIDS care systems. In addition to describing service needs and gaps, this assessment is meant to focus on *why* systemic gaps existed. We believe that this kind of dynamic assessment of these systems would identify opportunities for strategic planning to sustain and improve care systems developed through Title I in the Chicago Eligible Metropolitan Area (EMA).

The project utilized mixed research methods in collecting data from identified key informants within each system of care. A semi-structured interview guide of open-ended questions was administered to each key informant. Major question areas included: existing services in the system(s) described, gaps in services, systems linkages and interactions, existing and emerging patterns, development needs, and respondent recommendations.

**Methods**

A sample frame was developed to identify key informants in program and policy areas as well as selected direct service providers. Additionally, two focus groups of HIV/AIDS service consumers specifically identified service gaps and assessed systems linkages and barriers. Interview data from key informants were aggregated by question item. Each question’s aggregated responses were then analyzed for major themes or patterns of responses that emerged. Once patterns of responses were coded within each question, investigators compared these patterns with patterns of responses emerging from other questions within the same section in order to identify each section’s major themes. By analyzing patterns of responses across interviewees or “cases”, the themes that could be generalized across the Chicago EMA began to emerge.
Who are the Key Informants?

Sample

A sample frame was developed to identify key informants in program and policy areas as well as direct service providers, advocates, and consumer representatives. A list of professionals in the fields of medical care, mental health treatment, substance abuse treatment, as well as associated fields including child welfare, housing, criminal justice and corrections, and HIV case management, was assembled by the research team. Individuals sampled were chosen based on their professional experience in their fields and their respective positions that gave them insight into larger systems outside of the HIV-specific service sector(s) they either direct, manage, or provide. A total of 35 interviews are included in this analysis. Most of the respondents (82.3%) came from organizations described as being part of at least one of the three targeted systems. Two focus groups with a total of 20 HIV service consumers were conducted in Chicago and Wheaton to solicit consumer input specifically on service gaps.

Systems’ Characteristics

Key informants reported numerous strengths in the systems they described in many cases, including medical expertise in disease management; mental health, substance abuse, and case management services; the provision of free services for a high volume of indigent clients; a strong commitment to advocacy; and a “one-stop shopping” approach to care. Despite these strengths, the respondents also listed numerous systemic weaknesses, including a lack of HIV-specific training in working with MISA (mentally ill and substance abusing) clients; disincentives to treatment and testing; a lack of provider knowledge regarding cultural competence, stigma, harm reduction methods, and domestic violence; lack of resources for outreach, surveillance, housing, pharmacy, and dental services; lack of resources for funding opportunities and technology improvements; and a lack of specialized medical care for the uninsured. Key informants acknowledge internal and external barriers and weaknesses to providing services to persons with HIV/AIDS. Most external barriers had to do with funding, including restricted funding, competition for public dollars (with HIV/AIDS now seen to be competing with recent emphasis on bio-terrorism), and a lack of health education and prevention reimbursement by Medicaid. Multiple organizational barriers, such as a lack of staff training in HIV/AIDS service provision, hiring freezes, lack of administrative support, low pay, and low staff retention, face the agencies that continue to survive in a time of scarce resources.
Where are the Gaps in Services? How do the Systems Link and Interact?

Data from key informants reveal that HIV/AIDS care is not consistently well coordinated among systems of care, and the reasons for the lack of coordination and collaboration among systems are due to **structural factors** and **different treatment paradigms**. The over-arching structural issue that inhibits collaboration is the way self-contained care systems are set up by distinct funding streams, which results in (1) **inconsistent eligibility criteria for clients**, (2) **data reporting requirements from funders that preclude effective collaboration among providers**, and (3) “**turf battles**” that may emerge among providers as competition for scarce public funding resources increases. Other structural issues identified by the key informants include the different ways in which formal and informal linkages among providers develop and are implemented, and the qualitatively different nature of service coordination within large multi-service provider (or “co-located”) agencies and service coordination among geographically dispersed agencies.

Different treatment paradigms within medical care, mental health, and substance abuse treatment also influence the degree to which effective service coordination occurs. Divergent care models often result in (1) a **lack of knowledge among providers regarding the treatment delivered by other professional disciplines** and (2) **conflicting approaches to treatment** (e.g., harm reduction vs. abstinence-only) which create barriers to accessing services by clients.

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**What Do Consumer Representatives Say About Service Gaps?**

*The need for mental health assessment and services upon entry into systems is paramount.* For these persons, mental health needs might range from depression due to initial HIV diagnosis to long-standing pre-existing mental illness.

*There is a significant gap between the 28-day residential substance abuse treatment and the 90-day “clean” requirement to become eligible for supportive housing.* In addition, most participants agreed that the 28-day length of stay is not long enough to allow substance abusers to deal with the issues that brought them into treatment.

*The lack of harm reduction model in substance abuse treatment is a major factor in persons “dropping out” or not being retained in coordinated HIV/AIDS care.* Several participants agreed that a long-term substance abuse treatment model structured around harm reduction was needed in order to improve client outcomes.

*Client-centered services improve assessment and treatment.* The lack of client-centered service delivery on the part of some physicians results in a less than complete assessment of client health status. This opinion was also expressed regarding mental health, substance abuse, and case management services.
Existing and Emerging Patterns in HIV/AIDS Service Delivery

While services to persons living with HIV/AIDS are often delivered using different treatment paradigms as described in the previous section, respondents maintained that with the introduction of antiretroviral therapy the overarching model for service delivery has shifted to a medical care model, both in terms of funding priorities as well as location of services. An emphasis on increasingly sophisticated treatment, including expanding numbers of antiretrovirals, laboratory testing techniques, and treatment complications, and the belief that HIV/AIDS has shifted from being treated as an acute disease to a chronic disease characterized the majority of opinions expressed. The shift to a medical care model of service delivery was viewed by several informants as deemphasizing prevention and supportive service models implemented earlier in the epidemic.

Funding levels, in general, were considered insufficient to meet the expanding needs of the population. Specifically, inadequate resource allocation to communities of color, adolescents in unsafe or unstable environments, and mental health programming was viewed by many of the key informants as coinciding with an increased emphasis on a medical model of service delivery and a corresponding de-emphasis on supportive systems.

While some informants criticized reliance on a medical model of service delivery, there was a shared recognition among many that co-locating services in a single location improved patient access to care and presented opportunities for improving the coordination of care. The concept of “one-stop shopping”, or housing and coordinating multidisciplinary services at one location to facilitate patient access, was viewed by several respondents as one of the innovative service models that have been designed to respond to the needs of the patient population. Peer-driven programming was another innovative model mentioned by several informants that was seen as having the potential to meet future trends in the epidemic, especially around behavioral issues such as prevention and medication adherence.

The major policy change affecting systems of care in the present and near future identified by respondents was faith-based initiatives and preferences given to faith-based programs by the federal government. While some informants saw faith-based initiatives having the potential to increase access to service delivery for HIV-impacted populations, others viewed faith-based programs as overly dogmatic and creating barriers to effective care through the perceived rigidity of their philosophies. Other issues raised by several informants as potentially having significant impact in the EMA included (1) anticipated problems regarding access to medications in the face of inadequate AIDS Drug Assistance Program (ADAP) funding and (2) rapid testing and its implications for case finding and integration into standards of care.
Respondents identified six major areas that needed development in order to support high quality HIV/AIDS care in the future. Expanding the availability of housing, mental health, and substance abuse services, as well as developing a continuum of services that includes prevention, case finding, testing, and behavioral health programming for persons living with HIV/AIDS, emerged as service priorities. Developing integrated systems of care was cited by almost one-third of respondents as a priority, both in terms of locating multiple services at the same location and combining systems of care at an administrative level. Key informants stressed the importance of provider development, in the ongoing training of physicians regarding increasingly specialized care, cross-training of mental health and substance abuse professionals, and emphasizing the importance of integrating evidence-based practices into treatment settings. Improved collaboration, planning, and data systems were viewed as important mechanisms for eliminating duplication of services in order to maximize resources. Respondents also described what they saw as a lack of leadership in addressing many of the issues raised in this project’s inquiry, and the need for the development of vision and leadership commitments among stakeholders to effect constructive change in these systems. Finally, several participants proposed policy changes to improve the systems’ functioning, including local efforts such as the establishment of state and local advocacy networks, lowering provider caseloads, and establishing cross-[Ryan White]-Title goals for the region to national shifts in policy such as viewing substance abuse as a health problem rather than a moral problem and the establishment of universal health care.

What’s Needed?

Integrated systems of care: locating services at single location, and combining services at the administrative level.

Expansion of mental health, substance abuse, and housing services

Development of a continuum of services including prevention, case finding, testing, and behavioral health services.

Provider development: specialized care; cross-training regarding mental health and substance use treatment; evidence-based practices.

Improved collaboration, planning, and data systems.

Development of vision and leadership commitments to effect changes.

Policy changes at the local, state, and national level.
Discussion

The findings presented in this summary constitute an overview of issues facing stakeholders in improving systems of care that provide services for persons living with HIV/AIDS. This project utilized a purposive opportunity sample focused on three systems of care in relationship to Ryan White CARE services. While it is not possible to ensure that the opinions are representative, they do provide some very specific ideas by the respondents, and sufficient saturation was achieved to assure that these represent trends for further consideration; however, there was insufficient focus on specific sub-populations, including racial/ethnic subgroups and age subgroups, as well as persons living in suburban and rural areas, and persons involved in the criminal justice system. It was by design that future studies might address these specific areas more fully; notwithstanding these limitations, the findings do provide use information about current issues and trends that should be useful for future planning.

In the face of substantial state and federal budget deficit projections over the next decade, current and any upcoming increases to the Ryan White CARE Act may not keep up with expanded needs among the patient population. Strategically examining structural factors such as funding and reporting mechanisms, eligibility criteria, and location(s) of services could provide opportunities for improved patient access and retention and reduced duplication of services. Forthright discussions of the philosophical barriers to effective coordination of services might focus on improving the collaboration of providers in providing patient care, planning how services are designed and coordinated, as well as all stakeholders’ future leadership commitments and advocacy efforts.

The findings suggest that mechanisms to capitalize on systems and inter-systems opportunities for formal systemic collaboration need to be implemented. Respondents reported that collaboration and sharing of resources occurs more due to informal relationships than because structures or programs are in place; yet, a willingness to consider cross-systems opportunities was a prominent theme indicative of most study participants. Future efforts should recognize and build in differences in treatment approaches within the current scarce resource environment in order to develop ongoing infrastructures.
What Do We Do Now? Proposed Next Steps

In light of the findings reported in this assessment, several opportunities exist for improving systems coordination for persons living with HIV/AIDS in the Chicago metropolitan area.

- Developing **integrated systems of care** should be a priority, both in terms of locating multiple services at the same location and combining systems of care at an administrative level.

- There is need for **further analysis of populations** not specified in this study, such as persons in the corrections systems and in post-correctional service settings, to determine how these systems interact with the systems focused on in this study. This should be done with consideration of existing and ongoing research and planning initiatives, including ongoing corrections research at Cook County Jail, and the 2001 AFC Housing Plan. In addition, more data on subpopulations such as women, adolescents, older adults, and African American and Hispanic groups is needed.

- There is a need for **coordinated data systems** across HIV/AIDS providers to better plan, coordinate, and evaluate care services to PLWHIV. The current lack of client-level data across the Chicago EMA inhibits effective systems coordination.

- There should be **dedicated funding for Mental Illness/Substance Abuse pilot projects** that propose innovative ways of providing services for dually-diagnosed persons with HIV/AIDS. Priority should be given to developing programs that are integrated with existing HIV primary care programs. Consensus meetings of stakeholders could be held to discuss emerging models that could lead to specific pilot projects.

- Several **policy issues** require organizing by stakeholders in order to better advocate for improved service systems for persons living with HIV/AIDS, including:
  - lobbying for **increased ADAP funds**;
  - closer examination of **disclosure issues regarding rapid testing** and its implications for screening, testing, counseling, and referral; and
  - lobbying for **expanding the maximum length of stay** in residential substance abuse treatment.
The challenges and advantages of working effectively with faith communities need to be summarized in consideration of future planning efforts. Faith communities bring several opportunities for strengthening HIV/AIDS service systems, particularly in the areas of prevention and case finding in communities of color; however, they also may present challenges in providing effective services to groups that are traditionally stigmatized by faith communities, and in providing culturally competent services to diverse populations.

There are several training needs identified in this study, particularly in the area of cross-training primary care, mental health, and substance use providers. While cross-training has traditionally served to train discipline-specific providers in delivering services in other disciplines, strategic cross-training might focus on overcoming barriers to service coordination between systems.

There needs to be a focused discussion in HIV/AIDS planning and regional implementation groups on how to work with leadership in different disciplines. Such discussion would begin to examine HIV/AIDS care within larger care systems, versus it’s traditional role as a free standing system developed from federal, state and local funding streams.

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