Community AIDS Partnership

HIV Prevention, Service and Care Systems

Report of Project Process and Findings

December 2008

Submitted to:
The Bingham Program

ACKNOWLEDGEMENTS

This document attempts to summarize a project that was conceived in 2004, endorsed by the Maine HIV Advisory Committee (HIVAC) in 2005, funded by The Bingham Program in 2006, actively conducted from late 2006 through 2007, and used as fuel for discussion and planning throughout 2008.

The Maine Community AIDS Partnership (MCAP) remains committed to working with stakeholders and funders to devise and implement efforts to better and more effectively shape the HIV prevention, care, and service delivery structure in Maine.

Unfortunately, "the community" was not able to unite around a shared vision or even agree on where it wanted to go. There were those who doubted if the goals of the project could be accomplished. They were right. However, it is important to note that many individuals and organizations have, during these three years, undertaken steps to move forward and modernize systems and structures. They have done this with the benefit of information brought forward during this project's process and at some risk to themselves, but for the greater good. They have risked changing programs and organizations that were developed in response to a different epidemic than the one that we know today. For that we would like to honor and acknowledge their courage.

MCAP would like to express its appreciation and gratitude to the staff and trustees of The Bingham Program for supporting our ideas and encouraging us to continue in our efforts to pursue the discussion among advocates, consumers, and stakeholders.

MCAP would also like to thank Lauren Fiola, who worked with us for several months in 2007 and was responsible for co-facilitating some of the community discussions. Lauren also listened to the community discussion tapes and wrote up the key points and ideas document. I counted on her objectivity and dispassionate execution to help assure that this project reflected in an objective way the voices of the consumers and providers.

Phyllis Verge has been the backbone of MCAP since it arrived at Medical Care Development (MCD) in 2004. Her professionalism and support are key to all that MCAP undertakes, and we would accomplish very little without her support. Thank you, Phyllis!

Written by:
Kate Perkins for the
Maine Community AIDS Partnership

Executive Summary

In the 25 years since HIV was first diagnosed in Maine many things have changed and a few have remained the same. Concerned that economic and epidemiologic trends might result in significant service disruptions, the Bingham Program agreed to fund a strategic planning process intended to engage key audiences in assessing and if necessary revising the HIV infrastructure. In late 2006 the Maine Community AIDS Partnership (MCAP) convened this endeavor – engage stakeholders, consumers, and advocates in a process of exploring the HIV prevention, services, and care delivery system.

MCAP Project goals included:

- Bringing together the various reports, assessments, and plans that address different components of HIV prevention and services in Maine to create a holistic understanding of what is known;
- Developing a process to build consensus regarding HIV prevention and services; and
- Designing a mechanism that creates a path toward the HIV prevention, services and care structure identified by stakeholders.

The process was conceived as a convening and facilitation of a series of meetings among:

- Persons living with HIV, their friends, families, and advocates;
- Program providers and agencies that offer prevention services to those at risk of contracting HIV and care to persons living with HIV;
- agencies providing funding for HIV related services; and
- Various other HIV stakeholders.

The project plan, timeline, and process were modified to reflect changing personnel, group dynamics, and reactions to both the process and the discussion as it progressed. Therefore the resources section contains citations or links to documents that reflect the situation at specific points in time in Maine. At periodic intervals the project process and findings were shared with the HIV Advisory Committee and input was solicited from that body. Input from providers and consumers were limited by other initiatives in the HIV community that reduced willingness to participate in discussions for this project. Groups were conducted in northern, eastern, and southern parts of the state. The providers in the central and western regions were for various reasons unavailable to collaborate with this project and thus the perspectives of people with HIV as well as providers in these areas are less well represented in the project process and documents.

Many of the issues, ideas, and themes that emerged from the project process were reflected in a subsequent and parallel initiative from the State of Maine (SOM). The SOM convened service providers in 2007 for a Summit on HIV Care. Therefore this document contains information collected by MCAP and others over the past three years that relate to the HIV infrastructure but does not repeat or re-iterate the information that was folded into the SOM process as reflected in the Final Report authored by Susan Farnsworth and Gen Meredith. The final recommendations contained herein are those of MCAP alone.

Project Environmental Scan:

Challenging economic times only accentuate the difficulties faced by small organizations attempting to provide HIV prevention, care, and services to the people of Maine. These "providers" are being asked to meet higher and more fully defined quality measures while serving more people for the same or less state and federal funding. Private sector funding continues to be focused in other areas and difficult to secure locally.

Forty-five to sixty new individuals are diagnosed with HIV each calendar year in Maine, adding to the number of individuals seeking services.[i] Many are diagnosed late in their disease process, suggesting a need for additional prevention efforts more HIV testing. Overall the need for prevention, care, and services continues to grow while agencies have increasingly fewer resources available per person living with HIV in Maine.

According to national sources, agencies with annual budgets of under $500,000 are at increased risk of failure due to limited diversity of funding resources and limited capacity to maximize scale for reduced per unit costs. Agencies in rural areas are unlikely to have sufficient client numbers to be or remain fully independent AIDS exclusive organizations.

Project Findings:

1. Stigma continues to exist, especially in rural areas. The lack of public attention to and normalization of HIV status contributes to both real and perceived barriers to care.

2. People living with HIV are more concerned about maintaining their relationships with their individual providers than they are about maintaining a relationship with a specific organization. They understand that funding is tight and want to see maximum utilization of funds for programming and services rather than organizational expenses. They are uncomfortable with the growing role of hospitals in the delivery of formerly community-based services for HIV prevention and care.

3. Providers are frustrated by external requirements and systems that are imposed upon them by funders and payers which take time and energy away from actual service provision. They are concerned about their ability to adequately serve growing numbers of people with HIV with limited, if not reduced, resources (time, talent, and treasure).

4. There are housing funds which are provided to qualifying people living with HIV, known as the HAVEN program. HAVEN services are valued throughout the state. The functional structure is reported to work well for community agencies. Unlike most other HIV services, this housing support program is centrally managed by staff at Frannie Peabody Center but accessed by people living with HIV through HIV Case Management at their local service agency.

MCAP Recommendations:

1. General public education about HIV needs to be supported and expanded. This is a strategy for increasing social understanding and empathy as well as improving the charitable giving environment. It is not intended as a behavior modification --transmission prevention strategy.

2. State and federal support needs to be maintained or increased for: MaineCare HIV waiver maintenance and expansion, needle exchange, comprehensive sexuality/HIV/STD education in schools, HIV prevention programs, and clinical health care services for middle and high school students.

3. HIV service providers affiliated with medical or other large organizations need to develop better relationships with consumers and while creating infrastructure that is more flexible and “patient centered” than may be common in other parts of their organizational super-structure. This might include locating staff in low barrier community locations rather than in or at hospitals. Such efforts may also include increased organizational support for non-billable programs and services, such as community outreach and education. Referrals and program integration need to be improved for existing programs that have been incorporated into hospital system structures.

4. Hospitals need to educate staff, especially non-medical staff and everyone in the Emergency Room with a focus on reducing HIV-related stigma and emphasizing patient confidentiality.

5. State agencies are encouraged to continue to expand efforts begun in 2007 that allow data sharing and improve coordination of activities. To the extent possible, efforts should be made to better align income and other eligibility criteria across benefit programs.

6. Agencies and organizations not currently affiliated with medical or other large organizations should consider merging or re-structuring staffing models to reduce non-service related costs and increase service provision flexibility. The HAVEN program is an example of how this might work. In general, there are two models that might provide a platform for initiating such discussions.

    a. <u>Hub and Spoke:</u> One central agency that employs, trains, monitors, and supports service-providing staff. Staff are located throughout the state, co-housed within other agencies or, when feasible, in agency locations.
        i. Advantages: “no wrong door” access to services and consistency of offerings, centralized records accessible through secure internet portals, and continuity of services if not service providers regardless of where person lives. Centralized billing, CAREWARE, benefits and fundraising increase benefits of scale and auditing.
        ii. Dis-Advantages: potential isolation of service providers in outlying areas, need for quality high-speed internet connections, necessity of staff in the field being knowledgeable about full range of services, potential lack of access to professional staff back up and support.

b. Service Matrix Integration: HIV programs and services fold into existing medical service providers, hospitals, or other large agencies. Federally qualified health centers may be preferable to hospitals or CAP agencies because of location, commitment to consumer engagement in governance, and cost-based reimbursement, though there may be barriers to offering syringe exchange at FQHC.
   i. Advantages: Staff are employed by organizations with broad base of funding and diverse service offerings, well beyond just HIV. Better benefits packages for employees, reduced administrative burden for billing and related tasks. Increased negotiation clout with funders and payers to improve rates. Broader fundraising expertise and reach.
   ii. Dis-Advantages: Potential increases in bureaucracy and organizational barriers to programs and services, potential for location of services in ways that reduce or eliminate "one stop" access to programming and support services. In rural communities, potential for reduced confidentiality due to large number of individuals employed by local hospital/large organization learn of HIV status through interactions when clients contact ancillary services (scheduling, pre-authorization, registration, etc). Care managers may not have sufficient HIV-specific knowledge or understanding of local services outside of hospital or large organization structures. The support and prioritization of primary prevention activities may suffer unless there is adequate institutional and volunteer leadership.

7. Statewide organizations need to merge and integrate activities. HIV stakeholders would likely benefit from a consolidated vehicle through which legislators and others receive unified messages from HIV advocates and clear communication back to the community on what is happening and for what to advocate, when. Consolidation could reduce duplication of program and policy advice structures (federally mandated vs. those established by Maine law vs. others).

8. HIV needs to be consciously included in discussions, planning, and implementation of primary care integration with specialty care, chronic disease care as well as self-management, and patient centered medical home.

9. HIV testing needs to be better and more routinely integrated into a number of systems, including primary care, corrections, and emergency care.

Project Process:

July 2006 - February 2007

- Development of process, creation of discussion questions, and creation of revised project plan
- Interviews with key informants and stakeholders
- Meetings of leadership and stakeholders from statewide organizations, state government, and Part C provider organizations.
- Posting to web and distribution of findings of meetings of statewide entities.

March 2007 – September 2007

- Refining of program process and questions for discussions with community members
- Group discussions with providers and people living with HIV.
- Posting to web and distribution of findings from community and organization discussions.

October 2007 – September 2008

- Informal discussions with key stakeholders and organizations about findings, changes, needs, and options.
- Information from MCAP process shared with invited participants to HIV Care Summit.
- Publication of Maine's HIV Care Summit: Collaborative Care Systems – Maine Leading the Way
- Sharing of key information and insights with policy makers and influential stakeholders.
- Interviews with key stakeholders

October – December 2008

- Drafting of project report for consideration by Maine HIV Advisory Committee (HIVAC), key stakeholders, and the project funder.
- Finalization and online publication of project report.

Changes among HIV/AIDS organizations and programs during project period:

2006

- January: *new* MAA Executive Director begins *(Sue Crawford)*
- June: MAA Executive Director steps down *(Sue Crawford)*
- July: *new* MAA Executive Director begins. *(Juan Antonio de Jesus)*
- August: *new* MCAP part time project consultant begins *(Sue Crawford)*
- August: MAA Executive Director steps down *(Juan Antonio de Jesus)*
- September: *new* MAA Interim Executive Director begins *(Sharon Pree)*
- October: MCAP initiates new AIDS Walk event in Augusta

2007

- January: *new* EMAN Executive Director begins *(Greg Music)*
- February: MCAP systems part time project consultant resigns *(Sue Crawford)*
- April: EMAN Executive Director steps down *(Greg Music)*
- June: HIV Testing and Syringe Access statues revised and signed into law.
- June: Wabanaki Mental Health Association aligns with Sweetser.
- July: MAA Interim Executive Director *(Sharon Pree)* turns operations over to the *new* MAA Executive Director begins *(Andrew Bossie)*
- July: *new* EMAN Executive Director begins *(Patricia Murphy)*
- October: MCAP and partner agencies sponsor AIDS Walk in six locations

2008

- January: HIV/STD Program manager retires *(Bob Woods)*
- February: *new* HIV/STD Program Manager begins *(Gen Meredith)*
- March: DEAN Executive Director steps down *(George Russell)*
- May: MCAP and partner agencies sponsor AIDS Walk in seven locations
- June: *new* DEAN Executive Director begins *(Steven Richard)*
- July: ME DHHS CDC Div. Infectious Disease Director retires *(Sally-Lou Patterson)*
- September: HIVAC unable to recruit member to become Chair for new year and acknowledges concerns about relevance and viability in current HIV service and policy landscape.
- October: Frannie Peabody Center closes Peabody House (non-medical supported living facility for people living with HIV).
- October: HIVAC begins exploring re-structuring or dissolving
- October: HIV Program Manager for City of Portland steps down *(Lisa Moorhouse)*.
- November: *new* ME DHHS CDC Div. Infectious Disease Director begins *(Peter Smith)*
- November: ME DHHS CDC HIV/STD Program Manager steps down *(Gen Meredith)*; vacancy cannot be filled due to hard freeze on hiring of state employees.
- November: Maine AIDS Alliance finalizes an arrangement with Medical Care Development (MCD) in which MCD will serve as employer and fiscal agent starting 1/1/2009.
- December: MAA Board of Directors and MCAP Advisory Committee vote to move forward with steps to integrate MCAP grant making and other programs with MAA initiatives. Full programmatic and Board integration expected to be completed by July 1, 2009.

Key Reference Documents and Resources:

All MCAP sourced documents relating to the project were and are posted to the MCAP website on a documents and discussion page, www.maineaids.org/board.asp including the following: meeting agendas and notes; statewide stakeholder groups grid and annotation; summary of discussions with clients and community-based providers.

State of Maine (SOM) sourced documents relevant to the project are available at their website, http://www.maine.gov/dhhs/boh/ddc/hiv_std_vh.htm including the following: 2006 HIV CPG Needs Assessment Report and the 2004 Title II Program Needs Assessment. The Final Report from the 2007 HIV Care Summit is not currently available on the SOM website. As an interim step, we have posted this document to the MCAP website at http://www.maineaids.org/board.asp

On November 27, 2007 Funders Concerned About AIDS (FCAA) hosted a funders-only national teleconference titled "Domestic ASO Sustainability: Mergers and Redefining Missions: What Funders Should Know." They produced from this a *One-Sheet Report* that is a brief sketch of the issues covered by the teleconference. Several proprietary documents were utilized in that discussion. Information from that meeting has substantially influenced MCAPs perspective on HIV system options for the future. The publically available FCAA summary is **One-Sheet Report: What Funders Should Know About AIDS Service Organization Sustainability: Mergers and Redefining Missions** which can be accessed at http://www.fcaaids.org/publications/Publications_programs_Research2.htm

The Maine Community AIDS Partnership (MCAP) is the local affiliate of the National AIDS Fund. For more information about the National AIDS Fund, visit their website at www.aidsfund.org

MCAP is housed at Medical Care Development (MCD). For more information about MCD go to www.mcd.org

For more information about MCAP programs and initiatives, visit www.maineaids.org

Medical Care Development

[i] 2008 State of Maine HIV/AIDS Epidemiologic Profile, downloaded 12/9/08 from http://www.maine.gov/dhhs/boh/ddc/documents/pdf/maine_2008_hiv_aids_epidemiologic_profile.pdf