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Confronting Disparities while Reforming Health Care:
A Look at Massachusetts

Health Reform in the States

As health care costs and the number of uninsured rise steadily throughout the nation, the lack of a federal solution to this growing crisis has prompted more and more states to take matters into their own hands. Innovative health reform plans have been popping up across the country, from Maine to California. These reform efforts present a unique opportunity to harness the growing political momentum to fix our health care system and to bring attention to the persistent racial and ethnic disparities that plague the system.

It is a common misconception that efforts to provide universal health care will automatically translate into equitable, quality health coverage for all. This is simply not the case: Access alone will not eliminate health disparities.[1] The issue of health disparities must be specifically addressed within health care reform efforts so that inequities can be eliminated.[2]

In 2006, Massachusetts made national headlines when it passed health reform legislation that extended coverage to nearly all Bay Staters. Health advocates from across the country have looked to Massachusetts as an example of how to successfully enact bold health policy reform. However, Massachusetts can serve as a model for more than its work to expand coverage—recent experience there can also provide guidance in how to address health disparities in the context of health reform.

Massachusetts: A Unique Health Policy History

Massachusetts has a long history of progressive health reform, which has served as a necessary foundation for its most recent expansion.[3] In 1985, the state legislature created the Uncompensated Care Pool, which reimburses hospitals and community health centers (CHCs) that provide free care to eligible low-income uninsured people. That same year, the legislature also established a special commission charged with developing a plan for achieving universal health coverage in Massachusetts. A bill based on the commission's plan was signed into law in 1988, and parts of this legislation are still in place today, including programs that provide coverage for children, pregnant women, uninsured workers, adults with disabilities, and college students.

In 1996, the state undertook a massive reform that reinvented its Medicaid program and created MassHealth, which extended Medicaid coverage to an additional 300,000 residents. That legislation also included expanded coverage for children, limits on the amount of out-of-pocket money seniors were required to pay for prescriptions, as well as assistance for low-wage workers purchasing health insurance.

In 2004, health care advocates in Massachusetts once again saw the opportunity to move forward with new health reforms. Health Care for All (HCFA), a prominent health policy organization in the state, led a diverse coalition of stakeholders in drafting legislation that would expand health coverage to virtually all state residents. The coalition was made up of consumers, patients, community and religious organizations, businesses, labor unions, doctors, hospitals, health plans, and community health centers. It came to be known as the Affordable Care Today (ACT!) Coalition.

ACT! was largely responsible for the passage of the most recent health care reform legislation, commonly known as Chapter 58. Passed in 2006, Chapter 58 was designed to expand health coverage to nearly all Massachusetts residents through several mechanisms, including the creation of the Commonwealth Health Insurance Connector (a program designed to help individuals and small employers purchase affordable insurance more easily), a modest expansion of MassHealth, and an individual mandate.

Racial and Ethnic Health Disparities in Massachusetts

As all of this work to expand health coverage was taking place, momentum was also building around the effort to eliminate health disparities. Soon after the landmark Institute of Medicine report, *Unequal Treatment: Confronting Racial and Ethnic Health Disparities in Health Care*, was released in 2002, Boston Mayor Thomas Menino called for city hospitals and community clinics to develop concrete strategies to reduce racial and ethnic health disparities. Menino later established the Mayor's Task Force to Eliminate Racial and Ethnic Disparities and charged it with developing a set of standards and recommendations to help eliminate health disparities in Boston.

In 2005, Menino declared health disparities to be the city's most pressing health care issue and, drawing on recommendations from the task force, launched The Disparities Project to combat health disparities.[4] The Boston Public Health Commission took the lead and created a "blueprint" that laid out 12 sweeping recommendations designed to eliminate disparities in Boston. Mayor Menino raised more than $1 million to fund implementation of the blueprint recommendations through contracts with local groups that were already working to eliminate racial and ethnic health disparities.[5]

The effort to eliminate disparities was not limited to Boston. At the state level, a Special Legislative Commission on Racial and Ethnic Health Disparities was investigating health disparities and developing recommendations and an action plan for addressing such disparities statewide. HCFA played a leadership role in writing this commission into state statute.

The key political support of Mayor Menino and the array of disparities reduction campaigns helped move health disparities into the public eye. Suddenly, people who had never heard of health disparities were opening *The Boston Globe* to find stories on The Disparities Project. The strong support of the health research community also helped to make health disparities a serious legislative issue. The general public and, perhaps more importantly, state legislators, were hearing about health disparities around the same time that they were hearing about broader health reform efforts. This timing created a political climate that was favorable to the inclusion of provisions that addressed racial and ethnic health disparities in the new health reform legislation.

In addition to Mayor Menino, Governor Deval Patrick, who took office in 2007, has shown a real commitment to eliminating health disparities. Not only did he speak at the state's first ever disparities advocacy event (see page 8), leading officials in his administration have also pledged to work with disparities advocates around developing the state's health disparities agenda.

Chapter 58 Legislation and Health Disparities

The Chapter 58 legislation contains four provisions that address racial and ethnic health disparities:[6]

1. **Section 160** calls for the creation of an ongoing **Health Disparities Council** that is charged with developing recommendations on several minority health issues, including workforce diversity, disparate disease rates among communities of color, and social determinants of health.
2. **Section 16 L. (a)** calls for the creation of a **Health Care Quality and Cost Council**, which will focus on health care quality issues with the goals of lowering costs, improving health care quality, and reducing disparities.
3. **Section 13B** develops standards for **Hospital Performance and Rate Increases**, with a specific stipulation regarding hospital rate increases being based on quality issues such as reducing racial and ethnic health disparities.
4. **Section 110** requires a **Community Health Worker Study** to be conducted by the Public Health Department to determine the effectiveness of community health workers in reducing racial and ethnic health disparities.

The Health Disparities Council mandated by Section 160 convened its first meeting in December 2007. The council established several broad initial goals, such as implementing the recommendations of the State Commission to End Racial and Ethnic Health Disparities, as well as ensuring that implementation of Chapter 58 included a consideration of the unique needs of communities of color. More specifically, the council discussed how to integrate the disparities agenda into larger efforts around improvements in health care quality via the Health Care Quality and Cost Council, which was also established by Chapter 58.

Including these provisions in Chapter 58 was an important and necessary step in beginning to tackle health disparities. However, disparities advocates in Massachusetts recognized that reducing disparities would require more than these provisions: Although these measures created a solid foundation, many advocates working on minority health issues felt it was necessary to build more substantive policy on this foundation.

Expanding Health Disparities Legislation

To build on the disparities provisions in Chapter 58, and to more thoroughly address the host of issues that affect health disparities, a coalition came together to file omnibus legislation whose sole focus was reducing racial and ethnic health disparities. HCFA once again took the lead in bringing the project together, and it was joined by a wide range of individuals, organizations, and institutions, ranging from the Boston Public Health Commission to the local chapter of the Service Employees International Union (SEIU). Others involved in the process included legal associations, research organizations, community health organizations, large health care providers, health policy organizations, as well as multi-issue organizations concerned with equity and justice in health policy. Together, they formed the Disparities Action Network (DAN).[7, 8]

The DAN formally convened for the first time in June 2006 with the goal of drafting omnibus disparities legislation for the 2007-2008 state legislative session. Its work was based partly on recommendations put forth by the Special Legislative Commission on Racial and Ethnic Health Disparities. From there, the group determined what it thought was missing from Chapter 58, drawing upon the collective knowledge of its diverse membership to come up with real policy solutions.

Members of the Disparities Action Network (DAN) [9]

Action for Boston Community Development

AIDS Action Committee

Alliance for Community Health

American Cancer Society

American Diabetes Association

American Heart/American Stroke Association

American Red Cross of Massachusetts Bay

Association of Haitian Pastors

Association of Haitian Women

Berkshire Area Health Education Center

Boston Center for Community & Justice

Boston Medical Center Haitian Health Institute

Boston Public Health Commission

Boston University Center for Excellence in Women's Health

Boston Urban Asthma Coalition

Cambridge Health Alliance

Caring Health Center

Center for Community Health Education Research and Service

Community Catalyst

Community Change Inc.

Conference on Boston Teaching Hospitals

Critical MASS

Diabetes Association Inc.

Greater Lawrence Family Health Center

Haitian Multi-Service Center

Haitian Nurses Association

Health Care for All

International Medical Interpreters Association

Jewish Alliance for Law and Social Action

La Alianza Hispana

Latin American Health Institute

The Lawyers' Committee for Civil Rights under Law of the Boston Bar Association

Lowell Community Health Center

Lynn Health Task Force

Mass CONECT, Harvard School of Public Health

Massachusetts Asian and Pacific Islanders for Health

Massachusetts Association of Community Health Workers

Massachusetts Breast Cancer Coalition

Massachusetts General Hospital, Disparities Solutions Center

Massachusetts Hospital Association

Massachusetts League of Community Health Centers

Massachusetts Medical Society

Massachusetts Public Health Association

Medical-Legal Partnership for Children

Multicultural AIDS Coalition

NAACP Boston

NARAL Pro-Choice Massachusetts

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Oral Health Advocacy Task Force

Physicians for Human Rights

Planned Parenthood League of Massachusetts

Project RIGHT

SEIU 1199

Tobacco Free Massachusetts

Vietnamese American Civic Association

Whittier Street Health Center

YMCA of Greater Worcester, Central Community Branch

Youth and Family Enrichment Services

The DAN wrote its legislation using a collaborative work group process, meeting several times throughout the summer and fall of 2006 to write and review the legislation before it was filed. First, the coalition held a brainstorming session to determine what should be included in the legislation, which yielded an exhaustive list of policy recommendations and ideas. The final legislation grew from one key premise, which was the need to create a Health Equity Office. The members of the DAN believed that the abundance of projects, programs, and other efforts to eliminate racial and ethnic health disparities in Massachusetts could be greatly strengthened if they were not so fragmented. A Health Equity Office could serve as a coordinating body for all of the disparities work within the state. Under the guidance of such an office, disparities could be addressed in a systematic, cohesive approach through strategic planning and coordination of efforts on multiple fronts.

These efforts include programs that address both disparities in health and disparities in health care. More specifically, these programs involve developing standards based on best practices from across the state. These standards focus on health literacy, healthy communities initiatives that address environmental and social determinants of health, and workforce diversity (through coordination of existing labor standards). Other programs include support for medical interpreter services, community health workers, wellness education, community-based participatory research, and coordination of racial and ethnic data collection projects across public and private agencies.[10]

The legislation, entitled *An Act Eliminating Racial and Ethnic Health Disparities in the Commonwealth* (H. 2234), was introduced in the Massachusetts legislature on January 9, 2007, by Representative Byron Rushing. In anticipation of the bill's hearing, the DAN formed several committees to build momentum around ending health disparities. This included a grassroots advocacy committee to help bring a community voice to the policy process and to reach out to communities to help them understand more about disparities and why passing this legislation is important. The network also formed lobbying and communications workgroups to educate members of the Joint Committee on Public Health both about the bill and about health disparities in general, as well as to gain more publicity in local media to broadly publicize information on disparities and the DAN legislation.[11]

The bill was heard on May 16, 2007, and it remains in the Public Health Committee. A panel comprised of health care and disparities experts, community members, and the legislative leads for the bill used their testimony as an opportunity to further educate legislators about the importance of addressing health disparities within health reform efforts.

Since that hearing, the DAN has submitted one redraft of the legislation, which made the following minor changes per the recommendation of the committee chair: the grant programs have been consolidated and made less prescriptive by the language; all grant programs have been clearly designated as subject to appropriation; and the Environmental Justice provision has been shortened and simplified.

The redrafted bill was submitted in late November 2007, and it remains in committee. In the meantime, in November 2007, the Patrick administration announced that it would distribute $1 million in grants to agencies throughout Massachusetts to eliminate health disparities, and it released a report that documented widespread disparities in health across the state. Many of the grant recipients were DAN member organizations.

An Act Eliminating Racial and Ethnic Health Disparities in the Commonwealth includes the following provisions:[12]

- **Office of Health Equity**

  The Office of Health Equity will be housed under the State Executive Office of Health and Human Services and will be advised by the Health Disparities Council that was created by Chapter 58. The Office of Health Equity will be responsible for coordinating all disparities elimination efforts in the state. The office will publish annual disparities impact statements, put out annual disparities report cards on regional progress, set evaluation standards, determine reimbursement rates for medical translation services, and manage programmatic provisions of the legislation.

- **Community Agency Grants Program**

  The Office of Health Equity will run a grant program to support efforts by community-based health agencies to eliminate disparities in underserved populations.

- **Data Collection Coordination**

  The Office of Health Equity may choose to publish best standards on data collection. The office will also coordinate the data collection, analysis, and dissemination activities of all parties involved in the collection of data on patient race, ethnicity, and language spoken.

- **Community Health Workers**

  The Office of Health Equity will run a competitive grant program to provide funds to hospitals, community health centers, and nonprofit community organizations to employ community health workers to better the health of the communities in which they live.

- **Community-Based Participatory Research**

  The Office of Health Equity will run a competitive grant program to provide funding for research partnerships between community-based organizations and academic researchers focusing on the elimination of health disparities.

- **Health Literacy**

  The Office of Health Equity will designate and disseminate best practice guidelines for the creation of health-related materials and literature drawing on federal and public health standards. The goal is to make materials widely accessible to patients, including those with limited educational attainment and limited English proficiency.

- **Workforce Development**

  The Office of Health Equity will establish a council to coordinate state, local, and private-sector efforts to establish health care workforce diversity and development.

- **Environmental Justice**

  A statewide community health index will be created to demonstrate which communities suffer from high rates of death and illness based on a weighted set of primary and secondary indicators of health outcomes.

- **Chronic Disease Management**

  A chronic disease management program will be established in the Department of Public Health to begin wellness education of individuals who suffer from chronic disease.

DAN Advocacy Activities

Legislative Advocacy

The DAN has advocated broadly throughout the legislature, and it has rallied black and Latino caucus members in support of the legislation. In October 2007, the DAN hosted the first ever health disparities advocacy event at the State House. The event drew more than 350 attendees from around the state, many of whom were consumers of color. What's more, representatives from 42 legislative offices came to the event. One highlight of the program was a surprise visit from Governor Patrick, who affirmed his commitment to eliminating health disparities. After the event, DAN members and consumers visited those legislative offices to further educate members of the State House about the bill and about health disparities.

Budget Advocacy

The DAN has begun working on another approach to accomplishing the objectives of the original legislation. Because the bill has remained in committee since early 2007, the DAN has looked to the governor's budget as a vehicle for moving specific pieces of the legislation. In November 2007, the DAN submitted a request to the governor's office to include in his budget funding for many of the programs contained in the bill, such as the creation of an Office of Health Equity that would administer grant programs for community health agencies, community health workers, and community-based participatory research. The budget is expected to be released in late January 2008, and while this approach would provide immediate funding for some much-needed programs, the DAN will also continue to pursue its legislative strategy so that these programs become codified into state law.

What about the Social and Environmental Determinants of Health?

Racial and ethnic health disparities are not simply the result of disparities in access to quality health care. Rather, they result from complex social, economic, and environmental factors.

After the initial brainstorming process, the DAN work group realized that many of the provisions it had discussed were focused on the structural and social determinants of health, as opposed to reforms of the health care system itself. For example, there were several provisions that addressed access to healthy grocers, green space, healthy school lunches, and safe places for children to play within communities of color.

These provisions presented a challenge because the legislation was meant to be a "health care bill," and the group did not want to weaken the bill by spreading its focus too broadly. At the same time, the group did not want to develop a bill that focused solely on health care and ignored the larger environmental determinants of health—such a bill would send the message that policies that improve quality and access in the health care system are all that is needed to eliminate racial and ethnic health disparities.

Although the majority of the legislation was focused on reforms within the health care system, DAN advocates wanted to acknowledge the deeper roots of health disparities. They therefore included a provision that requires the Office of Health Equity to monitor social and environmental effects on health. The Office of Health Equity will be responsible for addressing these effects by engaging other state agencies, such as the housing and transportation authorities, and by generating annual disparities impact statements on the major initiatives of these agencies. The Boston Public Health Commission, a member of the DAN, also filed smaller-scale legislation on environmental equity issues (this legislation is currently on hold), while the DAN made a concerted effort to emphasize the important role of environmental and social justice in the effort to eliminate disparities.

Lessons Learned

The goals and ideas put forth by the DAN are far from unique. There was already an enormous amount of work going on around the elimination of health disparities prior to the convening of the DAN. Yet there is much to learn from the experiences of minority health advocates in Massachusetts as they move forward with their health disparities legislation.

- **Framing the Message and Getting Media Coverage**

  The DAN showed that by harnessing the political and media attention surrounding health care expansions and reforms, it is possible to successfully elevate a disparities policy agenda to the state level. As more and more states begin to develop their own health care expansion legislation, disparities advocates must be ready to seize any political opportunities that can move the issue of health disparities into the public eye. The DAN advocates were successful because they were able to use all of the public attention surrounding health reform in Massachusetts, as well as the media attention garnered by the mayor's Disparities Project, to successfully raise awareness about health disparities and simultaneously put forth a substantive strategy aimed at eliminating those disparities.

  At the same time, the DAN has faced some challenges in framing their message and fully addressing the disparities issue within the context of Chapter 58. For example, some stakeholders believe that the issue of health disparities is only an issue of health access, and they point to health care reform as the key to eliminating all disparities. The DAN continues to work hard to educate those audiences about factors other than access that can lead to health disparities, such as the social determinants of health and unequal treatment.

  Another challenge the DAN faces is garnering media attention that examines the nuances of disparities in health and health care. The group has found that when media outlets do report on health disparities, they tend to focus only on overt discrimination in health care settings, and they have less interest in investigating or reporting on the full breadth of disparities issues, or on possible solutions. Media outlets have also shown a bit of fatigue when it comes to reporting on health care issues, including disparities.

- **Coalition Strategy and Engagement**

  The collaboration among multiple groups coming together to write legislation focused on disparities demonstrated the political power that advocates can wield through collective action. The DAN has been a powerful driving force because it uses the knowledge, skills, resources, and political power that its diverse membership brings to the table. By drawing on these resources and developing a defined agenda, the DAN was well positioned to raise awareness about health disparities and to move its policy agenda forward.

  Advocates need to keep in mind that raising awareness around disparities is only part of the battle. Introducing disparities legislation is not easy, which is why collaboration is so crucial. Minority health advocates must look beyond their traditional partners and seek

out diverse partners. For instance, advocates who are working to expand health coverage may not be the same advocates who are trying to eliminate disparities and ensure health equity. However, these issues must go hand in hand: Conversations around expanding access are a natural place to discuss efforts to ensure health care equity and reduce disparities. Each of these individual efforts can be strengthened through collaboration.

The DAN has found it challenging to diversify its membership so that it includes more community-based minority organizations. Many of these groups have prioritized other important issues (such as housing, violence, or education) over disparities, and they have not had the capacity to join the DAN table. Disparities advocates can address some of these hurdles by taking a few practical steps, such as holding meetings outside normal business hours to attract interested volunteers, helping groups make the connection between larger social issues and policy goals and their own organizational goals, as well as recognizing that not all groups can devote staff time to health disparities efforts.

- **Policy and Advocacy**

  Another important lesson to be learned from the experiences of the DAN is that policy is a tool that minority health advocates can, and should, use to help eliminate health disparities. Advocates who work on minority health issues often focus on direct service or disease-specific issues in their efforts to reduce disparities in health and health care. Although these efforts are critical, it is important to look beyond these traditional strategies and use policy as a tool to help eliminate health disparities. Health disparities are a systemic problem that calls for systemic answers, and policy can serve as a powerful tool to address inequities. While the political and historical circumstances in Massachusetts were clearly unique factors that allowed the disparities legislation to advance, minority health advocates can still look to the state as a model for legislation in their own states.

  Finally, although expansions of health coverage can be a useful vehicle from which to address disparities in health care access and quality, because disparities are rooted in many sources, advocates must not limit their work to health care access. Disparities result from a wide range of factors, including social and cultural circumstances, physical environment, and individual socioeconomic status. With so many factors contributing to health disparities, it is unrealistic to believe that disparities can be eradicated by pursuing narrow policies that focus solely on health care access and delivery systems. To combat the complex ways in which health disparities affect minorities, advocates must explore program and policy solutions that can address the environmental and social determinants of disparities as well.

  Health disparities are complex. By looking at success stories like that of the DAN, minority health advocates can develop and strengthen tools that will eliminate racial and ethnic health disparities and, ultimately, lead to health equity.

Endnotes

[1] Kate Meyers, *Racial and Ethnic Health Disparities* (Oakland, CA: Kaiser Permanente Institute for Health Policy, 2007), available online at http://www.kpihp.org/publications/docs/disparities_highlights.pdf.

[2] Jack Geiger, "Race and Health Care—An American Dilemma?", *New England Journal of Medicine* 335 (September 1996): 815-816.

[3] ACT! Affordable Care Today, *Previous Health Care Reform Efforts in MA: A Brief Background* (Boston: Health Care for All, 2006), available online at http://www.hcfama.org/act/reform101.asp.

[4] Boston Public Health Commission, *The Disparities Project: Year One Report* (Boston: Boston Public Health Commission, 2007), available online at http://www.bphc.org/reports/pdfs_222.pdf.

[5] Ibid.

[6] ACT! Affordable Care Today, *Chapter 58 of the Acts of 2006: An Act Providing Access to Affordable, Quality, Accountable Health Care* (Boston: Health Care for All, 2006), available online at http://www.hcfama.org/act/mahealthreformlaw.asp.

[7] Health Care for All, *Disparities Action Network* (Boston: Health Care for All), available online at http://www.hcfama.org/index.cfm?fuseaction=page.viewPage&pageID=516.

[8] Camille Watson, "Policy and Advocacy Efforts to Eliminate Disparities in Massachusetts," presentation at Universal and Equal: Ensuring Health Equity in Health Reform meeting, March 9, 2007.

[9] Health Care for All, op cit.

[10] Camille Watson, op cit.

[11] Ibid.

[12] Health Care for All, *An Act Eliminating Racial and Ethnic Health Disparities in the Commonwealth: Summary* (Boston: Health Care for All, 2006), available online at http://www.hcfama.org/_uploads/documents/live/Dan%20Summary.pdf.

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