SUSTAINABILITY

a retrospective assessment
of DIABETES INITIATIVE PROJECTS

DIABETES INITIATIVE
A National Program of the Robert Wood Johnson Foundation

Sustainability: A Retrospective Assessment of Diabetes Initiative Projects

A Report from the

National Program Office

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Preface

The *Diabetes Initiative*, a national program of the Robert Wood Johnson Foundation (RWJF), was intended to demonstrate feasible and successful models of self management in primary care and community sites around the country and to promote such programs. The fourteen sites of the *Initiative* included urban, rural, frontier and Indian Country settings; Latino, African American, American Indian, and White populations – all representing groups experiencing substantial health disparities. The *Diabetes Initiative* National Program Office (NPO) oversaw and provided technical assistance to the grantee organizations. All fourteen *Diabetes Initiative* programs are described in detail at the website: http://diabetesinitiative.org.

Sites were funded from early 2003 through the end of 2006. During this time, staff from each site participated in a series of meetings several times a year designed to acquaint them with important features of diabetes education and self management and trends in the field. The meetings were also designed to facilitate sharing information among programs and, in a highly collaborative manner, encourage plans for program enhancement. Details of this process are presented in a report, "The Collaborative Learning Network: An Approach to Maximizing Program Effectiveness" available at: http://www.diabetesinitiative.org/lessons/documents/CLNReportFINAL5.22.08.pdf.

We recognized that even with demonstrated effectiveness[1], programs could not be considered to be successful unless they were sustainable. Therefore, one of the goals of the NPO was to guide grantees in developing and implementing strategies that would allow them to sustain their programs when grant funding ended (after 45 months). To assess how well programs were sustained and strategies that were effective in sustaining them, we conducted structured interviews with the project directors of each of the funded sites after grant funding ended. This report details and provides examples of successful sustainability strategies reported by RWJF *Diabetes Initiative* grantees, identifies threats to sustainability and discusses key ingredients for success in sustaining programs. The last section offers lessons learned from these grantee reflections and implications for practice. We hope that this report will prove to be a useful guide to those who want to develop and implement sustainable self-management interventions.

We gratefully acknowledge the assistance we received from a number of individuals as we developed this report. We are particularly indebted to the project directors who took time out of their busy schedules to be interviewed and to be available for any follow-up questions that arose. Interviewees were Joan Christison-Lagay and Daren Anderson at Community Health Center, Inc. in Middletown, Connecticut; Richard Crespo and Sally Hurst at Marshall University in Huntington, West Virginia; Lourdes Rangel at Gateway Community Health Center, Inc. in Laredo, Texas; Dawn Heffernan at Holyoke Health Center, Inc. in Holyoke, Massachusetts; Claire Horton at *La Clinica de La Raza* in Oakland, California; Devin Sawyer at Providence St. Peter Hospital Family Medicine Residency Program in Olympia, Washington; Emma Torres at *Campesinos Sin Fronteras* in Somerton, Arizona; Lucille Johnson at the Center for African American Health in Denver, Colorado; Darlene Cass at the Galveston

[1] The successes of the *Diabetes Initiative* are described in detail in a special supplement to *The Diabetes Educator*, Volume 33, Supplement 6, June 2007.

County Health District in Galveston, Texas; Natalie Morse at MaineGeneral Health in Waterville, Maine; Lydia Caros at the Native American Community Clinic in Minneapolis, Minnesota; Cheryl Belcourt at the Montana-Wyoming Tribal Leaders Council in Billings, Montana; Nilda Soto and Laura Bazyler at Open Door Health Center in Homestead, Florida; and Lisa Aisenbrey at the Richland County Health Network in Sidney, Montana.

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Background

Sustainability can be defined as the "capacity to maintain program services at a level that will provide ongoing prevention and treatment for a health problem after termination of major financial, managerial, and technical assistance from an external donor."[2] In the *Diabetes Initiative*, sustainability was addressed in the call for proposals[3] to potential grantees this way: "…One of the key ingredients to sustainability of any new initiative is to work toward changing policies and procedures of the environment within which the program/initiative is implemented. Sustainability requires that projects not only institutionalize and financially support system changes, program processes, services, and resources shown to be effective, but also to 'hold the gains' already made…"

The 14 grantees of the *Diabetes Initiative* were funded from 2003 to 2006. Beginning with the first annual meeting of grantees in July 2003, sustainability was a topic of discussion. Program staff from the Robert Wood Johnson Foundation (RWJF) gave a presentation intended to establish sustainability as a priority in program planning and development. The presentation discussed types of sustainability, factors that facilitate program sustainability, a review of the literature and examples from practice. The theme was reinforced at the following annual meeting in 2004, when a Senior Program Officer from RWJF led an "idea lab" on sustainability strategies.

In June of 2004, the National Program Office (NPO) of the *Diabetes Initiative* administered an e-mail survey of grantees on sustainability. Responses were then collated, shared via e-mail with the group and used to frame the presentation, "Sustainability – Questions, Issues, and Exercises," given by an expert at the 2005 Annual Meeting. To further support grantee efforts to sustain their programs, a presentation on "Building a Business Case for Self-Management Support" was given at a grantee meeting in 2006, followed by a participatory planning exercise with grantees.

Data Collection

Having created the expectation and provided consultation to grantees on sustainability, the NPO was interested in learning from the grantees *what* they were able to sustain and *how* they were able to sustain aspects of their programs after their RWJF *Diabetes Initiative* funding ended in October 2006. In September 2007, NPO staff drafted questions to be asked in structured interviews with the project directors of each of the funded sites. The questions were pilot tested with one site and revised before conducting the remaining interviews. Interviews were conducted from October through December 2007; they lasted 20-60 minutes each. The interviews were conducted by a trained staff person who also recorded them, took extensive notes, and developed a summary report. A qualitative analysis was conducted independently by a second staff person. Interview notes were coded using open coding to identify emergent themes, a process that involves deriving themes from the interviewees' words, grouping like themes and providing supporting quotes. Staff met to discuss and resolve any differences between the summary report and the original survey responses on which it was based. The following report summarizes the grantees' responses to the interviews.

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[2] LaPelle, NR; Zapka, J; Ockene, JK. Sustainability of public health programs: the example of tobacco treatment services in Massachusetts. *Am J Public Health.* 2006;96:1363–1369.

[3] *Diabetes Initiative* Phase II Call for Proposals: http://diabetesinitiative.org

Survey Findings

A. What Was Sustained

It is noteworthy that most sites reported being able to sustain key components of their programs after funding ended. Among the many program elements sustained were:

- Classes – e.g., diabetes self management, chronic disease self management, nutrition, and exercise classes
- Support groups –e.g., structured meetings led by professionals and less-structured meetings led by peers or group participants
- Clubs and informal gatherings –e.g., breakfast clubs, snack clubs, walking clubs
- Use of *promotoras*/community health workers – e.g., informally in the community, in support groups, and as part of the clinic staff
- Changes in the clinic system of care – e.g., group medical visits, depression screening, dental screening, use of the Transtheoretical Model (TTM) to stage patients on readiness to change, and increased emphasis on patient-centered care
- Organizational partnerships – e.g., clinic-community partnerships and inter-organizational partnerships
- Other program elements – e.g., worksite wellness programs, supermarket tours and case management services, and use of social marketing strategies.

In addition to being able to sustain critical elements of their programs, several sites reported expansion of their programs and services, addressed later in this report.

B. Successful Sustainability Approaches

This report focuses on how the *Diabetes Initiative* grantees were able to sustain key components of their self-management programs. Strategies reported in the interviews fell into four main categories: 1) broadening the scope of the programming; 2) making permanent system changes; 3) changing community and patient expectations; and 4) building new or enhancing existing partnerships. The following sections give specific programmatic examples of each as reported by the project coordinators.

1) Broaden the scope of self-management programming

a. Broadening the scope of self-management programs increased their value to organizations and allowed grantees to sustain many components of their programs. Because most diabetes self-management strategies are also applicable to other chronic diseases, some programs were expanded by offering the program to individuals with or at risk for other chronic diseases or by synthesizing program components in their clinics. For example, the Diabetes Community Council at the Minneapolis American Indian Center in Minnesota evolved into the Community Health Council so that they could focus on self management and community health more

broadly. In other cases, successful program models were emulated in other disease control programs. Select examples follow:

Cardiovascular Disease

- Gateway Community Health Center in Laredo, Texas, built on their successful diabetes program model to develop a proposal to the National Heart, Lung and Blood Institute to become a training site for the "Your Heart, Your Life" curriculum.
- Prior to the *Diabetes Initiative* grant, the Holyoke Health Center in Holyoke, Massachusetts, had six chronic care teams all working on self management, but with no collaboration among them. Following the *Diabetes Initiative* grant, collaboration was established, processes streamlined and redundancies eliminated.
- With the demonstrated success of the diabetes program, the Sunset Clinic in Yuma, Arizona, realized the importance and impact of the work of the *promotoras* from *Campesinos Sin Fronteras*. The clinic then recruited and hired *promotoras* to be involved in their cardiovascular programs.

Women's Health

- Because of its success in engaging patients, Holyoke Health Center used key elements from their diabetes program to develop their "Healthy Weight in Women Program."
- Community Health Center, Inc. in Middletown, Connecticut, used the self-management methodology developed during the *Diabetes Initiative* to implement an adolescent self-management weight management program. They received funding for this program from the Office on Women's Health.

Worksite Wellness

- The Miami Dade Area Health Expansion for Education Center implemented worksite wellness services for which they could bill. These services were modeled after *Diabetes Initiative* programs at the Open Door Health Center in Homestead, Florida.

Obesity

- Gateway Community Health Center received funding from the United Way to start a pilot project for children with obesity. Concepts from the adult diabetes self-management program formed the foundation of this program.
- The *promotoras* at *Campesinos Sin Fronteras* expanded their work by leading classes for parents to educate them about healthy ways to deal with food issues and physical activity for their children to prevent obesity.

b. Another approach to broadening the scope of diabetes self-management programs was to spread the programs to other communities and clinics, making self-management services available to more individuals with diabetes.

Several programs spread their programs to other **communities.** For example:

- MaineGeneral Health in Waterville, Maine, took advantage of Healthy Maine Partnership grants to spread their *Move More* community-based physical activity program to additional counties. With this spread, they were able to decentralize some of the program functions in order to enable local communities to tailor the program to their specific needs.
- Galveston County Health District in Texas worked with the Gulf Coast Black Nurses Association (an association of parish nurses), training them to offer diabetes self-management programs to members of their community churches.
- Marshall University in West Virginia structured a leaders training for the yoga component of their program so that organizations such as the United Mine Workers Health and Retirement Fund could lead their own programs in rural Appalachian communities.

Spread to other **clinics** also occurred. For example:

- After learning about the diabetes registry implemented for the diabetes program at St. Peter Family Medicine in Olympia, Washington, the Physicians of Southwest Washington (PSW) formed a committee to explore its adoption by other sites.
- In West Virginia, group medical visits were implemented at two additional rural health centers by Marshall University's *Diabetes Initiative* project.
- Holyoke Health Center greatly increased their capacity for agency-wide spread self-management programming by having staff trained as Chronic Disease Self-Management Program master trainers who, in turn, trained other staff members to implement programs in all five agency sites, reaching approximately 2300 patients with diabetes.
- Information about the Montana-Wyoming Tribal Leaders' diabetes program was disseminated at various meetings to tribal health directors at seven reservations in Montana and at one with two tribes in Wyoming. The response to the offer to share expertise, learning, reports and curricula was met with enthusiasm.

2) Systematize quality improvements

Improvements that can permanently change the capacity of providers and service delivery systems have the best chance of being sustained. A sustainability strategy used by many of the grantees involved embedding improvements into the way their organizations dealt with diabetes management. In some cases, extensive training of providers and staff in self-management principles permanently changed how they understood and executed their roles in supporting patient self management. As new staff were hired, they were also trained in those approaches, thereby improving the capacity of the entire staff and ensuring sustainability. In other cases, grantees made quality improvements in usual care to support self management which then became improved care for all patients. Examples of how quality improvements were integrated into existing systems follow:

a. Sustaining Intervention Approaches

- At Richland County Health Network in Sidney, Montana, the quality improvement requirements achieved for ADA recognition impressed administrators to the extent that they required a greater commitment to quality improvement in programs other than diabetes.
- Also in Sidney, greater awareness of diabetes and the behaviors that aid in its management led to some permanent changes in the community. For example, restaurants advertize "healthy fare", grocery stores offer more produce and healthy choice foods, and walking/biking paths are being used more frequently.
- At St. Peter Family Medicine, the group visit model got a great deal of positive support from physicians who wanted to use this model for treatment of other chronic diseases, thus making the use of this model routine in chronic illness care.
- At Holyoke Health Center, success of the *Diabetes Initiative* program resulted in administrators integrating *promotoras* into the primary care setting as a permanent system change and continuing to search for ongoing funding to support them.
- At the Community Health Center in Middletown, self management came to be seen as a major part of any behavior intervention with patients, regardless of whether they have diabetes or not.
- At Gateway Community Health Center, the main sustainability goal was to make the *promotora* program an integral part of the Center's medical operations. By reaching this goal (of 12 *promotoras* funded by the grant in 2003, eight were still employed in 2008), they were able to markedly improve self-management services. They accomplished this by:
  - Re-writing all policies and procedures to include *promotoras*
  - Training *promotoras* to fill multiple roles, including some activities previously done by certified diabetes educators
  - Getting buy-in and full support from providers by carefully documenting patient improvement for those interacting with a *promotora.*

b. Training Providers and Staff

- Holyoke Health Center identified training of providers and staff as the avenue to build capacity and promote continuation of their programs. They used several different types of training, including:
  - training staff in the Chronic Disease Self-Management Program
  - training providers in motivational interviewing, goal setting and problem solving
  - training nurses in patient empowerment and stages of change models
- *La Clinica de La Raza* trained providers, staff and *promotoras* in using the Transtheoretical Model (TTM) as a basis for their interactions with patients including those in classes and support groups. One of the long lasting effects is that although the *Diabetes Initiative* program has ended, the TTM approach continues to guide providers, staff and *promotoras.*
- Medical Assistant (MA) planned visits, open-office group visits, mini-group visits and the buddy system at St. Peter Family Medicine (SPFM) have been incorporated into the residency

training program so that all residents will graduate with competency in patient support and self management. Additionally, SPFM is pursuing steps to get the MA curriculum accepted by the Washington State Diabetes Collaborative.

c. Improving Tracking And Monitoring Systems

- Having all patients with diabetes in CDEMS (an electronic database) allowed the Minneapolis American Indian Center to track individuals with diabetes more efficiently so that the referral process was improved.
- Open Door Health Center did not have access to an electronic registry, but improved services to diabetes patients by color coding the patient charts. This allowed them to be more consistent in scheduling appointments.
- Community Health Center in Middletown imbedded a self-management folder in patient electronic health records so that goals could be recorded and tracked at each visit.
- At MaineGeneral Health, patients at the Diabetes Nutrition Center are automatically enrolled in *Move More*, a program to increase physical activity.
- At *La Clinica de La Raza* in Oakland, California, goal sheets developed during the *Diabetes Initiative* project that incorporate the stages of change processes were adopted for use in their Preventive Medicine clinics.

3) Increase expectations

Satisfied patients and providers create demand for continuation of high-quality programs and services; once quality programs and services are in place, there is an expectation that they will continue. Recognizing the need for support from those involved, several sites spent a great deal of time and effort establishing quality services and awareness of them among providers and people they served. Examples follow:

a. Increasing Public Awareness

- As the diabetes program at Open Door Health Center became well-known in the community, new patients came in expecting to receive services they had heard about. Established patients helped the new patients understand the system so that they could get maximal benefit from available services.
- Word of mouth was very effective in publicizing the “Whisking Your Way to Health” class in the Galveston area. For example, two people in one class recruited 15 of their friends for the next class. Also, a participant in a class at her church was very interested in starting a class at her worksite.
- As classes became more well-known through word of mouth, people in a Montana-Wyoming Tribal Leaders Council community started contacting the diabetes program to request more classes.

- The program at *Campesinos Sin Fronteras* was publicized by providers and through word of mouth in the community. For example, men did not initially come to educational classes or support group meetings offered by the program. Then, some started coming with their wives, and they realized that these services were helping them gain better control of their diabetes and improve their health. As a result, they became promoters of the programs and role models for other men.

b. Creating Participant/ Patient Buy-in

- Richland County Health Network learned that getting rid of the "diabetes" label on program activities increased participation and community interest markedly. Instead of calling a physical activity opportunity the "Diabetes Walk", they called it the "Walk Across Montana" and got much better participation.
- The *promotoras* at *Campesinos Sin Fronteras* generated greater influence in the community because many of the people they work with are prominent in the community (e.g., city council members and others involved in the community at the grassroots level). Because of these relationships, their many programs and the quality of their work, *Campesinos Sin Fronteras* earned tremendous respect from the community.
- Patients at Gateway Community Health Center initially were skeptical that *promotoras* had enough knowledge to assist them. However, after participating in classes and support groups led by *promotoras* and learning the importance of taking control of their disease, patients realized the value of the help they were getting from the *promotoras* and were willing to pay for their services if necessary.
- As patients at Holyoke Health Center changed their expectations, they became more engaged and took more responsibility for their health. For example, a group of very engaged patients started a community mentors program.
- At St. Peter Family Medicine, patients who participated in several components of the self-management program had higher expectations for their patient-provider visits. Residents who were expecting to tell patients what to do and give them advice were often surprised. Patients were more proactive, which required residents to respond in a more interactive way.
- Participants at the Center for African American Health in Denver, Colorado, have come to expect the Center to provide them with self-management education. As a result, Center staff feel that they would be letting the community down if they did not continue their programming so have initiated actions to continue providing services.

c. Getting Buy-in From Providers and Provider Networks

Getting buy-in from providers was often the most difficult part of making permanent system changes. Feedback to providers with data documenting improved patient outcomes for those who received self-management services facilitated the buy-in process. Once provider expectations were changed, providers often became the biggest supporters of self-management support processes. Specific examples of grantees getting provider buy-in are as follows:

- Providers at Gateway Community Health Center and *La Clinica de La Raza* came to accept and rely on the contributions of *promotoras* to improved patient outcomes. Improved communication via regular meetings between providers and *promotoras* helped the providers recognize that factors other than good medical care resulted in successful diabetes management. They came to rely on the services from *promotoras* that included patient education and emotional support.
- Buy-in of providers and staff at Holyoke Health Center resulted from multiple training sessions. Trainings in chronic disease self management, motivational interviewing, goal setting and problem solving were all very well received. Similarly, at Community Health Center in Middletown, trainings resulted in self management becoming a core part of medical practice and acceptance that promoting behavior change is an important part of patient care. Providers felt they had more support and more to offer patients.
- At MaineGeneral Health, local providers came to expect the resources that *Move More* gave patients, even to the extent that the capacity of the *Move More* program became stretched.
- Expanding the role of medical assistants was the key to getting buy-in from physicians at St. Peter Family Medicine. By having routine medical tests done and goal setting initiated by the medical assistants, physicians were able to focus on key issues and partner with patients to develop tailored management plans. This system was so successful that all family medicine residents receive training in these methods.
- *Promotoras* at *Campesinos Sin Fronteras* were able to develop relationships with providers that resulted in providers being comfortable referring patients to them for help not only with their diabetes, but also for depression and other important "life" issues.

4) Build new partnerships or expand the role of existing partners

Working with partners provided opportunities to sustain, and even expand, programs and services. Partnership efforts sometimes resulted in new financial support for program sustainability, but more often, working together created synergy among partners and opportunities for improved programs and services for clients.

a. Program Enhancements

Grantees leveraged successes and partnership relationships to strengthen or expand programs and services. For example:

- The Minneapolis American Indian Center (MAIC) and the Native American Community Clinic (NACC) had an existing partnership with the Running Wolf Fitness Center to allow MAIC/NACC patients to use the fitness center as part of the diabetes program. When the Indian organization running the fitness center lost funding and decided to close, NACC partnered with the Indian Health Board to take over and co-manage the center. As a result of MAIC/NACC expanding their role in the fitness center, they were able to build a new

partnership with the Indian Health Board that benefitted some of their other programs as well.

- Open Door Health Center attributes some of their success in partnering to their receiving the Robert Wood Johnson Foundation grant. They believe this earned them respect and changed their relationship with collaborating groups and the local community. As a result, the Center was able to gain better access to community resources, such as glucometers, medications and healthy food for their patients.
- The success of the *Move More* Diabetes Program led Healthy Maine Partnerships (community coalitions that received tobacco settlement funds) to adopt *Move More* as their community-based physical activity strategy. This effectively spread the *Move More* program to other geographic areas in Maine and resulted in shared responsibility for continuing the program, including sustainability of Mover training, maintenance of the website and the opportunity for primary care practices to offer Chronic Disease Self-Management Programs.
- Because of Gateway Community Health Center's thorough curriculum for training *promotoras* (developed during the *Diabetes Initiative*), the Texas Department of Health certified their curriculum and allowed Gateway to provide *promotora* training throughout the state. This, in turn, resulted in Gateway being contracted by Medicare and Medicaid Services to provide trainings outside of Texas.
- Because of the success of the Galveston County Health District diabetes program, the University of Texas Medical Branch expanded their partnership commitment to sustain the program by providing salary support for the outreach coordinator. In this expanded role, the coordinator trained members of the Gulf Coast Black Nurses Association to conduct diabetes self-management classes in their community churches.
- As part of the *Diabetes Initiative*, the Richland County Health Network (RCHN) partnered with the Lions Club to develop the *Wellness for Life* program. With the success of this program and to ensure its sustainability, RCHN expanded partnerships for this program to include Healthworks (the local fitness center), the Montana State University Extension Service, the Health Department and the Sidney Health Center. Representatives from each of these partners meet to plan the agenda for the following year.
- The main partner for *Campesinos Sin Fronteras* during the *Diabetes Initiative* project was the Sunset Clinic. As the program progressed, Sunset's role expanded from acceptance of *promotoras* as part of the care team to active advocacy for expanding *promotora* roles and gaining reimbursement for their services. In addition to partnering with Sunset Clinic, *Campesinos* brought in new partners including the Regional Behavioral Health Agency, AARP, the Area Agency on Aging and other state agencies.
- Two new partners of the West Virginia diabetes program ensured spread and dissemination of program materials. The state diabetes control program adopted the *Diabetes Initiative* social marketing materials with self-management messages and paid for duplication of these materials for organizations in West Virginia. The West Virginia Bureau for Senior Services adopted materials to be in compliance with federal Agency on Aging guidelines that require use of evidence-based practices.

- The new partnership between *La Clinica de La Raza* and their local WIC (Women, Infants, and Children) program resulted in WIC funding for printing a new cookbook to be used as a prize for participants who had all of their annual screenings done.

b. Financial Support

While some aspects of programs could be sustained without continued financial support, others required further funding. Acquisition of additional financial resources followed a few basic patterns:

Operating Expenses from Host Organization with Small Grants from Other Sources

- The Minneapolis American Indian Center pieced together a budget to sustain their program from several small grants. Pharmaceutical representatives agreed to continue to provide funding for the diabetes breakfasts. A local health plan (UCare) provided funds to continue the community council. Small grants were funded by the state (Indian Health Grant Program), a private foundation (the Healthier Minnesota Community Council Fund), and private industry (Medtronics) to support general diabetes programming.
- Open Door Health Center continued to receive funding for their operation as a Free Clinic from the Hospital System and Health Foundation of South Florida. Smaller grants from local foundations and from the Office of Women's Health supplied salary support for the outreach worker and a peer educator.
- MaineGeneral Health received the mainstay of their funding from the Community Health Improvement Fund, but decentralized many functions so that smaller grants from foundations and other state sources could cover program expenses in many small communities.
- *Campesinos Sin Fronteras* received a grant from the Office of Minority Health to address chronic disease from a family perspective. Support from the Margaret Casey Foundation supported administrative expenses.
- The Center for African American Health used new funding for additional training of staff to change how they interact with patients. They received a grant from the Colorado Department of Public Health to train 19 facilitators in the Chronic Disease Self-Management Program and a grant from the Colorado Trust Equality in Health Initiative to train staff in motivational interviewing techniques, both strategies used successfully in their *Diabetes Initiative* project.

Large New Grants and/or Smaller Pilot Grants Based On Diabetes Initiative Projects

- Gateway Community Health Center has been able to continue their programs through leveraging their success with the *Diabetes Initiative* project to successfully compete for other relatively large grants. For example, they were asked by the National Heart, Lung and Blood Institute to be a training site for programs addressing cardiovascular disease and hypertension, using a model developed in their *Diabetes Initiative* project. Large pharmaceutical companies (e.g., Pfizer) supported their work in projects such as the Alliance for Healthy Borders. With these large grants, they have been able to support personnel

expenses and have the freedom to continually expand to other chronic conditions through pilot projects, such as their project aimed at preventing childhood obesity.

- Community Health Center in Middletown applied for and received several large grants to continue and extend their work. From the Office of Women's Health, they received a grant to use self-management training in an adolescent weight management program. From the Connecticut Health Foundation, they received a grant to explore telephonic disease management. Both of these programs build on and extend their *Diabetes Initiative* work.

Innovative Reimbursement Strategies

- Administrators at Gateway Community Health Center proposed an increase in the charge for patient visits from $12 to $15 and allocation of the $3 per visit to the education and diabetes self-management programs. The proposal was supported by several board members as well as patients.
- Holyoke Health Center worked with new partners to cultivate reimbursement for self-management support. At the time of the surveys for this report, they were in negotiations with:
  - The Senior Care Options program in the Commonwealth Care Alliance Plan to gain reimbursement for all self-management services accessed by seniors. This would include reimbursement for diabetes program services not usually covered by reimbursement, including contact with a *promotora*, attendance at a snack club, participation in an exercise class plus all of the other diabetes program offerings.
  - The pharmacy at Holyoke Health Center to have them stock reimbursable diabetes supplies, such as glucometers, strips and medications and to use some of the diabetes self-management program staff as part time pharmacy workers.
  - The Bureau of Primary Care and *Health Care for All* to try to get reimbursement for the Chronic Disease Self-Management Program.
  - Blue Cross Blue Shield to broaden reimbursement guidelines.

C. Threats to Sustainability

Grantees identified several potential threats to being able to sustain all or parts of their programs. These included:

1) Time and effort to maintain effective partnerships

Bringing partners to the table early was recognized as critical to program effectiveness and sustainability, but making the time to nurture those relationships and sustain meaningful levels of communications proved challenging:

- Two programs (Holyoke and Gateway Health Centers) cited the need to keep providers and administrators within their organization aware of program offerings and successes. They reported

that without continued program staff efforts, busy clinical providers and administrators tended to revert to pre-program practices.

- Two other programs (MaineGeneral Health and Minneapolis American Indian Center) cited the need to find ways to continue to support volunteer efforts. MaineGeneral approached this by decentralizing staff support of volunteers, shifting responsibility for this to Healthy Maine Partnerships. The Minneapolis project reported the need to continue to engage their Diabetes Community Council in organizational planning.
- Other programs cited the need to continue efforts to nurture collaborative, mutually advantageous relationships with outside partner organizations. A good example is the experience of *Campesinos Sin Fronteras* (CSF) with their main collaborator, the Sunset Clinic. CSF reported that maintaining this relationship was not difficult, but that they had to be proactive. For example, when CSF applied for a grant from the Office of Minority Health and asked Sunset for a letter of support, they learned that Sunset was planning to apply for the same grant, but without CSF as a collaborator. After a meeting between the two agencies, Sunset agreed that CSF had the best chance of getting the grant, joined the CSF effort and dropped plans for their independent submission.

2) Staff turnover

Maintaining core staff for in a program is important for the development of team capacity and program efficiency; stability also promotes continuation of successful programs. However, staff retention can be challenging. Grantees commented as follows:

- *Retention of program staff whose services may not be reimbursable is difficult when grant funding runs out. Positions like case manager, coordinator, lifestyle coach or promotoras are often lost when funding runs out.*
- *Loss of primary care providers presents a challenge to sustainability. New providers are often not familiar with diabetes self-management models and, therefore, must be trained in that approach if program activities and services are to continue. This frequently requires time-consuming commitment from existing staff to gain buy-in from the new providers.*
- *Decreasing turnover of volunteer staff is a continual challenge. In addition to the usual challenges of keeping volunteers interested, motivated and knowledgeable, programs are faced with dealing with many volunteers who themselves have diabetes. As their disease progresses, they may be less able to continue their volunteer work.*

3) Need for continual grant writing

Several grantees expressed frustration with having to continually apply for new grants to keep their programs operational.

- Minneapolis American Indian Center and Open Door Health Center have taken a patchwork approach to grant writing, looking for available funds and trying to find ways to get grants that support parts of their programs.
- The staff at Gateway Community Health Center report that they have found it difficult to look for new funding while trying to keep up the momentum of their programs with providers and administrators.
- The issues are a little more complex for *La Clinica de La Raza* in Oakland. Their need for continued funding for their *promotora* programs is complicated by issues related to immigration. It is further complicated by the fact that grant writing is done agency wide by the planning department, not necessarily specifically for diabetes.
- *Campesinos Sin Fronteras* only employs *promotoras* whose immigration status is clear and has been able to gain ongoing funding for their salaries from the Area Agency on Aging. But this funding is not specifically for diabetes programs, so there is a need to write grants for project-specific activities.
- Similarly, Holyoke has been able to gain ongoing funding for staff salaries through a health disparities grant from Blue Cross Blue Shield. Other funding comes and goes with varying regularity and, therefore, affects the ability to provide consistent programming.

4) Thinking about sustainability too late

Several grantees expressed regret that they had not seriously considered issues related to sustainability earlier in the grant cycle.

- MaineGeneral Health encountered difficulty gaining support for the Movers program after it was well established. Initially, stakeholders were interested in being part of the planning process in order to tailor development of the program to their specific interests. The business community and local supermarkets were identified as potential stakeholders who should have been involved from the start of the project.
- Gateway Community Health Center reported that at the beginning of the program, they were too busy thinking about how to make the program work that they neglected to consider how it would be sustained. Success of their program quickly created excitement that made organizers forget that the grant money was not going to last forever. Although they were able to sustain most of their successful program, they reported encountering more difficulty than anticipated because of their lack of foresight.
- Ongoing program evaluation would have given Richland County Health Network the information necessary to determine which program elements warranted sustaining. By not thinking from a sustainability perspective soon enough, they continued unsuccessful programs too long and had less time and information from which to develop sustainability strategies.
- Community Health Center in Middletown expressed regret that they had not done a good enough job of collecting pre- and post-intervention data to demonstrate the clinical effectiveness of the program. Because the data collection process was not careful and systematic, they were not able to prove how much was accomplished.

D. Critical Success Factors

Despite programs having different components and different strategies for sustaining all or parts of their programs, two factors emerged as critical to successful sustainability. Consistent with factors commonly cited in the literature as being important for sustaining health programs, the key ingredients identified by the *Diabetes Initiative* grantees included having data to support the work and the passion to carry it out. Examples of how these factors promoted sustainability are detailed below.

1) Data to support work

Grantees reported that many different kinds of data can be useful in promoting acceptance and demand for self-management services. For example:

- Based on outcome data from a telephonic diabetes self-management program, MaineGeneral Health was able to get reimbursement for their services from employers who were self insured.
- Data collected over the four years of the Gateway Community Health Center project gave providers the kinds of numbers necessary to demonstrate overall improvement in patient outcomes for those who worked with *promotoras.*
- Clinical and program data demonstrating success of the program at Holyoke Health Center resulted in buy-in from administrators who then made continued efforts to sustain it.
- *Campesinos Sin Fronteras* made evaluation a continual process and, as a result, have been able to make regular changes to improve programs.

2) Passion

There was universal agreement among *Diabetes Initiative* grantees that among the most critical ingredients in building a sustainable diabetes self-management program is passion – dedication and enthusiasm and for the work. An example mentioned frequently was the work of community health workers/ *promotoras* who routinely worked above and beyond expectations, regardless of compensation. No less important is the passion of program leaders, providers and staff who were committed to achieving excellence in providing self-management supports. Grantees observed that their enthusiasm helped them connect with the people they served, which in turned created more successful and satisfying results.

Lessons Learned and Implications for Practice

The reflections of the *Diabetes Initiative* grantees include the wisdom of early planning and also bring attention to the natural tension between developing quality programs and services and planning for sustainability at the same time. Improving support for self management and quality diabetes care clearly follows a developmental path; sufficient time is required to move from the initial planning phases to having program results of sufficient import that warrant sustaining and sharing. On the other hand, this report suggests that there are key strategies that, if considered early on, could increase the likelihood of program sustainability. An implication of this report, then, is that the *processes* of planning and building programs for sustainability are at least as important as having effective programs and services to sustain.

Grantee staff also spoke to the critical role of collecting and using data. Often, grantees are required to collect data as a condition of funding; yet the experience of the *Diabetes Initiative* was that few sites had been in the practice of using their data to evaluate the impact of changes in patient services or systems of service delivery. This suggests that it is critical to build capacity among grantee staff for using data to improve quality and measure effectiveness of their services. Indeed, this skill is as important as data collection itself. Programs will likely be stronger as a result, and the increased skill among staff may benefit future programs as well.

Finally, it was clear from the comments of the respondents that getting more money was not in and of itself the only mechanism for sustainability. These projects demonstrated creative and practical ways to create synergy with other programs and services, create interest in and demand for their services, and build strategic relationships – all to the benefit of the people they serve.

The difficulties posed by limited financial resources, demands on time, and staff turnover are reminders that providing quality care and self-management support is still a challenge. The ingenuity and determination of program leaders to gain support for sustaining key intervention components is remarkable. However, the value such programs may contribute to health and management of diseases such as diabetes will not be realized until they are incorporated and supported as core components of health care. We hope that the experience of the *Diabetes Initiative* will be useful to funders, program administrators and practitioners and that it will help stimulate strategies and successful advocacy for ensuring that such quality programs and services are indeed supported and sustained.

For more information on all aspects of the *Diabetes Initiative* programs, please see http://diabetesinitiative.org.