Bringing Lessons Home: Bristol-Myers Squibb Foundation's *Together on Diabetes*™ Initiative

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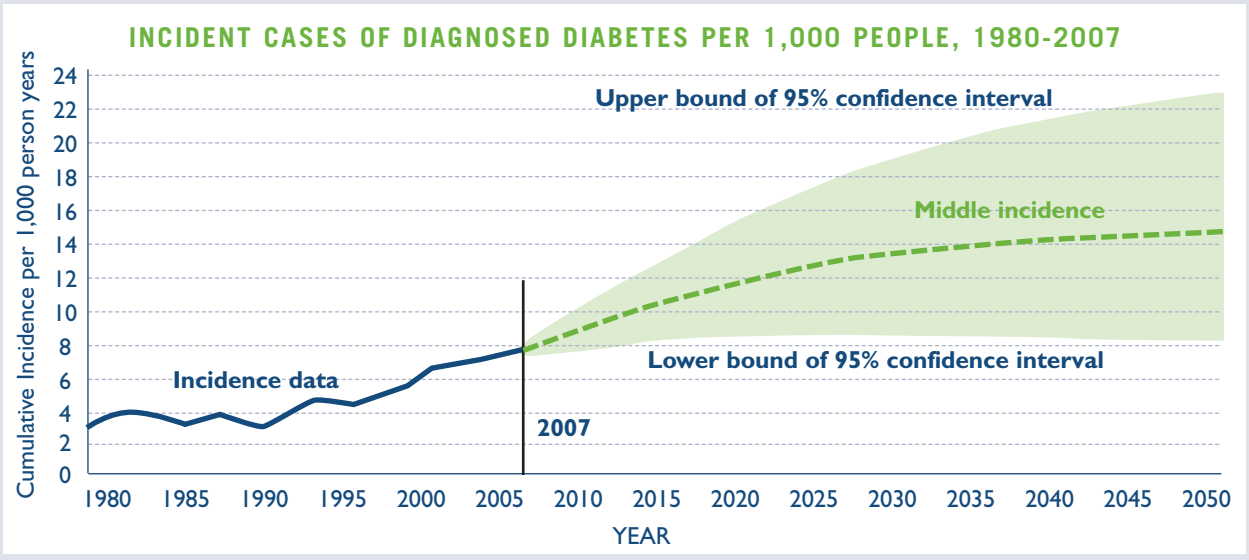
The mission of the Bristol-Myers Squibb Foundation (BMSF) is to promote health equity and improve the health outcomes of populations around the world who are disproportionately affected by serious diseases and conditions. In November 2010 BMSF launched the $100 million, five-year *Together on Diabetes*™-U.S. (TOD) initiative to address the type 2 diabetes epidemic in the United States. In designing TOD, the foundation was challenged by its board to draw upon lessons learned from more than a decade of partnerships and programming and through investments of over $160 million toward *Secure the Future*® (STF), an initiative addressing the HIV/AIDS crisis in Sub-Saharan Africa, and apply them to the new initiative.

This commentary shares the story of how the strategy, focus areas, and grantmaking approach of the TOD initiative were developed and implemented to-date and how the STF experience and learnings helped inform those decisions and actions.

THE NEED: THE TYPE 2 DIABETES EPIDEMIC AND HEALTH INEQUITIES IN THE UNITED STATES

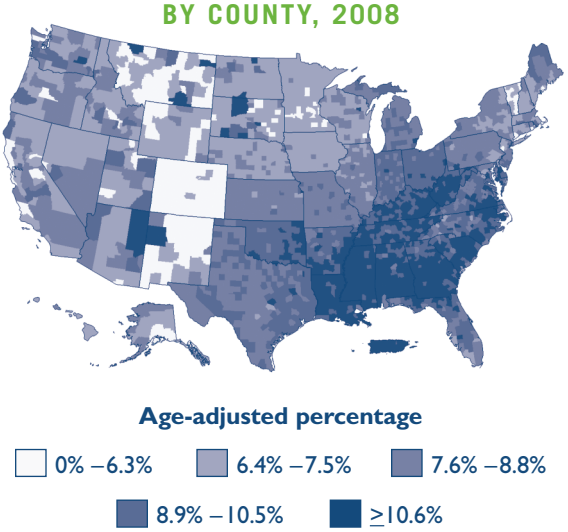
Type 2 diabetes is one of the most serious public health problems facing the United States, and it is one that is getting worse from year to year. According to the Centers for Disease Control and Prevention (CDC), about 25.8 million Americans—or 8.3 percent of the population—are living with diabetes. Of these, 18.8 million people know they have diabetes; the other 7 million have yet to be diagnosed. Another 79 million Americans, age 20 or older, are prediabetic and at high risk for developing type 2 diabetes in their lifetime. If current trends continue, one in three adults could be living with diabetes by 2050 (Boyle et al. 2010).

From a health disparities perspective, a number of subpopulations, such as racial minorities, the poor, the elderly, and people living in rural areas, bear a disproportionate burden of the disease. For example, diabetes prevalence rates are higher among racial minorities: 18.7 percent of African Americans, 16.1 percent of American Indian/Alaska Natives (with some tribal communities in Arizona as high as 33.5 percent), and 11.8 of Hispanic/Latino Americans over age 20 are living with diabetes (CDC 2011; IHS 2012). Among seniors over 65 years old, 27 percent have diabetes. Rates of gestational diabetes range from 2 to 10 percent of pregnancies, and women who have had gestational diabetes are at high risk of up to 60 percent for developing diabetes in the



Source: Boyle et al. 2010

PERCENTAGE OF U.S. ADULTS AGED ≥20 YEARS WITH DIAGNOSED DIABETES, BY COUNTY, 2008



Source: CDC 2012

next 10 to 20 years. Their children are also at higher lifetime risk of developing diabetes (NIDDK 2011). Prevalence in the "diabetes belt," identified by the CDC, in the southeastern part of the country is 11.7 percent (Barker et al. 2011). In the Appalachian region's most economically distressed counties, prevalence is 13.1 percent.

Compounding the disparities in prevalence are disparities in access to the services and supports needed for successful and sustained control of diabetes. These disparities, in turn, contribute significantly to poor health outcomes and shortened life expectancy. The graph from the 2011 *National Healthcare Disparities Report* shows that the proportion of people ages 40 to 46 diagnosed with diabetes who accessed four annual services recommended by the American Diabetes Association was significantly lower for poor to middle-income individuals, non-Hispanic blacks, and those without at least some college education compared to their respective comparison groups.

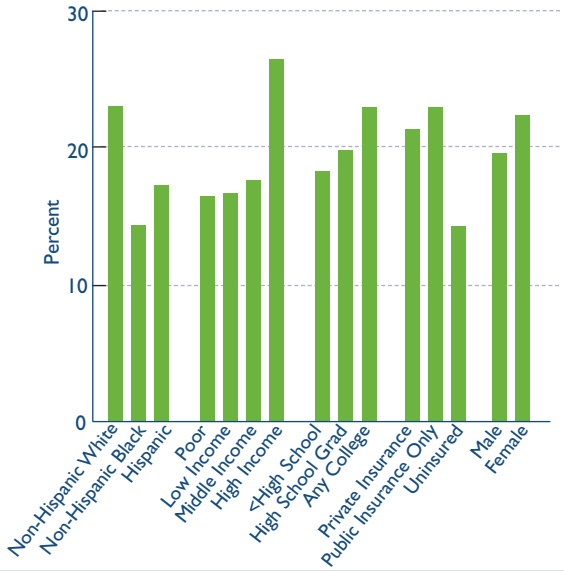
Similarly, a study of Medicaid insured and uninsured adults showed that neither were accessing the "adequate amount, type, or quality" of Diabetes Self-Management Education needed to control their diabetes successfully over the long term (Shaw et al. 2011). The most recent *National Vital Statistics Report* indicates that when compared to non-Hispanic whites, the death rate from diabetes is twice as high among African Americans with diabetes, 1.3 times as high among Hispanics, and 1.7 times as high among American Indians/Alaska Natives (Kochanek et al. 2011).

MOBILIZING LESSONS ACROSS CONTINENTS TO ADDRESS THE SHARED CHALLENGES OF TWO DIFFERENT EPIDEMICS

Taking lessons learned from projects in countries classified by the United Nations Development Program's Human Development Index as "medium" and "low"—particularly on a development issue like health—and applying them in a country classified as "very high" may seem counterintuitive and play against traditional development aid and philanthropy thinking. BMSF, however, focused on the key commonalities of the HIV/AIDS epidemic in Africa and the type 2 diabetes epidemic in the United States and the insights they provide for mounting an effective response.

HIV/AIDS and type 2 diabetes are both large-scale epidemics that have reached high prevalence in the general population and even higher prevalence and heavier disease burden among at-risk and vulnerable populations like the poor, racial and ethnic minorities, socially excluded persons, and those living in rural areas (USAID 2012; CDC 2011). They are also both preventable and chronic diseases managed through a combination of services that span clinic and community-based settings: routine medical care and monitoring, treatment, daily self-care, and behavior change to reduce the risks of disease progression and complications, enhance quality of life, and extend life expectancy. Both have also been

ADJUSTED PERCENTAGES OF PEOPLE AGES 40 TO 46 DIAGNOSED WITH DIABETES WHO RECEIVED FOUR RECOMMENDED SERVICES ANNUALLY, 2002-2008



Source: AHRQ 2012

described as "social" diseases fueled by poverty, culture, beliefs and attitudes, social structures, and environmental factors that affect the individual's capacity to make healthy choices—if they even have choices available to them or the information to know which choices are healthy to make.

➤ ***Lesson 1: "1/2 Hour" in the Clinic + "23 1/2 Hours" at Home and in the Community*** – One of the major accomplishments of the STF initiative was the development, validation, and dissemination of a "blueprint" called the Community-Based Treatment Support Program (CBTSP) that BMSF; people living with HIV/AIDS; community-based organizations; and the ministries of health of Botswana, Lesotho, Namibia, South Africa, and Swaziland developed to support the equitable and effective rollout of antiretroviral treatment (ART) to large numbers of patients in resource-limited settings. The program was created in response to a common set of challenges raised by national ART programs regarding rollout to resource-limited communities. Many regarded these communities as too challenged by poverty, lack of health care infrastructure, health care worker capacity, food security, unemployment, and high levels of stigma to establish and sustain long-term efficacious treatment. These social determinants of health raised not only issues of equity for heavily impacted, rural, resource-limited communities at risk of delayed access to treatment, but also the need for innovative models and comprehensive action to be developed to ensure that ART could be provided to large numbers of people living with HIV/AIDS in these communities.

At the center of the CBTSP model is the idea that medical care dynamically integrated with community-based supportive services (rather than just a referral system without follow-up or feedback loops) enhances health outcomes and quality of life. In the words of BMSF President John L. Damonti, "The CBTSP model is about integrating the '1/2 hour' of medical treatment that patients receive in the clinic with the '23 1/2 hours' of community-based psychosocial and supportive services that they receive between clinic appointments in their homes and communities in order to achieve better health outcomes." Importantly in this model, clinic and community service providers function as a single team with members participating in regular huddles and case review, and all dedicated to comprehensively serving patients and optimizing their health and quality of life.

The CBTSP model was validated through the evaluation of a five-site demonstration project and a multicenter, prospective, observational cohort study of HIV-infected individuals receiving ART who were provided with community-based supportive services designed to assess key patient outcomes and their determinants in resource-poor, Sub-Saharan African settings (Kabore et al. 2010). The results of the study confirmed "the feasibility of providing decentralized, effective ART for a large number of patients in resource-limited settings and the added value of concomitant community-based supportive care services." With respect to outcomes, the study found that "[p]atients receiving medical care, including ART, who were exposed to concomitant community-based support services, when compared with patients not exposed to those services, reached higher CD4 cell counts and reached them more rapidly (particularly among patients with a baseline CD4 cell count less than 50), demonstrated improved HRQOL [health-related quality of life] indicators, and achieved higher levels of treatment adherence at 12 and 18 months" (Kabore et al. 2010).

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Subsequently, detailed case studies from the sites and an operational roadmap were published in 2008 as the *SECURE THE FUTURE® Manual: Seven Steps to Involve the Community in HIV/AIDS Treatment Support Programmes*. Starting in 2008, clinical and community leaders from the five sites along with other outstanding STF grantees have served as faculty for the STF Technical Assistance Program. This South-South approach dispatches African experts to share their experience and knowledge with other communities in Africa that wish to adapt and implement the CBTSP model.

➤ ***Lesson 2: The Power and Necessity of Community Mobilization*** – From its inception, STF supported and championed the critical role that affected communities themselves can and must play a role in the response to HIV/AIDS. Communities have inherent knowledge and intelligences, strengths, resiliencies, and resources that can be brought to bear on the response. And given the scale of the disease and its chronic nature, there is no way to achieve spread or sustain progress over the long term without them.

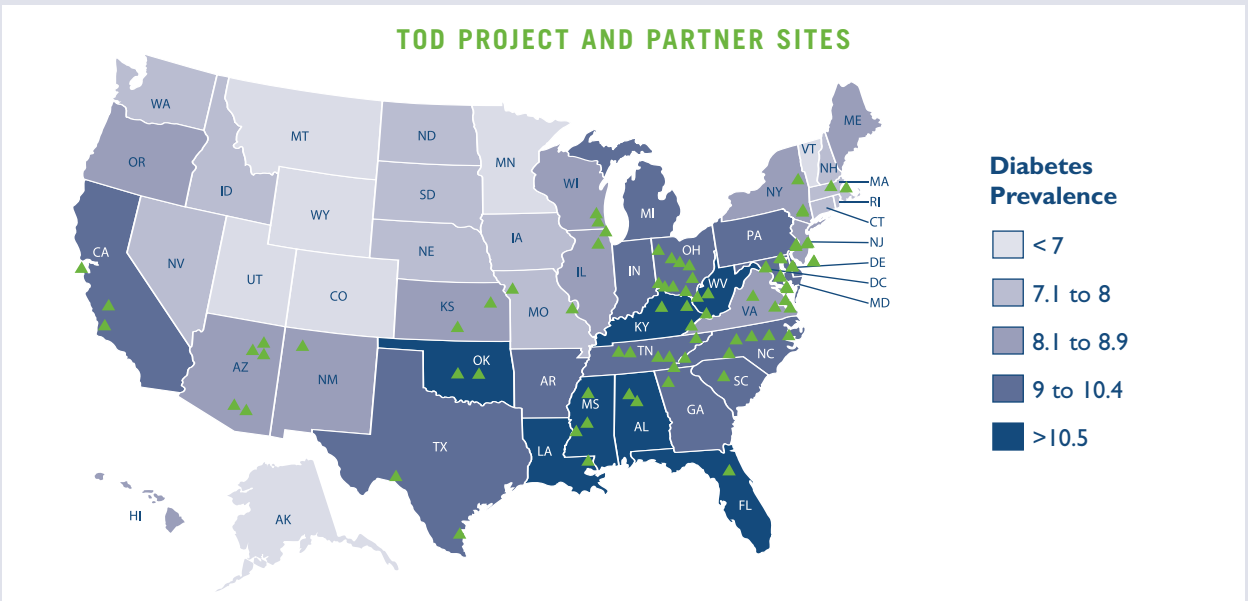
STF engaged communities continually and in a variety of ways. It always started with consultations with community leadership and taking in their concerns about HIV/AIDS, the impact it was having on their people and community, what was working, what was not working, where the gaps were, and what strengths and resources had yet to be engaged in the fight. STF then broadly engaged communities in designing projects like the CBTSP, delivering interventions, conducting monitoring and evaluation activities, reviewing and making sense of the data coming in, owning that data, implementing improvements, and conducting advocacy and sustainability efforts. This approach helped STF mitigate "blind spots" that could quickly lead to project failure. It also helped communities mobilize from a broader and more diverse base—now involving "unusual suspects" who previously were neither regarded, nor regarded themselves, as having a useful role to play in the response—and a base that had gained critical capacities as well.

Through many projects, STF witnessed firsthand how important community mobilization is to transforming the attitudes and beliefs that exacerbate the epidemic from health and human rights perspectives. For example, the stigma of having HIV/AIDS isolates even family members from one another. It also keeps many individuals from getting tested and knowing their status, seeking medical care and treatment, and staying in care. As part of the launch of community-based antiretroviral programs, large community events and door-to-door educational campaigns were held to share information about transmission and prevention, the process of getting treatment, and the health benefits of treatment. These efforts were well received by communities and smoothed the path to treatment, care, and support for people living with HIV/AIDS.

TOGETHER ON DIABETES U.S. TAKES SHAPE

With powerful lessons from STF in hand, BMSF started the process of shaping the TOD initiative. We considered the full spectrum of need, from primary prevention to complications caused by type 2 diabetes, and scanned the U.S. environment for major government, private sector, and philanthropic initiatives that focused on improving diabetes outcomes in disparity populations. We quickly noticed that while there were several significant health promotion, environmental, and health education initiatives to strengthen primary prevention at the community level, such as *Let's Move*, CDC Community Transformation Grants, and the CDC/YMCA-USA/UnitedHealthcare Diabetes Prevention Program partnership, there were few significant initiatives to address the needs of people living with diabetes. The response to type 2 diabetes in the United States has been largely a medical response and focused on the "1/2 hour" in the clinic. A public health approach had not been broadly adopted to address the other "23 1/2 hours" in the home and community. This is where BMSF saw it could play a role.

This process helped BMSF narrow the scope of the initiative to the needs of people living with diabetes. The lessons of continuum of care, community-based participatory action,



Source: BMSF 2013

and mobilization from STF and Africa helped BMSF refine our approach. The urgency of the diabetes crisis and the inadequacy of the response to stabilize the effects of the epidemic prompted BMSF to explicitly state its commitment to create an "innovation sandbox" for testing out new ideas, integrating ideas from other diseases and development disciplines, and forging new constellations of partners and public-private partnerships.

TOD projects should be relevant, aligned with, and actively tied into the major quality improvement efforts in health going forward in the country. Whether these efforts are catalyzed by Affordable Care Act implementation, new Healthy People 2020 goals and indicators for the social determinants of health, health care and public health quality organizations, health professional associations, or academia, they are commonly working to transform public health and the health care system from one that is good at providing "sick care" for acute illnesses and conditions to one that is good at providing "well care" and disease management for chronic diseases and conditions. Below is the resulting program statement:

> TOD targets adults living with type 2 diabetes—both diagnosed and undiagnosed—who are disproportionately affected by type 2 diabetes. There are three focal points for funding and partnership:
>
> - Help adults living with type 2 diabetes to better self-manage their disease and navigate care with sustained and relevant support for the course of their disease journey.
> - Help communities build, integrate, and coordinate medical, nonmedical, and policy efforts, and expand the base of community organizations actively involved in and bringing their know-how, reach, influence, and assets to the fight against type 2 diabetes.
> - Foster a radical rethink and test new ideas about how diabetes control efforts are approached, designed, implemented, and measured given the current and future scale of the epidemic and the long duration of the disease journey.

Now just over two years into this initiative, BMSF has committed $43.2 million in grants to 21 lead organizations (with numerous community-based partners) working in 28 states and over 55 communities across the country.

Looking at current grants and partnerships, they can be put in three groups for the strategies they are applying to the focal points. One set targets the highest risk and most heavily burdened populations like African-American women, American Indians, and Appalachian people. A second group is forging new partnerships to bring evidence-based practices like the Stanford Diabetes Self-Management Program and the Ashville pharmacist coach model to disparity populations. The third group is undertaking large, multi-component, community-wide demonstration projects and outcomes research and attempting to bend the curve of the diabetes burden at the population level.

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As TOD got up and running and the work of the grantees progressed, BMSF saw the need to forge partnerships with a number of organizations that provide support to grantees in order to optimize the impact of their projects and of the overall initiative. The National Network of Public Health Institutes facilitates the TOD learning community and annual grantee summit. The University of Kansas Work Group for Community Health and Development provides monitoring and evaluation and quality improvement support. And Harvard Law School Center for Health Law and Policy Innovation supports grantee advocacy efforts and provides state and federal policy analysis and recommendations.

As initial results and lessons come in from the projects, it is clear that these grants are challenging and expanding current thinking and laying important groundwork for a more comprehensive and effective diabetes response going forward. With the expansion of the TOD initiative in May 2012 with additional funding of $15 million to China and India, TOD is now working in the three countries that have the most people living with diabetes worldwide. It also has another opportunity to bring lessons home and send lessons abroad that meet the shared challenges of diabetes facing affected individuals, families, and communities around the globe.

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