



The Campaign for Better Care: Summary Evaluation Findings

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In 2012, Atlantic Philanthropies funded a major initiative entitled, “Campaign for Better Care” (CBC) with the aim of engaging consumers – patients and their families – to participate actively in the formulation and implementation of systemic changes in health care delivery and financing to improve health and health care for vulnerable populations at the national, state and local levels. To achieve these goals, the CBC funded three national organizations, Community Catalyst (CC), National Partnership for Women and Families (NPWF), and PICO, to design and test models of consumer engagement in institutional decision-making. Through this initiative, the CBC sought to ensure the inclusion of the voices and perspectives of vulnerable populations and their families, to ensure that health care reflects and meets patient needs.

Evaluation

As part of the initiative, Atlantic Philanthropies commissioned an evaluation of the effort. Its purpose was to describe grantees’ approaches to consumer engagement, measure short (and possibly intermediate) term outcomes for the CBC initiative overall and for individual grantees, and identify lessons learned from the grantees’ experiences for expanding and/or replicating effective approaches to engaging consumers in health system reform. The evaluation utilized several qualitative data collection methods (key informant interviews, focus groups, record review, and observation). This brief presents summary findings from the evaluation.

The CBC Advocacy Organizations

The three CBC organizations, CC, NPWF, and PICO, were selected because of their extensive experience and expertise working to improve health and health care for vulnerable populations. All three have a presence in Washington, DC and each played a significant role in the passage of the ACA, as well as ensuring inclusion of language that ensures a major role for consumers in its implementation. As skilled advocates,

community and coalition organizers, and technical consultants on programs, policy, health care financing and delivery, each has also achieved success in supporting consumers engage in decision-making at the state and local levels.

The roots of the organizations are diverse. Founded in 1988, Community Catalyst focuses on expanding health care access and coverage and improving quality; “holding health care institutions and corporations accountable to the public interest;” and spurring community action to address social, economic, and other factors that affect the health of communities. CC carries out its work through a nationwide network of local and state health advocacy organizations and coalitions through which it shares its expertise via technical assistance, creating learning communities, and providing resources, relationships, strategies, and information to strengthen those advocacy organizations and coalitions. National Partnership for Women and Families, based in Washington DC, advocates at the federal level for policies and laws that help women and families and supports effective implementation of these policies at local and state levels through technical assistance, consultation, and learning communities. Substantively, NPWF works on a wide variety of social, economic, and health issues, including ensuring income fairness in the workplace, reproductive health and rights, access to quality, affordable health care, and policies that help women, partners, and their families meet the dual demands of work and family. PICO is the oldest of the three organizations having been founded in 1972. PICO utilizes faith-based community organizing to address multiple problems and concerns within congregations and communities based on shared values, such as access to health care, improving public schools, making neighborhoods safer, building affordable housing, redeveloping communities and revitalizing democracy. PICO has 44 affiliated and 8 statewide networks in 150 cities and 17 states.

CBC Grantee Approaches to Consumer Engagement

Within the context of the CBC, the three grantees were unified in the shared goal of transforming the health care system to better meet the needs of vulnerable populations by ensuring the genuine involvement of consumers/patients in decision-making. That said, the arenas in which they targeted consumer involvement (e.g.,

medical practices, health care systems, legislatures and regulatory bodies), their advocacy styles and strategies for achieving consumer engagement, and to some degree, their target populations, varied considerably.

Community Catalyst sought the implementation of federal policies affecting “dual eligibles” (persons enrolled in Medicare and Medicaid) by working with state level advocates to influence the implementation of the Centers for Medicare and Medicaid Services (CMS) State Demonstrations to Integrate Care for Dual Eligible Individuals. CC functioned partially as a funder, re-granting foundation funds to state-based advocacy organizations to support their advocacy efforts around the Medicare-Medicaid demonstration projects, as well as to provide training and technical assistance to those state-based organizations. Among the central functions of the state- and local-level advocates was to gather stories from consumers about their experiences under the new policy. This feedback helped identify unanticipated challenges and shape both policy recommendations at the federal and state levels and the content of technical assistance to state and local advocates.

For example, consumers in several states reported that they were unaware of the pending “merger” of Medicare and Medicaid and had no notion of how it might affect their care. Armed with this information, CC and its partners conveyed it to state administrators, many of whom believed they had already adequately communicated the upcoming changes. Subsequently, additional efforts were made to inform consumers – sometimes by the states and sometimes by the advocates – presenting details and implications for relationships with existing providers and how consumers could proactively plan for the changes. CC and their state partners also broadly disseminated information to consumers about their rights under the new program and the recourse available if their rights were violated. In other states, the limited comprehension about the changes among both consumers and providers was so alarming that CC and its partners sought delays in the implementation to allow for better preparation before launch. The lessons learned from the advocacy efforts in their CBC states were also shared with advocates around the country through webinars and tool kits. These

lessons also supported CC's on-going efforts to incorporate consumer interest advocacy at the federal level as the demonstrations were refined.

National Partnership for Women and Families' work under the CBC involved supporting the implementation of consumer engagement provisions in new models of care delivery and quality improvement being tested by the CMS Innovation Center (CMMI). In this vein, NPWF operated as a direct resource to providers (medical practices, hospitals and health systems) attempting to implement patient-centered practices. Funding for these technical assistance services was primarily derived from the Atlantic grant, enabling sites to access information and support to help comply with federal requirements. Three federal demonstration projects were the focus: the Comprehensive Primary Care Initiative (CPCI), aimed at improving primary care practices; the Partnership for Patients (PfP), aimed at improving hospitals; and the Pioneer Accountable Care Organizations (ACOs) health care plans. NPWF provided targeted technical assistance around the country with the aims of helping to produce better results in the demonstrations, as well as to identify best practices in adopting the new delivery and quality improvement models.

Over the course of the CBC, NPWF worked directly with many of the 500-plus primary care practices implementing the CPCI, either through the direct provision of outreach technical assistance, or through responsive "office hours" tailored to questions that individual sites raised as they faced new challenges of implementing substantial system change informed by consumers' voices. This included support for the formation and operationalization of 230 Patient and Family Advisory Councils (PFACs) in 13 states that led to improvements such as expanded hours of operation for phone services so patients could reach their doctors' office during the lunch hour, routinizing discussions by health providers about the importance of advanced directives and allowing families to be present during shift changes to help with the hand-off of vital information from shift to shift. From that experience, NPWF developed additional national webinars and resource materials to support broader adoption, reaching some 3,732 organizations.

In contrast to state and federal focuses, PICO sought to empower consumers at the local level to become involved in collective action targeting health and health care issues prioritized by the consumers. Under the CBC, PICO was initially poised to replicate the Camden, New Jersey “Hot Spot” program in four communities around the country. The Hot Spot model is a systematic approach to identifying and supporting “super utilizers” of inpatient and emergency room services with comprehensive medical care, care management, and social services to address underlying issues that contribute to high utilization of services. PICO’s particular role was to invite Hot Spot participants to join area residents to address shared issues, such as environmental concerns, problems of access to care, and poor housing. By addressing these community-wide issues that affected health, PICO sought to support eradication of the causes of the super-utilization at the community level. PICO applied its unique model of organizing, which involves supporting communities to identify collective concerns and potential solutions, and methodically work towards adoption of that solution.

In each of the PICO CBC communities, community advocates determined that poor transportation services for Medicaid patients were both a significant barrier to access to care and an issue that community members could influence. PICO, with the involvement of community members, advocated for changes within state Medicaid agencies regarding contracting rules with transportation vendors. Though significant challenges stymied the Hot Spot replication efforts (e.g., providers in some communities resisted sharing patient data with PICO, making it virtually impossible to coordinate patient care and organizing activities), several incremental changes were advanced. For example, some of the PICO CBC communities were successful in moving state Medicaid agencies to introduce more transparency into the contracting process. Similarly, where less concrete progress was made, previously isolated individuals came together with greater common purpose, setting the scene for collective work in the future.

Lessons Learned

Though the three CBC organizations utilize different strategies and tactics, they shared a common goal of transforming the health care system to better address the needs of underserved populations by ensuring that those very populations have a voice in shaping the delivery of health care. Through their efforts under the umbrella of the CBC, important lessons for consumer engagement were learned.

- Consumer engagement is always challenging, especially with populations targeted for this initiative. Organizing and strengthening consumers as advocates in the health care arena is almost always difficult reflecting power dynamics typically skewed in favor of providers and payers as the principal decision makers concerning service selection and delivery. Efforts to engage low income adults, dual eligible people and other vulnerable populations can be especially difficult as they tend to face multiple health issues, social isolation, and the added daily demands associated with limited incomes. Some of these challenges relate to their complex health conditions which can limit mobility and/or require constant attention. Other challenges can relate to socioeconomic status which can produce special demands on time and resources simply to meet day-to-day needs of food and shelter on top of health care needs. When combined, these circumstances too often overwhelm one's interest and ability to participate in efforts to reform programs and policy. PICO, for example, discovered that its initial plan to recruit patients for the organizing efforts in the early days and weeks of the program were not successful because the patients were focused on addressing their health and social needs with the Hot Spot teams. PICO adjusted their intervention, introducing the organizing opportunities after individuals had graduated from the training program when their health and circumstances had stabilized and when they were less likely to be distracted by the day-to-day challenges.
- Keeping consumers engaged in campaigns around policy change can be especially difficult. Not only do consumers within the grantees' target populations

face multiple demands on their time and attention, but sustaining engagement when the work can seem abstract and often slows in the face of structural resistance, requires understanding, patience, and creativity from organizers. Given that the fruits of their labors may not be immediately felt. Hopes for quick results must be balanced to promote positive expectations while avoiding disappointment. Some organizations address this issue by identifying shorter-term milestones that represent progress towards the larger policy goal as motivation to maintain interest in the work. In the case of PFACs whose members typically serve terms of two to four years, NPWF recommended that PFACs be encouraged to identify some projects that can be accomplished in a short period of time, along with projects that require more time, along with keeping an eye towards recruitment of new members should anyone drop out.

- Organizational support is key to initial and on-going consumer engagement, yet resources to carry out the work are limited. As indicated, consumer engagement efforts like those under the CBC umbrella depend on two especially fragile and elusive conditions: the engagement of vulnerable populations which tend to face even more competing demands on their time and attention than consumers in general face, and the involvement of those consumers in health care transformation projects which typically require local or system-wide policy changes. Bringing consumers fully into the process is an enormous undertaking, providing training and support, helping guide consumers to specific roles for which they are best suited to succeed, and keeping them engaged. Consumer-empowering organizations need the resources to do this work, even though few traditional funders provide financial support for such activities. In this manner, Atlantic Philanthropies played a key role during the funding of this initiative to provide the necessary infrastructure to advance the agenda of meaningful consumer engagement.
- To make the case for consumer involvement policies and resources, a more compelling evidence-based case is needed. Most providers and other health care

decision-makers have yet to be convinced that the consumer voice is of value to them and so are, at best, reluctant “partners.” Increasingly, providers and funders involved in health care decision making are on board with the concept of shared decision making around individual clinical care. However, far fewer who are in these roles are persuaded of the value of the consumer voice in decisions related to health care delivery at the practice, health plan, or health system levels. Often, they see it as far more efficient and efficacious to make decisions within traditional circles of power and professionalism. Policymakers and administrators may similarly believe that the decisions they tackle are too complex for consumers to offer valuable input. Unambiguous data is needed to build the case. While there is mounting evidence of the value of patient-centered care on some health outcomes, the literature is less well developed in terms of the impact of involving consumers in decisions that have traditionally been the purview of professionals (i.e., how medical practices, hospitals and health systems are organized; how services are delivered; what health plans cover). In time, evidence concerning any added value of consumer engagement is expected from assessments of current pilots, largely funded by CMS/CMMI. Meanwhile, advocates face a major challenge in bringing willing providers and other policy-level decision makers to the table, given the relatively modest outcome measures available exploring the links between consumer engagement and health.

- Developmentally sequenced steps may be needed to facilitate progress in individual sites, requiring a specific and tailored set of "tools" to accommodate to local needs and context. While trainings and education regarding the concepts of consumer engagement can occur at a global level, operationalizing what specific elements can be implemented, by whom, and by what specific timeline requires ongoing fine tuning in light of more immediate history and conditions. Technical assistance and other support has to be balanced with the "readiness" of the local site to move forward with the consumer agenda. This requires training and support of different levels of local policy makers, from the CEO of a hospital to a

local nurse supervisor, and tailoring support to meet the unique needs of the “client” as well as demonstrating an understanding of the other pressing demands upon each of the systems. While this level of intensity is not viable for all sites, having concrete examples of success helps to build the level of momentum for future success.

Conclusion

Though their specific approaches varied, the three CBC organizations served as important catalysts within the communities they worked, projecting considerable advocacy, policy and organizing expertise and experience, while enlisting other local organizations as partners. Through this grant, Atlantic Philanthropies provided these national organizations, as well as other individuals and organizations around the country an invaluable opportunity to pursue their longer-term plans via specific activities that reflect their philosophies and strengths. At the same time, the national-local partnerships made a variety of incremental steps toward greater consumer input in a selection of community health care reform efforts.