



The Path to a People-Centered Health System

Next Generation Consumer Health Advocacy

EXECUTIVE SUMMARY

January 2015



COMMUNITY CATALYST

Because we all should have a say in decisions that affect our health

Executive Summary

BACKGROUND

Despite its challenges and flaws, the Affordable Care Act (ACA) represents a monumental leap forward in access to health coverage and care for millions of Americans. But, while consumer advocates continue the important work of ensuring full implementation of that law, they must also now pivot to a significant and growing challenge: the rapid transformation already underway in our health care financing and delivery system.

The impetus for health system transformation, from our perspective, is two-fold. First, our current levels of health spending pose a threat to the sustainability of the ACA and Medicare and Medicaid. We spend almost twice as much per capita on health care than any other western democracy. Second, our health status and outcomes are generally poorer than those of our peer nations despite all of this spending. Our system is notable not only for its excessive prices but also for its variable quality, inefficiency, fragmentation, health inequities and lack of people-centeredness. Quite simply, we are not getting enough “bang for our buck.”

There is general agreement that the status quo is not acceptable, but there is a concern among consumer advocates and their allies that the proposed “fixes” will focus primarily on the spending aspect. They fear it will be easier for policymakers and others – both conceptually and in practice – to shift costs to consumers through higher premiums and co-pays, benefit cutbacks and reduced eligibility. To counter these negative approaches and promote those that will actually benefit consumers, advocates must become fully engaged in this work – and do so very quickly.

The ultimate goal for all stakeholders should be a health care system that operates effectively and efficiently to ensure all people get the care they need and that invests in keeping them healthy. Closing the gap between the current system and this goal will require a fundamental alteration of the way health care is currently financed and delivered. It will also compel re-thinking how we define health and the factors that influence it, with particular attention to the disproportionate impact those factors have on certain groups. Most importantly though, it will require creating a system that incorporates structures – at all levels – that enable consumers to highlight problematic health care delivery and financing experiences and that can act on systemic issues revealed through those experiences.

As with any paradigm shift, this will be no quick and easy task. Educating consumers about how the system could better meet their needs is a key aspect. Mobilizing public support will likely be hampered by the number and complexity of issues to be addressed. Industry stakeholder and interest group dynamics – including dynamics within the advocacy communities – will also be complicated, not least because there will be economic and policy winners and losers. And overlaying it all are the politics. The partisan fights around solutions – driven by both ideology and money – will likely persist, creating impediments to federal and state government testing of new models and approaches.

Are consumers and their advocates up to the task? History suggests they are, but they will need significant support to take on this challenge. Even though they are at the center of the health system, consumers have been the least empowered of all stakeholders. The government, in its payer role, wields tremendous power, but so do the many well-financed industry groups that use

their resources to protect and expand their own turf. Nevertheless, consumers and their advocates have been key participants in successful federal and state health access and coverage initiatives for decades. There is also a long tradition of consumer involvement in altering certain structural and care delivery aspects of the health system over the same period. Advocates for women's health, HIV/AIDS activists, and parents of children with special needs have fought – and won – battles at both the policy and system levels to improve the approach to and quality of care for these populations.

In this new phase of work, advocates – and consumers – must be prepared to operate on three levels:

- **Policy advocacy:** Many of the transformation-related proposals will arise in the federal and state policy arenas. Medicare, Medicaid, and federal and state budgets, will likely be principal vehicles for such activity, but policy issues may also arise in local government contexts. Indeed, this community level may well be where many of the upstream factors that affect health are best addressed. Advocates will have to operate within both legislative and executive branches at all levels.
- **System-level advocacy:** Many transformation-related activities will occur at the implementation/operational level, i.e., within the hospital systems, health plans, Accountable Care Organizations, etc. Therefore, consumers and their advocates must be able to engage with the delivery system itself. This is necessary to ensure that providers and health plans operate in ways that place priority on the needs of consumers relative to those of other stakeholders, and also to ensure that system players contribute to population and community health.
- **Individual-level advocacy:** Consumers must also, where possible, become active, engaged and knowledgeable participants in their own health and health care, and advocates must promote changes that facilitate such participation. Consumers will need quality information and support from policymakers and the health system that enables them to build their understanding of health system transformation issues and make sound and informed choices on their health and health care options. There is a growing body of evidence which demonstrates that patients who are more engaged in their own health care have better health outcomes and care experiences. Consumers must also be prepared to share the consumer/patient experience within the permanent structures we envision to ensure that “course corrections” are directly responsive to consumer experiences – whether positive or problematic.

KEY OBSERVATIONS

We wanted to understand what kinds of challenges consumer advocates will face as they become more fully engaged in this new phase of work, and what types of support will maximize their effectiveness. To do this, we consulted with consumer advocates from more than 40 states and a diverse group of other system stakeholders. Key observations are:

- While there is consensus on the general direction for health system transformation, i.e., pay for value, people-centered, etc., there is little clarity as to what that means in practice or how to achieve it.

- Consumer advocates are already engaging on some transformation-related issues, and, at least with respect to health equity topics (e.g., language access, cultural competency and data collection), are often leading the work in their respective states.
- Building and sustaining effective coalitions is expected to be a challenge. Compared to access campaigns, advocates see health system transformation as a broad, diffuse and often technical topic. Moreover, the “wins” aren’t clearly defined or immediately evident. There may also be reluctance on the part of some key partner and ally organizations and constituencies to support certain common features of delivery system change because of funder relationships or unique constituency needs or preferences.
- Consumer advocates need help building their capacity to conduct legal and policy research and analysis on complex financing and delivery system issues. They also cite an urgent need for assistance and/or tools to help them assess their political and market environments, identify openings for action, understand and prioritize the various “handles/levers” for health system transformation and set realistic priorities for transformation-related work. Assistance must be tailored to the particular political, policy and delivery system environment.
- Building a grassroots base of support and developing new consumer leaders may also be a challenge. Understanding what individuals and families experience in the health system is key to establishing a consumer agenda. Ensuring there are mechanisms in place to capture these experiences is critical. Additionally, providing coaching and support to prepare consumers to play meaningful roles on boards, councils and advisory committees will require new resources.
- Consumer advocates anticipate needing advice and support to develop effective working relationships with other system stakeholders. In contrast to coverage campaigns, there may be fewer points of intersection between consumer interests and those of other key players, but these relationships are viewed as critical to advocates’ success because consumers can’t reshape the system on their own.
- Advocates need resources – at least initially – to address these challenges. While many see the potential to institutionalize support for consumer assistance and participation in the future, effective engagement now will require an investment in capacity strengthening.

RECOMMENDATIONS

Health system transformation is a long-term undertaking, and the needs of consumers and their advocates may shift over time. What we offer here are the building blocks for a durable foundation that will serve this work both now and into the future.

Recommendation 1: Articulate a proactive vision and framework for a transformed health system. An initial task for consumer advocates is to articulate a positive, unified vision of what health system transformation would look like. National groups must come together, along with state and local community advocates, to shape that vision, which will serve as the basis for development of federal, state and local agendas.

Recommendation 2: Strengthen and expand coalition building at the state and local levels.

Although federal law and regulations set parameters for many of the changes underway, much of the development and implementation of new models occurs at the state, local and institutional level. A shared vision and strategy that is responsive to each state's local market and policy dynamics will be critical to developing an effective consumer voice to shape the changes underway. State advocates should consider establishing a table of consumer groups around the vision of transformation, seeking agreement on a basic framework, with transparency and thoughtful exchange about specific differences. There should be focused outreach to those groups that represent or work with vulnerable populations, and to advocates that work on "upstream" issues, such as housing, community planning and youth development.

Recommendation 3: Build policy and delivery system expertise. Consumer advocates face a significant learning curve with regard to transformation-related policy content, both in terms of the breadth of issues involved and the technical depth required. This is further complicated by the significant variation in local health care markets and state health policy environments, so effective policy interventions will vary from place to place. But transformation will also require advocates (and consumers) to engage at the delivery system level, so in addition to building policy knowledge, advocates must also immerse themselves in developing delivery system expertise.

Recommendation 4: Build – or strengthen existing – grassroots engagement and leadership development work. Giving voice to consumer experience and needs is fundamental to the paradigm shift we seek. The capacity to identify problems, analyze individual experiences, find patterns and express ways to improve the system is critical. An initial task will be to elicit consumer concerns and offer opportunities to learn some health system basics. This process will help identify potential public and private policy targets and also serve as an organizing tool.

Recommendation 5: Build – or strengthen existing – stakeholder alliances. Transforming the health system to put the individual patient/family and the community at the center will require new kinds of working relationships with other system stakeholders. Consumer groups by themselves do not have enough power to drive system change, so they will need these alliances. This may range from finding common ground with employers and private payers around a shared interest in reducing low-value care, to working with health plans and providers to design new and more effective ways of both delivering care and supporting people and communities to better manage their own care.

Recommendation 6: Build a communications program for use at all levels of advocacy that generates public support for health system transformation. Framing and communicating health system transformation issues will be a long-term process that starts with building public knowledge and moves to building public and political will for change. It will take an investment in public education to better inform and engage the public in conversations around challenges with the system and potential approaches to addressing them.