



IMPACT!

HOW CONSUMERS HAVE SHAPED HEALTH SYSTEM DELIVERY REFORM

APRIL 2019



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Acknowledgments

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INTRODUCTION

We are at a crossroads in American health care. The significant gains in coverage made under the Affordable Care Act created a solid foundation that have allowed policy makers and stakeholders to pursue changes in the health care system to improve efficiency and person-centeredness in the delivery of care. In this moment of innovation, we have a once-in-a-generation opportunity to reorient the health care system to be more person-centered, but this opportunity will only be successful if we incorporate consumer input into this realignment.

The Center for Consumer Engagement in Health Innovation (the Center) is strongly committed to actively and meaningfully engaging consumers in every aspect of health system transformation. We have long sought to demonstrate that the guiding philosophy of the disability rights movement – “nothing about us, without us” – should be the standard in health system redesign. Advocating for structures for meaningful consumer engagement is the [Center’s top policy priority](#), and this requires consumer engagement at three levels – in the clinical setting, in health care organizations and in policymaking. This paper focuses on the health care organization and policymaking levels, where strong consumer representation is critically important in the governance and quality improvement activities of health care organizations, including health care delivery systems, hospitals, practices and health plans. At the policymaking level, consumers must also have a seat on stakeholder advisory bodies, working groups and in “ad hoc” meetings.

A growing body of evidence suggests that consumer engagement may result in better health outcomes and reduced costs.¹ Given that there is general, at least theoretical, recognition of the importance of meaningful consumer engagement, why doesn’t it happen all of the time? The answer is that it takes time, expertise and resources to make meaningful and sustained consumer engagement work. In particular, consumers with complex health and social needs who seek to participate in a meaningful way on a policymaking body face a set of barriers that stem from a reality that has been historically challenging for hospitals, health plans and state governments to address. Namely, unlike someone participating on an advisory body as *part of their job*, consumers are generally on that same body as *volunteers*. This means they must juggle this volunteer work with managing their own health needs, as well as any employment or family responsibilities without the benefit of a salary or an employer’s support. Consistent participation under these circumstances often requires a heroic effort on the part of the consumer. Given this reality, the barriers that consumers, particularly those with complex health and social needs, face in participating on these types of advisory bodies include:

- **Lack of Institutional Support** – Consumers often need help with transportation to get to meetings, child care and a stipend for their time.
- **Inaccessibility** – Meeting forums must be made accessible to people with mobility, visual, auditory and other disabilities.
- **Unequal Power Dynamics** – It is intimidating to express your opinions in a room full of hospital administrators, physicians and others who often speak in jargon that is incomprehensible to lay people. To be effective, consumers need training, accessible materials distributed in advance, time to ask questions and learn, allies at the table and people they can talk to before and after meetings.
- **No Feedback Loop** – Consumers need a consistent feedback loop that demonstrates that their input results in change.

¹ Frampton, Susan et al, [Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care](#), National Academy of Medicine, January 31, 2017.

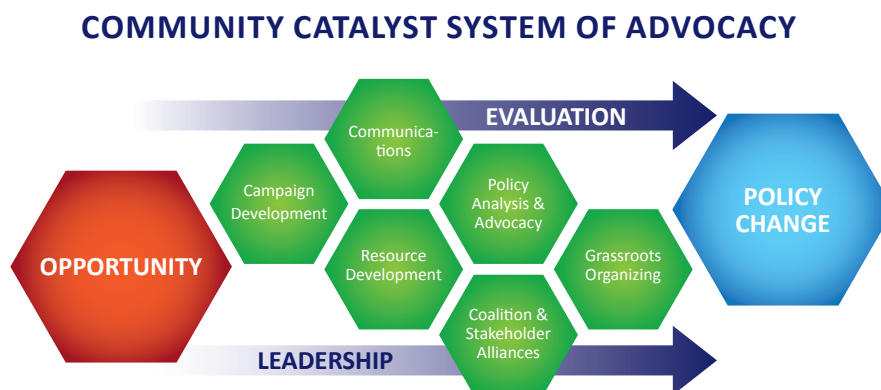
What the Center has found is that health care organizations and governmental agencies that want genuine consumer input would be wise to partner with state and local advocacy groups. These groups regularly engage with consumers with complex health and social needs and thus have a unique ability to reach out to, recruit and support consumer leaders. They have strategies to reach consumers, identify potential leaders, move leaders up a [pyramid of engagement](#), present a broad array of opportunities to provide input and support consumers as they participate throughout the process. It is particularly important to note that these advocacy organizations are not just identifying single consumers, but are growing a constituency². They can, with resources, build a base to draw on over time, thereby building a powerful and effective consumer voice.



THE CENTER’S ROLE

Over the past six years, we have partnered with advocates in states and local communities to support just this kind of work. The Center has provided these advocacy organizations with strategic assistance, tools, and funding to build strong grassroots networks and increase the impact of consumer feedback. We have helped state and local advocates understand the intricacies of health system change, and used [our tested advocacy model](#) to build advocates’ skills and power to establish and sustain an effective consumer voice at all levels of the health care system.

This paper highlights examples of how consumers with complex health and social needs, organized and supported by the Center’s state and local advocacy partners, have shaped policy and practice in delivery reform initiatives. With our technical assistance and funding, these organizations have built structures for meaningful consumer engagement and then organized and built the skill and knowledge base of consumer leaders who now participate in those structures and effect consumer-driven change.



² For more information about organizing grassroots consumers around complex delivery reform issues, please see Center publication [Where the Magic Happens](#).

A FRAMEWORK FOR UNDERSTANDING CONSUMER IMPACT

In the six states featured in this brief, we have found that the examples of consumers having a positive impact on the health system tend to fall into one of three categories:



Process Impacts – Process impacts involve consumers impacting the *way in which an advisory or other policymaking body operates* so as to make participation by consumers easier and more realistic to sustain. For example, changes in when a body meets or how it presents material are examples of process impacts.



Communications Impacts – Consumers can have a significant impact on *how a health plan, the state or other entity communicates with its members or enrollees*. Consumers have successfully advocated for changes to wording, formatting and presentation style, and they have also convinced policymakers to alter the medium used for communicating with consumers in the first place.



Policy Impacts – Consumers have successfully pushed states and health systems to *change policies and practices* to orient them toward the true needs of consumers.

Advocates in the states highlighted on the following pages have demonstrated the kind of impact that engaged, empowered consumers can have in each of these categories of change.



ALABAMA

ALABAMA

The state of Alabama has been back and forth over the past five years on Medicaid reform proposals. In 2013, the state Legislature overwhelmingly approving a Regional Care Organization (RCO) structure modeled on [Oregon's Coordinated Care Organization](#) approach, only to scrap it a few years later. The state is now pursuing a somewhat scaled-back, but still potentially significant, reform program grounded in the [existing health home structure](#), scheduled to go live in October 2019. Even as the state equivocated about delivery reform, however, consumer advocates in Alabama continued to doggedly build a cadre of educated consumers prepared to provide feedback on implementation of reform programs. One result of this ongoing work is that the private sector entities in Alabama – managed care organizations, insurers, the state nursing home association and others – are today even more receptive to robust consumer engagement than public sector organizations.



Even though the RCOs never quite made it out of the starting gate, consumer input through the fledgling RCO Consumer Advisory Board in 2016 did result in changes at the health home level that are likely to remain in effect as the state implements its new reform program, the [Alabama Coordinated Health Network \(ACHN\)](#). These changes include:

- The Consumer Advisory Committee (CAC) of one health home entity expressed concerns about communication with members and the entity incorporated this feedback into the design plan for their ACHN website. Changes include text written at a more appropriate reading level and access to languages other than English. They are also exploring the use of pictures and symbols in addition to text for non-readers.
- Consumer input on the need for transportation support prompted this same entity to host a transportation forum with members of the community. As a direct result, the health home augmented its transportation assistance services by purchasing bus tickets in bulk for members in Jefferson County, one of the few places in Alabama with an extensive public transit system. The organization also began coordinating with other health providers to ensure that rehabilitation consumers were transported *with* their motorized wheelchairs rather than without them, which had previously been a common practice. This health home will likely form the core of the region's ACHN, so this consumer-driven emphasis on transportation assistance should continue.



MARYLAND

MARYLAND

In Maryland, advocates have focused on getting consumers appointed to statewide policymaking bodies. For example, in 2017 advocates placed a consumer on the state's [Health Information Exchange Policy Board](#), which develops policies that ensure a high level of privacy and security protections for health information exchanges in Maryland. Since her appointment, that consumer has successfully advocated for a variety of process changes in how the board operates that make it more accessible to non-industry insiders.

- About a year after the consumer joined the Policy Board, the Exchange developed – at the consumer's urging – an orientation webinar that they now conduct annually to orient new members to the body. They've also put the slides and a recording of the [presentation](#) on their website, where anyone can access it.
- Additionally, the whole approach of the Policy Board staff has changed. As staff members have gotten to know the consumer they've learned to anticipate her consumer-related questions, much like they do with other long-serving members of the Board. Consequently, staff members arrive at meetings having already completed the research needed to answer the questions that the consumer representative is likely to ask.
- The consumer on the Policy Board also alerted consumer advocates in Maryland to a piece of legislation they would not otherwise have noticed. As a result, the advocates were able to weigh in on that bill using the consumer's newly-developed expertise in the content area. The bill in question subsequently passed and was signed into law. *In other words, advocates built consumer power in the state by working in collaboration with the consumer they trained and supported.*

In mid-2018, the [Health Services Cost Review Commission \(HSCRC\)](#), which sets all hospital rates in the state under Maryland's global budgeting waiver, set up a Potentially Avoidable Utilization Sub-Committee filled with many industry stakeholders to look at reducing unnecessary hospitalizations. The HSCRC agreed to allow a staff person from a consumer advocacy organization on the committee and this advocate in turn pushed for the addition of an actual consumer. There was some resistance, but ultimately the HSCRC agreed to appoint a consumer to the sub-committee as well. These two individuals then worked together to raise consumer concerns about Emergency Room misdiagnosis, with the staff person presenting focus group results and the consumer demanding action.





MASSACHUSETTS³

MASSACHUSETTS

In response to vigorous advocacy, Massachusetts agreed to develop an [Implementation Council](#) with a 51 percent consumer majority to provide meaningful consumer input on its One Care program, the state's demonstration project for people eligible for both Medicare and Medicaid (dually eligible individuals). The Council successfully advocated for a variety of process changes that made Council meetings more accessible to consumers and enhanced the ability of consumers to participate:

- In response to consumer suggestions, the Council agreed to include a public comment session at each meeting to hear from individual enrollees about their experiences with the One Care program. Over time, this practice resulted in non-Council consumers participating throughout Council meetings, not just during the public comment section.
- At the suggestion of consumers, the Council organized virtual Town Halls, which allowed people with travel challenges to provide feedback and engage with the Council.
- When a Council member with an intellectual disability left in frustration after not being able to participate meaningfully, Council members sought to slow down the meeting process, follow written agendas more closely and minimize the use of technical terms and acronyms to improve accessibility.



These strategies greatly enhanced consumer input into the One Care program, and in turn resulted in a number of communications and policy changes:

- Consumer feedback uncovered the need for additional provider and enrollee education about the role of and access to the [Long-Term Supports Coordinator](#), the individual on the care team responsible for finding resources and services in the community that can support a consumer's wellness, independence and recovery goals. In response, the One Care program enhanced consumer education about this role.
- At the urging of consumers, questions about sexual orientation and sexual/reproductive health were added to the comprehensive assessment completed at the time of enrollment in the One Care program.
- Consumers shared their concerns with federal policymakers that the One Care program's design was not financially sustainable, and helped to convince CMS to provide \$43 million in funding to enhance the program's financial stability.

³ For more information about the success of the Massachusetts One Care Implementation Council, please refer to the Center's publication, [One Care Implementation Council: Stakeholder Engagement Within a Duals Demonstration Initiative](#).



PENNSYLVANIA

PENNSYLVANIA

Advocates in Pennsylvania have achieved remarkable results by supporting meaningful consumer engagement in the development and implementation of the state's [Community HealthChoices \(CHC\)](#) program, a mandatory managed care program for dually eligible individuals and Medicaid beneficiaries with long-term care needs. In addition to helping instigate changes in the CHC program itself, this consumer engagement has also increased the focus of state officials on addressing the social determinants of health.

The CHC program seeks to better coordinate medical care and to create a more person-centered approach to providing Long-Term Services and Supports (LTSS). Pennsylvania launched the program in January 2018 in the Pittsburgh area, but by then advocates had been providing input to the state on the design of the program for well over a year. One significant focus of the advocates' work was to build in structures that would provide feedback directly from consumers to both the state and the Managed Care Organizations (MCOs) contracted to provide services in the CHC program. CHC has now been fully implemented in southwestern Pennsylvania and it was launched in the Philadelphia area in January 2019. The advocates' efforts to find ways to include consumer voices in the program have paid dividends throughout, with both the state and MCOs making process, communications and policy changes in response to consumer feedback.

For example, consumers insisted on hearing directly from state officials themselves about how managed care would work and whether or not it would effectively reduce their benefits. At one meeting in the southwestern part of the state, over 80



consumers showed up and shared their stories. The meeting not only allowed for resolution of individual problems, but it also helped state officials to understand concretely what they were missing without direct consumer input. MCOs also changed how they conducted their Consumer Advisory Committees (CACs) in response to consumer feedback. These changes included:

- Asking advisory committee members in advance for topics for the agenda rather than having staff set the entire agenda.
- Having a staff person call CAC members to remind them of upcoming meetings.
- Helping consumers to arrange transportation to and from the meeting.
- Providing consumers with the meeting schedule for the entire year rather than setting up meetings with a week's notice.

On the communications front, consumer feedback fundamentally altered how the state talked to consumers about CHC. The first educational presentations by state officials were difficult to understand and not consumer-friendly. After consumer feedback, presentations were revised to include more pictures, graphics and far less text. Consumer feedback also resulted in concrete changes to the printed materials the state provided on the CHC program. For example:

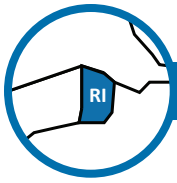
- Consumers expressed great anxiety about potential changes to Medicare, so the state added information reassuring consumers about their Medicare benefits.
- The state's original materials about CHC included only a short paragraph about behavioral health benefits. After consumer feedback, the state added considerable information about how the CHC program would address behavioral health. The behavioral health section of the materials is now far more robust and comparable to the physical health section.
- Consumers expressed great confusion about who to call if they had questions – their doctor, the MCO, the state, etc. On every page of their printed materials the state now includes information about who a consumer should call first if they have questions.

But it is in the policy and practice area that consumers in Pennsylvania – always with the support and guidance of consumer advocates – have achieved impressive changes that have affected not only the CHC program, but also other health care programs in Pennsylvania. Advocates convinced the state to conduct weekly calls with consumers as the CHC program rolled out in the Pittsburgh area. Through these calls, advocates were able to keep the consumer experience at the forefront of the rollout and to expedite policy and practice changes that reduced confusion and removed barriers to care. For example, in response to consumer feedback from Medicaid-only enrollees, the state removed the requirement that MCOs list a primary care physician on the CHC membership card. Prior to this change, Medicaid-only enrollees were receiving cards with a randomly assigned primary care physician listed. While it was convenient for the MCOs to issue the same type of card to everyone, inserting a randomly chosen physician's name caused widespread confusion for the Medicaid-only consumers. Changing this practice helped to better align the CHC program with the needs of consumers, rather than those of the health plans, in mind.

Another area where consumer feedback had a tremendous impact was in the selection of an enrollment broker for the CHC and other waiver programs across the state. Consumer stories illustrated how dysfunctional the entry point to applying for LTSS was, particularly for non- or limited-English speakers. In response, the broker implemented a new cultural competency training around language access and agreed to address the frequency of dropped calls when using telephonic interpretation. Despite these improvements, in August 2018 the state decided to [cancel the existing procurement process for an independent enrollment broker](#), noting that they would use the “experiences with the implementation of the Community HealthChoices Program . . . to inform an increased focus on improved participant experience. . .” Advocates are now using consumer input to influence the new state procurement, which is scheduled to be released in April 2019.

Consumers also influenced policies related to network adequacy for home and community-based service (HCBS) providers in the CHC program. Consumer feedback resulted in the state agreeing to a new network adequacy standard developed by the advocates, one of the first examples in the country of an HCBS network adequacy standard. The state then further agreed to at least informally apply this same standard to other kinds of in-home services offered by the Office of Long-Term Living.

Finally, and perhaps most significantly, consumer interactions with state officials have influenced policy beyond the CHC program, emphatically and indelibly bringing issues related to the social determinants of health to the attention of policymakers. For example, in mid-2016 advocates organized a meeting at a Philadelphia-area Patient Centered Medical Home (PCMH) that included consumers and state officials. During the meeting, consumers’ struggles with stable housing emerged as an issue in a way it hadn’t previously. The result was a requirement that future contracts with PCMHs focus on linking patients to housing by both screening for housing insecurity and providing a warm handoff to community-based agencies who could help. In addition, the state is reconsidering the role of transportation and supportive housing in rural areas in particular. This was not even on the radar before consumers raised these issues in various forums.



RHODE ISLAND

RHODE ISLAND

Following the example of Massachusetts, Rhode Island has developed an [Implementation Council](#) for the [Integrated Care Initiative \(ICI\)](#), the state's dual eligible demonstration project. The Council has included a majority of consumer representatives from the start, but in 2018 consumers really came into their own on the Council. Consumers were elected as both Chair and Co-Chair and relatively quickly there was a noticeable decrease in the use of jargon and acronyms in Council meetings. The state changed the way it presented information, shifting away from complex slide presentations. This has helped the meetings become more productive and useful for *all* participants, not just consumers.

The state and consumer advocates have worked together to help educate consumers serving on the Council, increasing their knowledge base and their ability to make meaningful contributions. The consumers on the Council now talk with one another outside of Council meetings and often work as a team during the meetings to achieve the outcomes they're collectively seeking. In addition, the nature of communication between the ICI program and enrollees has changed. Early on, information only traveled from the ICI to the consumers on the Council. Now that information goes a step further, with consumers communicating information to members of the community, and in turn relaying feedback from the community to the ICI.



In addition to these process improvements, consumers on the Implementation Council have also looked at drafts of communications from the state to enrollees in the ICI and made suggestions that have resulted in consumer-friendly changes. Examples of these changes include:

- Use of colored paper to make important notices stand out.
- Use of a larger font size.
- Elimination of acronyms and jargon.

One interesting example of eliminating jargon involved the phrase “fee-for-service,” a phrase commonly used by health policy experts. Consumers pointed out that many Medicaid enrollees understand that phrase to mean that they need to pay a fee to get a health service. As a result of this feedback, ICI communications now use the phrase “traditional Medicaid” instead.

On the policy front, consumers on the Implementation Council have played a key role in changes that the state has made to the administration of the state’s Medicaid Non-Emergency Medical Transportation (NEMT) benefit. The brokerage system for NEMT in Rhode Island had experienced years of complaints about extremely late or non-existent pickups and poor customer service, among other problems. In 2017, the consumers on the Council demanded that representatives from LogistiCare, then the statewide NEMT broker, report on NEMT services at a Council meeting. At the subsequent meeting, LogistiCare acknowledged for the first time that it had a service problem and pledged to improve. For a time after this meeting, LogistiCare became somewhat more responsive to community concerns and worked more closely with consumer advocates to improve services.

In 2018, the state released a request for proposal (RFP) to re-bid its transportation broker contract, and included in the RFP more consumer oversight of the NEMT program as well as other changes suggested by the consumers on the Implementation Council. Ultimately, the state awarded its NEMT contract to a new broker and signed a contract that includes more consumer oversight as well as an improved complaint resolution system. Consumers on the Implementation Council are now monitoring the performance of the state’s new NEMT transportation broker.



TENNESSEE

In 2016, the state of Tennessee implemented an 1115 waiver amendment to consolidate its program of Medicaid home and community-based services into the state's capitated Medicaid program, TennCare. Through the integration of LTSS and medical services, as well as the capitation of services for people with Intellectual and Developmental Disabilities, the state is trying to significantly improve the quality, efficiency and reach of services for this highly vulnerable, underserved population. The program is called [Employment and Community First CHOICES \(ECF\)](#) and Tennessee advocates have been working for the last 18 months to organize the consumers and families impacted by the ECF program to shape the program's policies and practices.

Despite the short duration of this work, consumers in Tennessee have already driven communications changes. Consumers provided feedback on a draft outreach letter to individuals on the referral list for the ECF program, resulting in significant changes to the letter. These changes included:

- Opening the letter with “Why Are You Getting This Letter,” followed by a straightforward, three-sentence explanation.
- The addition of an FAQ document.
- Clarification and simplification of the language describing eligibility for the program.



Photo courtesy of Tennessee Disability Coalition

TENNESSEE

CONCLUSION

Our state-based partners have taught us that moving meaningful consumer engagement from the aspirational to the actual is very difficult. This is especially the case when working with consumers with complex health and social needs, like the dually eligible individuals in Massachusetts, Pennsylvania and Rhode Island, individuals with intellectual and developmental disabilities in Tennessee, or Medicaid enrollees in Alabama who, because Alabama's Medicaid program is so severely limited, are extremely low-income. *The advocates in all of the states discussed in this paper have cracked the code.* They have figured out how to recruit and organize consumers, identify potential leaders, train and support those leaders so they can effectively represent consumer interests on policymaking bodies, and develop a pipeline of new leaders that can continue to impact policy moving forward. They have done this in a variety of environments, from very conservative southern states to purple and blue states. But we know this didn't happen by magic. So what is the secret?

- **Credibility** – Because the work of organizing and supporting consumers is relationship-based, to be effective it must be done by organizations that have history and credibility in the community they are organizing.
- **Funding** – All of these organizations have received funding support from the Center and others that has allowed them to invest in the staffing resources needed to build a base of educated, effective consumers.
- **Technical Assistance** – These organizations have also received policy and other technical assistance from the Center. This has allowed them to learn from the experiences in other states and move forward more quickly.
- **Time** – Developing this kind of infrastructure doesn't happen overnight. We have found it takes a minimum of two years of consistent work to develop the kind of pipeline that the advocates in Pennsylvania have developed, for example. And the work doesn't end there – it takes ongoing effort and investment to maintain that pipeline.
- **Continuity** – None of these organizations are focused on plugging a single consumer into a specific engagement opportunity. Rather, they are all focused on organizing a constituency that will provide the kind of continuity needed to rectify the existing power imbalance between consumers and other stakeholders in the health care system.
- **Collaboration** – Consumer advocates and consumers working together is what creates consumer power in a community or state, power that is sufficient to go toe-to-toe with more traditional stakeholders.

The policy and other changes highlighted in this document are first and foremost a testament to the skill and persistence of the consumers who have advocated for them, often in the face of significant resistance. But they are also the result of the very significant investment by state and local advocacy partners in organizing and supporting consumers, and by the Center in supporting and funding advocacy partners. In this way, advocacy organizations are building power, working together with consumers to effect change. We hope that these mechanisms will build a stronger, deeper and ultimately more effective model of consumer engagement that, if broadly adopted, will advance the movement toward a more equitable and person-centered health care system.



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