



Consumer Voices for Innovation Grant Program Evaluation: Final Report

May 2019



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ICH is a nonprofit consulting organization that provides participatory evaluation, applied research, assessment, planning, and data services. ICH helps healthcare institutions, government agencies, and community-based organizations improve their services and maximize program impact

CONTENTS

Executive summary	2
Background	4
Program and evaluation overview.....	5
Institute for Community Health: evaluation activities.....	5
The Center: program activities	5
Grantee activities	6
Consumer organizing and outreach activities.....	6
Consumer leadership development activities.....	7
Working with decision-makers and coalition partners: activities	7
Best practices.....	8
Consumer leadership development: best practices	8
Working with decision-makers and coalition partners: best practices.....	9
Program outcomes.....	10
Grantee capacity	10
Consumer engagement	11
Leadership development.....	12
Decision-maker engagement and understanding	13
Program impacts.....	14
Sustainability: looking to the future	16
Cycle of success	16
Coalitions	16
Funding.....	17
Conclusion	18
Appendices	19
Appendix A – Logic model.....	20
Appendix B – Grantee profiles	21
Appendix C – Evaluation methods	31

EXECUTIVE SUMMARY

Increasingly, policy and health system leaders recognize the importance of engaging consumers in health care system design and implementation. Despite emerging consensus on the evidence, there remains uncertainty about the best strategies to accomplish this. To better understand the



most effective strategies for engagement, in 2017 the Center launched the Consumer Voices for Innovation 1.0 (CVI 1.0) Grant program, which funded 6 state health advocacy organizations to catalyze grassroots organizing and base building in health system transformation (HST). The program focused on consumer communities that have presented particular challenges for engagement: people from low-income communities, people of color, and/or older adults. Each grantee received funding, technical assistance (TA), mentorship, and group learning opportunities. Grantees used

a wide variety of strategies to engage consumers, including broad-reaching techniques (e.g., advertising in local media), smaller-scale strategies (e.g., house parties) and outreach via service provision (e.g., providing care coordination).

The Institute for Community Health (ICH) conducted a mixed methods evaluation, using surveys with grantees and consumers, interviews with grantees, consumers, decision-makers and coalition partners, conversations with Center CVI staff, and review of quarterly reports and TA tracking.

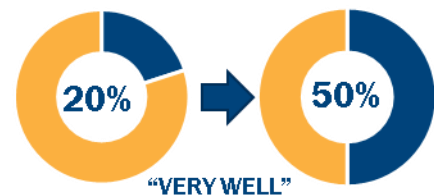


CVI 1.0 provides several lessons for engaging consumers in HST processes. First, CVI 1.0 demonstrates that dedicated funds, TA, group learning opportunities and health systems mentors can help grassroots organizers to mobilize a base of engaged consumers, build consumer leaders, and deepen consumer engagement. Indeed, during the course of a two-year grant, nearly 30,000 consumers were reached, nearly 5,000 were added to the base, and over 1,000 leaders were recruited and trained. Second, this engagement can lead to increased incorporation of consumer voice into decision-making.



Critically, CVI 1.0 demonstrated that a dedicated program can lead to a consistent and effective consumer voice at different levels of the health care system, as well as defense and/or implementation of policies and other local efforts that are responsive to the needs of underrepresented communities. In all five states, grantees achieved process changes, or changes in how policymaking bodies operated in order to facilitate consumer participation. Grantee efforts also led to consumer-friendly changes in how insurers communicated with members or enrollees in 2/5 states. Finally, grantee efforts led to policy or practice changes that were responsive to consumer needs in 4/5 states. For example, as a result of this initiative 18,000 seniors on Medicaid have access to transportation which supports social and health activities as well as overall well-being.

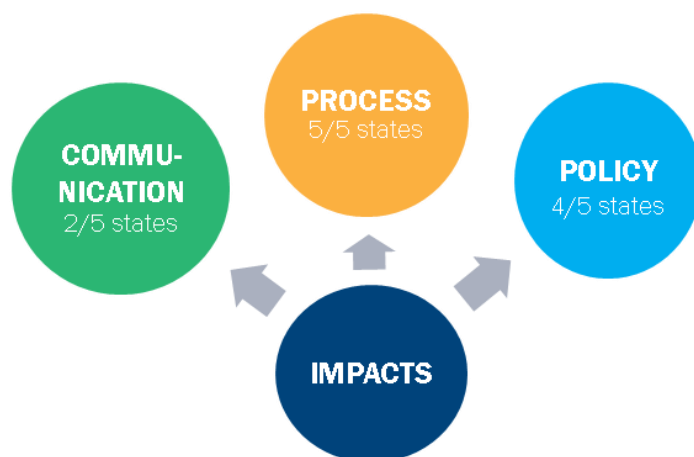
DECISION-MAKERS
IMPROVED HOW WELL
THEY INCORPORATE
CONSUMERS' EXPERIENCES



CVI 1.0 also identifies best practices for consumer engagement in HST.

Grantees' successful techniques for building consumer leaders included providing capacity supports, fostering a sense of self-efficacy, being optimistic and authentic, and investing in relationships and comradery. Grantees succeeded in influencing coalition leaders and decision-makers by serving as two-way "translators" between the language of policy and the everyday language of consumers; working closely with key individuals of relevant

professional backgrounds; and serving on consumer advisory boards or other committees that facilitated contact with decision-makers. Ultimately, these best practices established and strengthened a cycle of success which was described by grantees, consumers and decision-makers alike. In this "cycle of success," consumer participation in advocacy work, establishment of trust and strong relationships, and advocacy "wins" interacted in a reinforcing feedback loop that bred success and impact.



Lessons learned from the Center's CVI 1.0 program can inform policy makers, advocacy organizations, health systems, and funders working to advance consumer engagement in health systems transformation for low-income and vulnerable patient populations.

BACKGROUND

Increasingly, policy and health system leaders recognize the importance of engaging consumers in health care system design and implementation.¹ Despite emerging consensus on the evidence, there remains uncertainty about the best strategies for engagement,² particularly for engaging consumers from low-income communities, communities of color and/or older adults. To better understand the most effective strategies for engagement, Community Catalyst’s Center for Consumer Engagement in Health Innovation (hereafter, ‘the Center’) launched the Consumer Voices for Innovation (CVI 1.0) grant program in 2017.

The CVI 1.0 program was an innovative effort to catalyze grassroots organizing and base building in health system transformation (HST). The goal of the program was to support organizations’ state or regional efforts to build an engaged base of consumers in order to permanently strengthen their capacity to engage consumers in HST. Over the long term, the goal was to foster consumer activism in health advocacy, especially in low-income communities, communities of color, and/or communities of older adults. The program coincided with a significant shift in politics in the United States, with multiple national efforts to repeal, reduce or defund the Affordable Care Act (ACA).

CVI 1.0 funded a total of 6 grantees and 3 sub-grantees across the United States during the 2-year project (Table 1). Grantees started at different stages of organizing for HST; while some had significant experience with HST organizing, some were embarking on organizing for HST for the first time.

Table 1. Consumer Voices for Innovation 2017-2019 Grantees

Grantee	Program objectives
Maryland Citizens’ Health Initiative Education Fund	Expanding the Faith Health Network which uses lay leaders to support congregants’ needs during and after hospitalizations
The TakeAction Minnesota Education Fund (Year 1 only)	Organizing grassroots consumers and advocacy organizations to defend and improve the transparency and effectiveness of MN Medicaid innovations to better reflect consumers’ needs
Make the Road New York	Organizing grassroots participation in a Performing Provider System to be more responsive to community needs and to increase the role of community health workers
Oregon State Public Interest Research Group - Unite Oregon - Oregon Latino Health Coalition (Year 1 only)	Organizing grassroots participation in Coordinated Care Organizations (CCOs) in southern Oregon and aiming to increase the influence of consumers and focus on addressing social determinants of health in the CCO
Pennsylvania Health Access Network - Southeast Asian Mutual Assistance Associations Coalition (Year 2 only)	Organizing consumers affected by the rollout of managed long-term services and supports in PA’s Medicaid program, with a focus on mobilizing seniors
Rhode Island Organizing Project	Engaging older adult consumers in the RI duals demonstration by advocating for person-centered approaches and improving transportation for low-income consumers.

¹ Jacobs LM et al. Journal for Health Care Quality; 2018. <http://europepmc.org/abstract/med/28786845>.

² Frampton SB, et al: National Academy of Medicine; 2017. <https://nam.edu/wp-content/uploads/2017/01/Harnessing-Evidence-and-Experience-to-Change-Culture-A-Guiding-Framework-for-Patient-and-Family-Engaged-Care.pdf>

PROGRAM AND EVALUATION OVERVIEW

Institute for Community Health: evaluation activities

The Institute for Community Health (ICH) was the evaluation partner for the grant program. ICH began by reviewing relevant background documents, and proceeded to collaboratively develop a framework for the evaluation through the creation of a logic model (Appendix A). This framework reflects the Center's approach to consumer engagement, understood as a pyramid of five dynamic levels of engagement.³

These formative activities led to the following key evaluation questions:

- How many consumers (particularly from low-income communities, communities of color, and older adults) and consumer leaders were engaged through grantee initiatives? Did consumers become more meaningfully engaged as a result of grantee initiatives?
- What aspects of the consumer engagement strategy were most effective at encouraging and supporting consumer engagement and leadership development?
- How did policies, programs, or practices change in some states as a result of consumer engagement and action?

To answer these questions, ICH engaged in four broad evaluation activities including grantee surveys, consumer surveys, stakeholder interviews (including grantees, consumers, decision-makers and policymakers) and review of grantees' quarterly reports and the Center's technical assistance tracking (see Appendix C for details).⁴ An interim report found preliminary evidence that the program was achieving its goals and documented early outcomes.⁵

The Center: program activities

Funding: The Center provided just under \$1 million dollars to the grantees over the course of the two-year program (roughly \$100,000 per grantee per year).

Technical Assistance (TA): The Center's state advocacy managers (SAMs), policy analysts, communication staff and consultants provided TA. TA focused on six capacity areas: campaign development, communications, policy analysis and advocacy, resource development, coalition and stakeholder alliances, and grassroots organizing. SAMs conducted regular TA check-ins with grantees at least once per month and more frequently upon request, mostly by telephone. Over the two-year period, grantees received a total of 118 TA contacts, with the most common focus being policy analysis and advocacy (addressed in 85/118 contacts), grassroots organizing (61/118), and coalition and stakeholder alliances (54/118). Assistance from external consultants was arranged when grantees needed specialized assistance (e.g., longer-term financial planning).

³ Community Catalyst Pyramid of Engagement. <https://www.communitycatalyst.org/resources/tools/pyramid-of-engagement>

⁴ One grantee was not expected to continue into the second year; during the first year, this grantee submitted quarterly reports and participated in the qualitative interviews, however, they did not complete the follow-up grantee survey or administer the consumer survey.

⁵ Consumer Voices for Innovation Grant Program Evaluation Year 1 - Interim Report.

https://www.healthinnovation.org/resources/publications/Interim-CVI-report-Final_5-24-18.pdf

Leadership in Action (LIA): The Center matched each grantee with a mentor, recruited for their experience in a specific aspect of HST (such as knowledge of health plan finance, hospital operations, or policy). LIA mentors provided introductions to particular power brokers; knowledge of specific policies, standards, or contracts and their implications; help with messaging and constructing specific messages such as requests for funds; and even serving as a speaker at one grantee event.

Group Learning Opportunities: The Center offered multiple group learning opportunities for grantees and consumer leaders. Monthly learning community calls focused on a variety of topics and were supplemented by quarterly calls on two specific topics: Accountable Care Organizations and Non-Emergency Medical Transportation. Grantees participated in an

annual Advocates Convening where they heard from national speakers, participated in a wide variety of workshops and networked with their colleagues. Some grantees brought consumer leaders to these convenings, providing the consumers with an opportunity to increase their leadership skills and capacity. Finally, several of the grantees and their consumer leaders participated in a symposium in Washington DC about care for dual eligible individuals. This trip included visits to Capitol Hill so advocates and consumers could meet with their elected officials.

“The excellent support that we’ve received from [Center staff] . . . helped us be more strategic in building the network and how the network would function and how we would evaluate the network. We got additional consulting through Community Catalyst. . . which was very helpful in helping us frame the network in a way that could get it on more hospitals’ radar, helped us negotiate a much higher rate for providing the technical assistance that we provide so that it will be more likely to be sustainable, and helped with breaking down some of those costs, very kind of practical help. That was essential to where we are right now.” (Grantee, interview)

GRANTEE ACTIVITIES

Consumer organizing and outreach activities

Over the course of the two years of the program, grantees conducted a wide variety of activities as they attempted to reach out to consumers, engage consumers around HST issues, deepen consumers’ engagement, and develop consumers’ leadership skills around these issues. These activities ranged from broad-reaching techniques, smaller-scale but more intensive strategies and organizing consumers in direct actions (Figure 1).

For most grantees, especially during Year 1, unexpected and urgent efforts to defend the ACA and Medicaid occupied much of their time. The impact of these unplanned defensive activities was mixed. Some grantees found that they diverted volunteer and staff time and energy away from HST organizing. On the other hand, these public battles helped energize and mobilize consumers. Some grantees found that they were then able to divert engaged consumers’ energy into HST issues.

Figure 1. Consumer organizing and outreach activities employed by grantees



“[Due to the fight to repeal the ACA] we have a lot of people who it’s easy to turn out for things. Finding people who want to do the work and join boards, you know, the consumer advisory council is a little harder sometimes, but we started out with such an excellent list, I think it would have been harder had we not had that fight two years ago, there would have been a lot more struggle. But we had so many people who just wanted to stand up and fight back around health care within our local area, that I think we lucked out.” (Grantee, interview)

Consumer leadership development activities

In the second year of the grant, grantees shifted more of their time and energy into developing the leadership capacity of consumers. A number of them began with broad outreach efforts, including surveys, house parties, and education sessions, in order to connect with and “filter” large groups to locate people with the interest and personal resources to be trained as leaders. A key approach here was described by several as “meeting people where they’re at”, meaning tailoring the supports and education provided to the individual needs of the consumer. Grantees worked with people on an ongoing basis and made themselves available and accessible as resources for the consumers by answering questions and connecting people to resources. Finally, grantees provided leadership training and support for consumers, including how and where to speak up, securing positions on decision-making boards or committees, and advocating for structural modifications to make participation on these boards or committees more accessible and effective.

Working with decision-makers and coalition partners: activities

Grantees identified successful techniques for increasing their influence with decision-makers. First, several found that serving on consumer advisory boards or other committees facilitated their contacts with decision-makers – they were able to find out about pending decisions in time to influence them, for example, and through the contacts made on these boards were invited to serve on other, more influential working groups. Second, grantees found that working closely with people with relevant professional backgrounds, either by hiring or receiving mentorship from them (e.g., LIA mentors), was a helpful strategy. These relationships facilitated their understanding of the relevant

context and vocabulary of policy, and helped provide introductions to influential people. Finally, all grantees positioned themselves as resources for the decision-makers and communities they focused on. Indeed, decision-makers described an important role that grantees filled as two-way “translators” between the language of policy and the everyday language of consumers.

BEST PRACTICES

Best practices for consumer organizing and outreach are discussed in detail in the interim report.⁶ These included focusing on relationships and trust, investing time and patience, building a bridge from individual experience to the bigger picture of policy, and recognizing that details and preparation are critical for effective consumer outreach and engagement.

Consumer leadership development: best practices

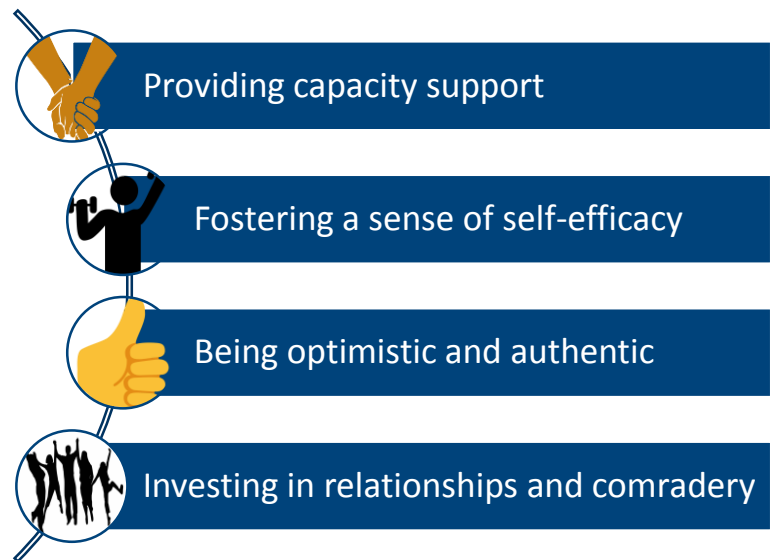
Four best practices for building consumer leadership emerged from this grant, represented in Figure 2, and described in detail below.

Providing capacity support: Consumers appreciated the support offered by grantees as they grew as leaders. In particular, consumers identified that grantees educated consumers about how to speak the language of policy – both in terms of being familiar with the issues, such as the details of the policy, and in terms of gaining confidence and skills to speak up in meetings with powerful people. In addition, grantees provided support by helping consumers be resources for their communities: several consumers described calling upon grantees to help provide connections to resources and information in order to help their friends, neighbors and acquaintances navigate the medical system. Support for consumers in this role not only helped the consumers but also enabled them to assist a wider network of community members in their turn.

Fostering a sense of self-efficacy: Consumers reported that grantees helped them not only gain specific leadership skills but also a sense of self-efficacy. One consumer contrasted the work of a CVI grantee with other organizations, who would tell

consumers “we’ve been doing this for a long time, we know how to do it, you just do what we say.” The grantee, in contrast, listened to the consumer’s ideas and encouraged them, while not micro-managing. This focus on self-efficacy in turn meant that consumers felt like their work made a difference – when the group won a policy battle, the consumers were filled with hope and were motivated to engage in even more activism.

Figure 2. Best practices for developing consumer leadership capacity



⁶ Consumer Voices for Innovation Grant Program Evaluation Year 1 - Interim Report. https://www.healthinnovation.org/resources/publications/Interim-CVI-report-Final_5-24-18.pdf

“...thinking that you can have an impact or change on the world, even your small little piece of it, is a positive message and one that’s sorely needed, especially at this time in my life and in the life of our country... it’s helped me just have hope, which I think is really important. ... sometimes you just get tired and weary and you feel like you’re fighting alone. ...When you feel like you’re doing something of value or worth, that’s going to help motivate you to maybe do some other things in your life that are going to help you make better choices, too. So physically it’s helping me; emotionally it’s helping me. I think it’s spiritually helping me.” (Consumer, interview)

Optimism and authentic devotion to cause: One common theme among consumers’ interviews was that they enjoyed the optimism of the grantees, and felt that the grantees were authentically devoted to the causes they were working for. Grantees’ authenticity was shown by their enthusiasm and their responsiveness to consumers, even in off hours and during busy periods. Their optimism was shown in their high energy and quality of their interactions with both groups and individuals.

Relationships and comradery: The relationships and comradery that consumers found while working with grantees were critical to their willingness to participate in leadership activities. This included the overall social feeling of the organization:

“The volunteers are awesome. The sense of community that they have with, you know, the regular folks, but also meeting the people who just show up more rarely, as well. But I’d say that’s the main thing is this is an amazing group of people, you know, with

common goals, and it’s a great space to be in, obviously, to feel like we’re working towards common goals, and with like-minded people.” (Consumer, interview)

These relationships also included the individual connections consumers built with the grantees who served as their mentors.

“The connection is really crucial with anything. ... I’m 63; I’ve never met anybody as young and as competent as [grantee staff] in my life. ... with everything she does: the way she treats people, her tone of voice, you know, everything. So I think that connection, I see as crucial.” (Consumer, interview)

Working with decision-makers and coalition partners: best practices

Interview participants described best practices for working with coalition partners and decision-makers as overlapping activities and approaches. Therefore, we describe them jointly here.

Communication and coordination of efforts: First, grantees, coalition partners and decision-makers described communication and coordination of efforts to avoid redundancy as key. They described relationships in which each member in the relationship had a specialty, and they worked together to accomplish bigger goals than would be possible individually.

“We probably have 20 partners on top of that. You know, we all have our skillsets. And I think all of that combined and then all of the skillsets and all the work of the people in the community. If you put that all together, I think that’s why we’ve been able to make a difference.” (Grantee, interview)

Approaching external organizations and decision-makers as allies: Second, decision-makers and coalition partners both expressed appreciation for the way that grantees approached them as allies

and partners in accomplishing improvements, rather than as competitors or enemies. This involved finding ways to connect, rising above policy differences to see the big goals, and building trust by working together.

Serving as a resource: Finally, grantees successfully built relationships with coalition partners and decision-makers by being available as a resource for them. One grantee described this relationship like this:

“They see us as a resource. They know when we come in there that we know what’s going on. That we talked to hundreds of people and we’re constantly out there. I think we’ve strengthened relationships there.” (Grantee, interview)

PROGRAM OUTCOMES

In the short- to intermediate term (i.e., during the two year CVI period), organizations were expected to have greater capacity to engage consumers, leading to an increase in the size of the consumer base and increase in the number of consumers who were deeply engaged. In the longer term (i.e., beyond the 2 year CVI period), grantees were expected to advance the development of leaders, and increase their influence on decision-makers, thus leading to increased consumer voice in policies and practices. Though they were not expected, some longer term outcomes were reached and are described below.

Grantee capacity

At the end of the grant period, grantees assessed their own capacity before and after the grant for organizing in each community of focus.⁷ Specifically, they rated their (1) overall capacity for mobilizing and organizing a strong grassroots base of support for HST; (2) capacity to recruit volunteers; and (3) capacity to recruit and train leaders. We created a summary measure by adding up the number of communities for which grantees reported strong to very strong capacity and dividing that by the number of communities served (n=14), thus giving us the proportion of communities for which grantees reported having strong capacity. During the grant, the proportion of communities for which grantees reported having strong or very strong capacity in all areas more than doubled from 43% to 93%. Consumer interviews corroborated how grantee capacity to organize advanced their engagement. As one consumer said:

“Now, I’m more of an advocate, I’m bolder, so-to-speak. And I can be bolder now, because I’ve got knowledge. As they say, knowledge is power. Whereas before I didn’t have the knowledge, I could never really speak out about things that mattered or made a difference.” (Consumer, interview)

⁷ This pre-post retrospective assessment was used to minimize the likelihood that grantees initially overestimated their capacity as high either because they were unaware of gaps in capacity – that is, they “didn’t know what they didn’t know”, or due to social desirability bias. However, it is also possible that social desirability bias, the tendency to answer questions in a manner that will be viewed favorably by others, may have influenced the pre-post retrospective assessment.

Consumer engagement

Size of consumer base: Increased capacity was expected to lead to (1) an increased size of the consumer base, and (2) increased numbers of consumers at every stage of engagement (advancing consumers' 'depth of engagement'). We assessed size of the consumer base by asking grantees to report the number of new consumers reached (e.g., via

4,754
CONSUMERS
ADDED TO BASE

community meetings and house meetings) and the number added to the base (i.e., grantees obtained contact information and put that information in their database) on quarterly reports. Grantees reported reaching 29,679 new consumers during the grant. While growth was seen across all grantees, one grantee reported that a particularly high number of consumers (~10,000) were reached through the launch of a survey in year 2 quarter 3. As a result of all of the grantees' outreach, grantees added 4,754

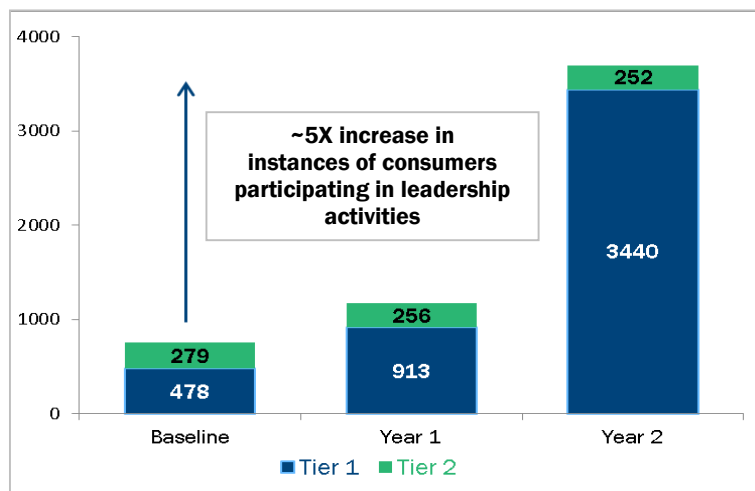
29,679
CONSUMERS
REACHED

consumers to the base.

Consumers participating in the evaluation survey provided information on the demographic characteristics of the consumers reached through these efforts, thus providing evidence that grantees reached members of the communities of focus. Of 184 survey respondents (n=112 at midpoint, 72 at final), 76% were a member of at least one of the objective communities: 41% were non-White; 29% were very low income (defined as food insecure, homeless or unstably housed, and/or at risk of losing utilities such as electric, gas, water or oil); and 76% were 65+ years old.

Depth of engagement is understood as five categories of increasing engagement from awareness, interest, participation, commitment to leadership.⁸ We focused on understanding the impact on the key goals of the program – to increase participation, commitment (hereafter 'tier 1 leaders') and leadership (hereafter 'tier 2 leaders').⁹ Grantees reported the number of participants in activities consistent with each level of engagement; because grantees could not report unique consumers in these activities, there is likely overlap of individuals in these categories.

Figure 4. Number of leadership activity participation instances



Grantees were expected to focus on increasing participation in the first year, and transition their focus to building leaders in the second year of the grant. Indeed, grantees reported that the number of consumers involved in activities consistent with participation increased in the first year and

⁸ Community Catalyst Pyramid of Engagement. <https://www.communitycatalyst.org/resources/tools/pyramid-of-engagement>

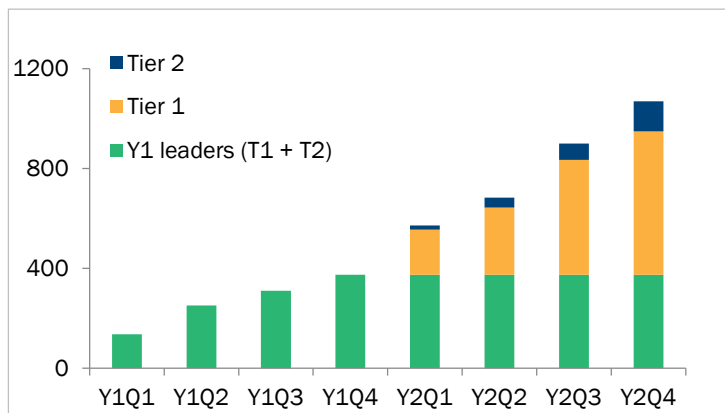
⁹ Tier 1 leaders spoke in person with a decision-maker, such as at a lobby day, through giving testimony, or attended a meeting; shared a personal health care story with the media or elected official; attended a training or workshop related to health system transformation; Tier 2 leaders served on boards, committees, public workgroups or regional partnerships relevant to health system transformation; attended a train the trainer workshop or trained people in their community about a health system transformation issue; regularly served as a spokesperson on health system transformation issues.

decreased in the second year (from 8,986 at baseline to 9,638 in year 1 to 4,666 in year 2). At the same time, the number of instances of people participating in leadership activities (inclusive of both tier 1 and tier 2 leadership activities) increased nearly fivefold, mostly as a result of growth in tier 1 leadership activities (Figure 4). In total, there were 2,935 instances of consumers participating in leadership activities.

LEADERSHIP DEVELOPMENT

Development of consumers’ leadership capacity was a major focus of this grant, particularly in the second year. We examined grantee capacity to develop leaders, the number of consumer leaders, and consumers’ leadership skills and empowerment.

Figure 5. Cumulative number of new consumer leaders

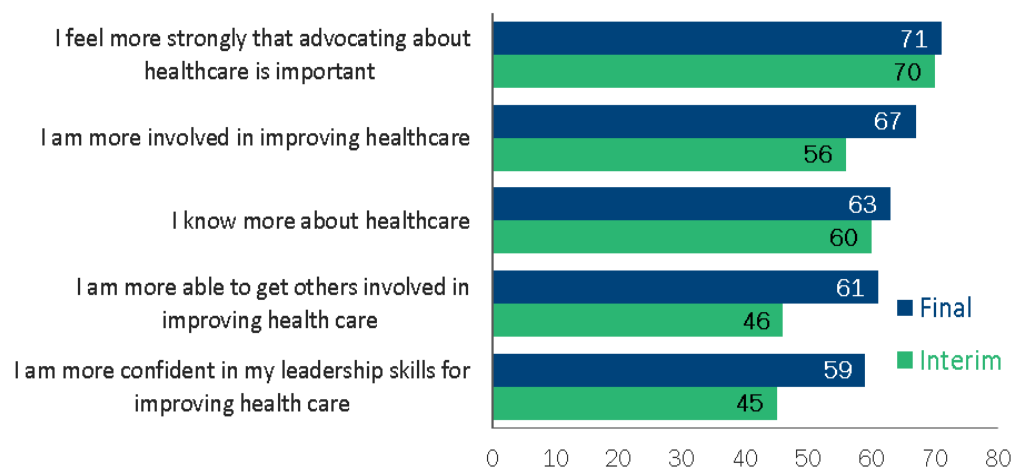


The number of leaders was measured by grantee report of new leaders in quarterly reports. In the second year of the grant, when grantees were more focused on growing leaders, grantees reported the number of tier 1 and tier 2 leaders separately. During the grant, grantees recruited and trained 1,066 consumer leaders (Figure 5)– as expected, most (695) were added in the second year of the grant and the majority of these (575) were tier 1 leaders. Nonetheless, 140 new tier 2 leaders were recruited and trained in year 2 of the grant, an average of 28 per state (range = 6-36).

Consumers’ leadership skills and empowerment to be involved in health policy and systems change was assessed by asking convenience samples of consumers if, compared to one year ago, they (1) were more confident in their leadership skills; (2) knew more about health care; (3) were more able to get others involved in improving health care; (4) were more involved in improving health care; (5) knew more about health care; and (6) felt more strongly that advocating about health care was important. In both

years, between 45% and 71% of consumers answering each question reported they agreed with these statements ‘a lot more’ compared to the year before (Figure 6). The proportion of consumers reporting agreement ‘a lot more’ remained stable or increased across all measures during the second year of the

Figure 6. Consumers reporting that compared to one year ago they felt the following had changed “A lot more” (N=112 at midpoint and 72 at final)



grant. Measures of self-assessments of leadership qualities (confidence in leadership skills and ability to get others more involved) increased the most (by 14% and 15%), consistent with the focus on building leaders in year 2.

The level of involvement of consumer leaders from the objective communities was particularly notable because advocating required significant courage and determination for members of the communities of focus. One grantee interview participant articulated what it takes for these consumers to advocate:

“They just showed a lot of courage. They got up there and they have to admit to the world that they're poor and they don't have any money. They can't pay for this Medicaid. They can't get to the doctor's any other way. They don't have family and friends to take them. You know, that's hard to do.” (Grantee, interview)

Decision-maker engagement and understanding

We assessed changes in (1) engagement between grantees and decision-makers and (2) decision-makers' understanding of and incorporation of consumer perspectives in their work. In order to assess these outcomes, we asked grantees to answer questions about the top two decision-makers or decision-making groups (hereafter 'decision-maker') they were focusing on. Grantees reported working with a broad range of decision-makers including leaders from state departments of health and human services (or the state-level equivalent); healthcare systems; state and federal legislators; and state-level executive branch representatives. The decision-makers of focus changed over the course of the 2-year grant period – only 3 decision-makers from 2 grantees were the same across all 3 time points.

Engagement between grantees and decision-makers was assessed by asking grantees to describe how often they had different types of interactions with decision-makers, including how often they had meetings or phone calls and were contacted by decision-makers (e.g., for information, meetings or stories). Reflecting the fact that many grantees were already engaged in HST work at the start of the grant, at baseline, grantees reported meeting with and being contacted by 6/10 decision-makers of focus at least every two months. Nonetheless, engagement between grantees and decision-makers increased with grantees reporting meeting with and being contacted every 2 months by 8/10 decision makers by the end of the grant.

Decision-makers' understanding of and incorporation of consumer engagement were assessed by asking grantees how well they felt that decision-makers (1) understood the goals of the grantees' work, (2) understood the importance of consumer engagement in HST and (3) incorporated consumer experience into health system policies and practice. As previously noted, decision-makers changed over the grant - likely leading to minimal changes in the number of decision-makers who understood the importance of consumer engagement. Nonetheless, the number of decision-makers perceived to be incorporating consumer experience 'very well' into decision-making increased from 2 to 5 over the course

Figure 7: Change in Decision-Makers Incorporating Consumers' Experiences



of the grant. Decision-makers described the difference of having the consumer perspective through this grant program at the table:

“It’s an enormous difference... Legislators certainly enjoy expert testimony, and they certainly enjoy testimony from the representative groups in government and others.... But I think they particularly value the very “curated” and broadly representative input from organizations like this. ... I think the legislative body always gives this organization a seat at the table in providing input, you know? And it doesn’t necessarily mean that their input is always accepted, but they are, I think, a respected source of public opinion.” (Decision-maker, interview)

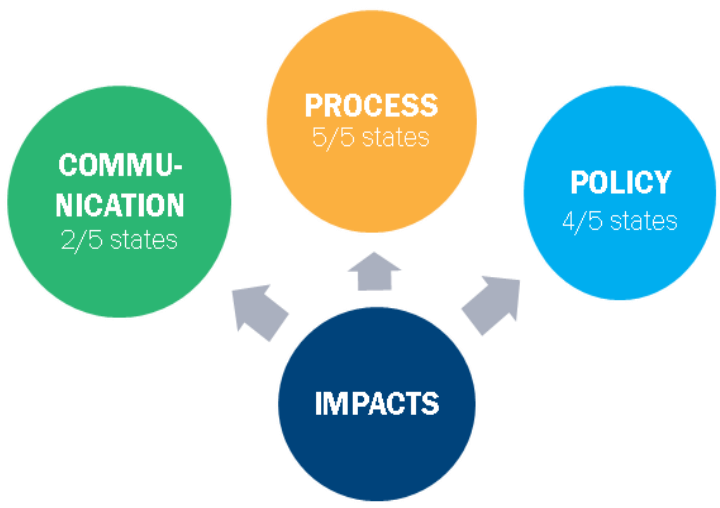
“[Grantee] does take a different kind of approach where it’s much more focused on education itself...I would say it’s in both in directions. Educate the consumers about the program and then also talk about education about us about some of the challenges both on products and the participant’s experience. So it’s education of the department as a government agency as well.” (Decision-maker, interview)

PROGRAM IMPACTS

In the long term (i.e. beyond the life of this grant), these outcomes were expected to have two main impacts. First, consumers would have a permanent and effective voice at all levels of the health care system. This voice would be supported through process changes that allowed consumer perspectives to be heard. Second, policies and other local efforts (for example, communication practices with members or enrollees) that are responsive to the needs of underrepresented communities would be implemented. While the full impact of this program has yet to be seen, early evidence demonstrates significant impacts in these areas (Figure 8).

In all five states, grantees achieved process impacts, or changes in how advisory or other policymaking bodies operated in order to facilitate consumer participation. Grantee advocacy led to the creation of new consumer oversight boards, new members in existing workgroups, and modified meeting processes that allowed consumer participation. Meeting process changes included advance scheduling of meetings, opportunity for consumer input into agendas, advance provision of background materials, orientation materials, and concrete supports (meals, transportation or compensation for consumer time). For example, advocates in one state succeeded in placing a consumer on a state policy board that ensures privacy and security protections for health information exchange. As a result of her advocacy, the board created a webinar that they now conduct annually to orient new members to the board and is posted on their website. Additionally, the state staff members began anticipating her consumer-related questions, much like they did with other long-serving members of the

Figure 8: Number of states achieving impacts



board. Consequently, staff members began arriving at meetings having already completed the research needed to answer the questions that the consumer representative was likely to ask.

Grantees noted that changing processes at healthcare systems was particularly challenging as these systems can be large, complex and take longer to enact changes. Nonetheless, grantees were able to achieve process changes within healthcare systems. One grantee successfully advocated for a new ongoing monthly meeting structure between a healthcare system, and the grantee and other community-based organization to provide regular consumer input. A staff member of this same grantee was accepted as a member of the healthcare system's main non-internal decision-making body, thus placing the grantee on a policy-making body in the health system.

Grantee efforts led to policy impacts, or changes in policy or practices that are responsive to

“The consumers’ voices make that process a more prolonged and challenging process, but by the same token it’s necessary, because the decisions that we make need to be focused on, majority or consensus or some other derivation of the aggregate of all of those consumer voices. And although it makes the process more challenging and difficult, it’s an essential ingredient. So the challenge is it makes our work harder. The benefit is it makes our work better.” (Decision-maker, interview)

consumer needs, in 4/5 states. These policy impacts included improved access to programs such as transportation, homecare programs, and managed care programs. For example, in one state, consumer advocates secured no fare bus passes for 18,000 low-income seniors; to date, this has provided 4 million rides that support social and health activities as well as overall well-being. In other states, grantee efforts advanced improved access to services for uninsured immigrants, reductions in exchange insurance costs for consumers, and ensured that 170K Medicaid recipients would not be charged medical co-pays. Grantee efforts also led to consumer-oriented changes in how services were provided and who provided them. For example, in one state, consumers using a non-emergency medical transport provider complained of late or non-existent pickups and poor customer service for years. With

grantee support, consumer advocacy eventually led to contracting with a new provider, more consumer oversight for the provider, and an improved complaint resolution system.

Another key change in practice was in how health plans, states, or other entities communicated with their members or enrollees ('communication impacts'). Consumers successfully advocated for changes to wording, formatting and presentation style, and convinced policymakers to alter the medium used for communicating with consumers in 2/5 states. In one state, consumer feedback changed how the state talked to consumers about a new mandatory managed care program for dually eligible individuals and Medicaid beneficiaries with long-term care needs. The first presentations to consumers were difficult to understand. Consumer feedback led to concrete changes in presentations and printed materials about the program. Not only were materials more consumer friendly with more pictures and graphics, and less text, but the context was modified to meet consumer needs as well. For example, the state's original materials included only a short paragraph about the program's behavioral health benefits. After consumer feedback, the state added considerable information about how the program addressed behavioral health.

SUSTAINABILITY: LOOKING TO THE FUTURE

Sustainability resulted not only from grantee ability to secure funding for ongoing activities, but also through coalitions that were built through the course of the grant and a self-reinforcing cycle of success.

Cycle of success

Interviews revealed a positive feedback loop that only develops, and accelerates, over time. This positive feedback loop is hereafter referred to as the ‘Organizers’ Cycle of Success’ (Figure 9). In its simplest form, this relationship can be stated as “Success breeds success.” Picking apart the pieces, though, we see three main components. First, the organization builds trust and relationships with individual consumers, communities, coalition partners and decision-makers. These relationships in turn lead to higher levels of consumer participation in the advocacy work of the organization. Both these high levels of participation and the strong trust and relationships facilitate more advocacy wins and successes. These wins, in turn, lead to greater trust and stronger relationships, and motivate consumers to participate more in advocacy.

Descriptions of this cycle emerged across all states and throughout all categories of interviews, from consumers through grantees and decision-makers. One consumer made the link between trust, advocacy success, and participation in this way:

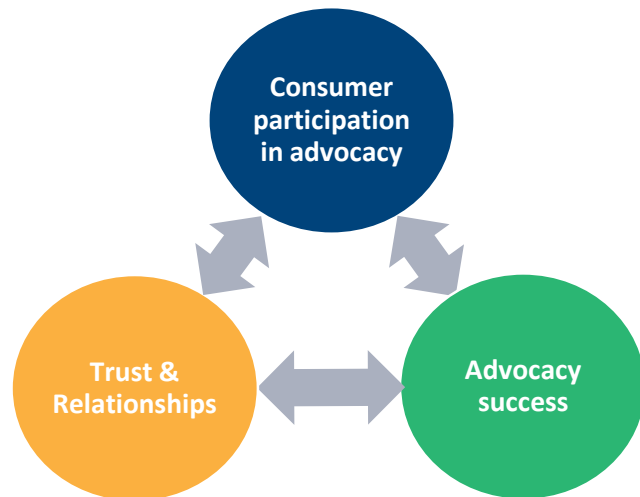
“...knowing that you can make a difference certainly motivates me, and knowing that there’s somebody there pulling for you as well, you’re not out there on your own, is also extremely helpful and motivating... So when you really find people of excellence like that, you know, you gravitate towards them. And you talk about motivation – that’s extremely motivating for me.”
(Consumer, interview)

It emerged clearly that this cycle begins slowly and only accelerates over time. However, the cycle also acquires momentum as it continues, and an initial investment of energy and resources can enable future success.

Coalitions

A few interviews revealed that coalition partners were important to the continuing sustainability plans of grantees. One of the questions in the grantee interview read “How do you plan to maintain the coalition partnerships that you’ve built once this funding has ended?” The assumption behind that question was that maintaining partnerships was an ongoing task that needed funding to keep it up. However, two grantees answered in ways that showed that rather than being just an expense, coalition partnerships could also lead to new revenue streams. For example, one said:

Figure 9. The organizer's cycle of success



“I think we’ve built a really strong relationship with [coalition partner organization]. Because of that, we’ve been fundraising with them on other issues that are completely unrelated to healthcare, but because we’ve built this strong relationship with them, we know have a trusted partner and they have one as well that knows that we know does great work and is reliable” (Grantee, interview).

Both another grantee and a coalition partner described partnerships as means to stretch tight budgets:

“We’re trying to be as creative as possible, and bring all of our coalition partners together, because why would we do two events that are the same when we could, you know, pool our resources and do one amazing event that has a better outcome for everybody? So that’s been our goal is to save our pennies where we can, and make them have the biggest impact” (Grantee, interview).

Funding

Though achieving long-term funding stability was not expected during this two-year grant, CVI 1.0 helped grantees plan for sustainability through a few mechanisms. First, the program established expectations that each grantee would achieve 50% matching funding, which was achieved by all grantees. Second, the program provided TA to some grantees that supported accessing increased funding such as how to pitching concepts to funders. Finally, the program provided TA and guidance on developing coalitions to health systems; fostering coalitions in turn was expected to yield ongoing attention to the topic across a broader range of organizations.

At the end of the grant, all grantees reported that at least some of the activities would continue after CVI 1.0 ended – four reported that some of the activities would continue while one reported that all activities would continue. The activities were expected to be supported through continued funding for three organizations and through incorporation into the operational budget for two. Not surprisingly, participants also discussed sustainability as a source of concern. For example, one decision-maker said:

“I think having this relationship continue for a significant amount of time is important and my worry, sometimes, with this is that if we can’t fund people to continue those relationships over several years that we get a good thing going and then it falls apart because that person can no longer be in that role. That’s important. Things in the United States, there’s not enough time invested. It’s like, “Well, we’ve got this thing. We’re going to go after it and we’re going to do it right now,” and then it kind of subsides or dies and you need to keep that momentum going and you need to keep people engaged with each other so they can keep the momentum going.” (Decision-maker, interview)

CONCLUSION

The engagement of consumers in health system transformation, particularly by vulnerable populations, has emerged as an important strategy for improving health. Yet best practices for doing so are not yet well established. The CVI 1.0 initiative provides several lessons for engaging consumers in health system transformation processes.

First, CVI 1.0 demonstrates that dedicated funds, technical assistance and health systems mentors can help grassroots organizers to mobilize a base of engaged consumers, build consumer leaders, and advance consumers up a 'pyramid of engagement'. During the course of a two year grant, nearly 30,000 consumers were reached, nearly 5,000 were added to the base, and over 1,000 leaders were recruited and trained.

Second, this engagement can lead to a permanent and effective consumer voice in the health care system, and changes in policies or other local efforts that are responsive to the needs of underrepresented communities. In all five states, grantees achieved process changes, or changes in how policymaking bodies operated in order to facilitate consumer participation. Grantee efforts also led to consumer-friendly changes in how insurers communicate with members or enrollees in 2/5 states. Finally, grantee efforts led to policy or practice changes that were responsive to consumer needs in 4/5 states. For example, as a result of this initiative, 18,000 seniors on Medicaid have access to transportation which supports social and health activities as well as overall well-being and 170K Medicaid recipients will not be charged medical co-pays.

CVI 1.0 identifies best practices for consumer engagement in health system transformation. To build consumer leaders, grantees focused on providing capacity support, fostering a sense of self-efficacy, being optimistic and authentic, and investing in relationships and comradery. Influencing coalition leaders and decision-makers was accomplished by serving as "translators" between the language of policy and the everyday language of consumers, working closely with individuals of relevant professional backgrounds, and serving on consumer advisory boards or other committees that facilitated contact with decision-makers. Ultimately, these best practices culminated in an organizers' cycle of success which was described by grantees, consumers and decision-makers alike. In this cycle of success, consumer participation in advocacy, advocacy success, and establishment of trust and strong relationships functioned as a reinforcing loop that bred sustainability.

Incorporating lessons learned from this program, the Center has now launched the CVI 2.0 program. CVI 2.0 aims to build an engaged base of consumers to advocate for policies and programs that expand how the health care sector addresses the social and economic drivers of health. Lessons learned from CVI 1.0 and 2.0 will help the Center as well as policy makers, advocacy organizations, health systems, and funders seeking to advance consumer engagement in health and social systems changes.

"...largely through the continued support that we've gotten from Community Catalyst and other organizations over the past five or ten years is that we are kind of the go-to consumer focused health care [advocacy] organization in [state]. So because we are that, I think our voice carries a lot of weight in the legislature and we're able to . . . advocate for the [consumer-focused legislation]. People trust us, that what we're saying is based in fact and based in what's in the best interest of consumers." (Grantee, interview)

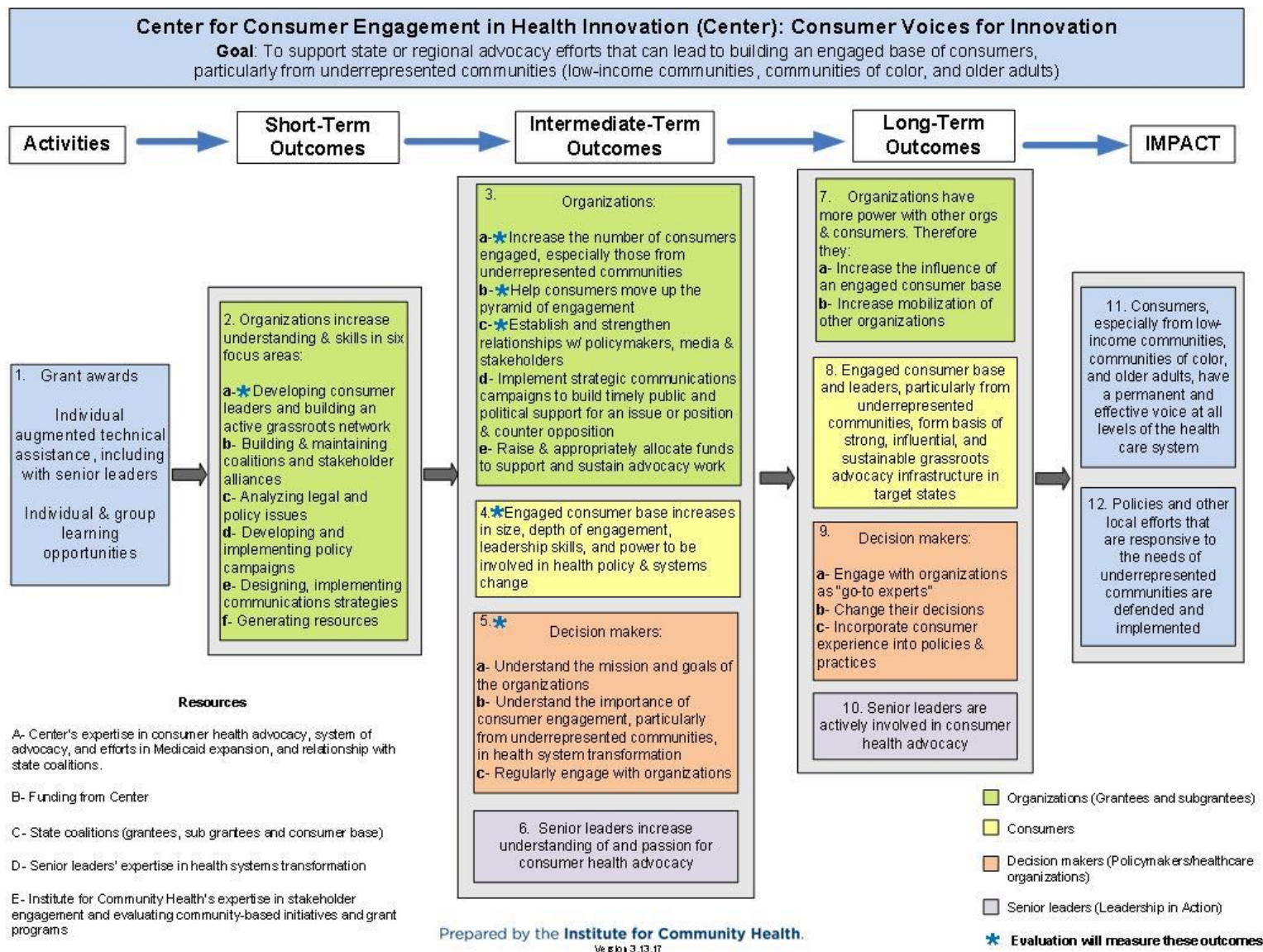
APPENDICES

Appendix A: Logic Model

Appendix B: Grantee Profiles

Appendix C: Evaluation Methods

Appendix A – Logic model



Appendix B – Grantee profiles

MARYLAND CITIZENS' HEALTH INITIATIVE EDUCATION FUND (MCHIEF) Baltimore, Maryland

Objective: communities of color, low-income communities, older adults

Overview

MCHIEF engaged stakeholders, particularly from the faith community, to drive health system transformation through a program called the Maryland Faith Health Network (MFHN). MFHN creates the infrastructure needed for hospitals to connect with faith communities when congregants are hospitalized. This helps provide timely support and quickly address issues that may arise once congregants are discharged.

Key activities

- Expanded MFHN by recruiting hospitals, congregations and congregants to collaborate on HST
- Trained liaisons to assist hospitalized congregants and provide consumer experience feedback
- Increased consumer engagement in public workgroups
 - Represented consumers' interests and recruited consumers to serve in major workgroups
 - Requested orientation materials about the State Health Information Exchange which were shared with workgroup members and made publicly available
- Hosted public forums on HST and ACA/Medicaid defense for consumers to learn and share ideas
- Defended ACA and Medicaid by securing the creation of the Maryland Health Insurance Coverage Protection Commission, which is working to protect coverage gains made under the ACA
- Championed a "Health Insurance Down Payment Proposal" to stabilize premium rates in the Exchange

Outcomes and impacts

Consumer engagement

- Reached out to over 8400 consumers
- Added over 1200 consumers to base
- Recruited and trained 60 new consumer leaders

HST promotion

- MFHN gained recognition as a mutually beneficial mechanism to support consumers and bring health into faith communities, especially for communities of color
 - Baltimore County Executive's Transition Team report recommended expansion of MFHN
 - MCHIEF was approached by the Maryland Health Services Cost Review Commission (HSCRC) to help conduct focus groups with consumers to get consumer input on the state's delivery reform initiatives
- MFHN became the only non-provider organization in the state able to upload information about a person's social connections in the State Health Information Exchange
- State workgroups changed their practices to better support consumer engagement

- MFHN is helping to ensure that patients' wishes are documented and honored through promoting completion of advance directives among MFHN partners
- Plans are underway for MFHN to expand technical assistance to an additional six health systems

Lessons learned

- Advocacy organizations can play an important role in bringing together health systems and consumers to collaborate on HST. Organizations should give careful consideration about when to integrate this work with broader advocacy efforts and when to keep this work separate
- Faith communities bring tremendous professional expertise and deep moral commitment to ensuring that their members and the community at large get the best possible care
- The trust built through this work, clearly demonstrating a shared commitment to improving health care experiences of those in our communities, is essential to convincing people that their time on these workgroups would be/could be impactful

MAKE THE ROAD NEW YORK (MRNY) New York City, New York

Objective: communities of color, low-income communities

Overview

MRNY operates a community health worker (CHW) program that, in part, advocates for the inclusion of immigrant voices in HST and is actively involved in ACA defense work. MRNY aimed to improve grassroots participation in a Performing Provider System (PPS) in order to make it more responsive to community needs and to increase the role of CHWs.

Key activities

- Advocated with PPS leaders for greater engagement with community-based organizations
- Developed informational materials to educate consumers about HST
- Trained CHWs to better understand HST
- Developed base-building training for CHWs: “[they] have refined their training such that they really have it down to a science now.... They've got a good training program here that helps spark interest in delivery reform issues that can be used by other groups.” –TA tracker
- ACA and Medicaid defense through consumer stories collection, calls to elected officials, and public events
- Held meetings with MRNY members and clients to discuss health system reform
- Prepared members to go to Coverage for All lobby days to share their healthcare stories with elected officials and to speak at press conferences
- CHWs used a social determinants of health (SDOH) screening tool to guide conversations with families and to identify unmet needs

Outcomes and impacts

Consumer engagement

- Reached out to over 2400 consumers
- Added over 340 consumers to base
- Recruited and trained over 230 new consumer leaders

HST promotion

- Selected to serve for one year on strategic advisory workgroup organized by a PPS to advance HST
- NYC Cares announced on January 8, 2019 after years of advocacy – a program to improve access to services for 600,000 uninsured undocumented immigrants. MRNY featured in press statements
- Helped consumers participate in the first-ever bilingual NY Coverage For All in person meeting; provided full logistical support to conveners and participants including facilitation of simultaneous interpretation, translation of materials and individual preparation for monolingual Spanish speakers to participate in the event
- Initiated and continued conversations with community and industry leaders to discuss issues in HST
- Provided feedback to a PPS on CHW contract provisions, some of which was incorporated into the final contract documents
- Consumer advocate was added to a PPS Executive Committee
- Continued to track challenges faced by consumers seeking to access the Health + Hospitals fee scale program
- Engaged CHW students in HST promotion as part of their coursework

Lessons learned

- There is no need to work on HST as a whole; picking a piece of HST is more effective
- Working on building coalitions is important
- Building a base specifically or only around HST is challenging; connecting HST to other topics of interest helps
- “They've had a lot more success with low volume, intensive touch strategies, like training, or working through their navigators and CHWs, who have significant contact with consumers.” – State Advocacy Manager, TA tracker
- Recruiting leaders who had worked with our CHWs or MRNY before was an effective strategy

OREGON STATE PUBLIC INTEREST GROUP (OSPIRG)
Unite Oregon (year 1 & 2) & Oregon Latino Health Coalition (OLHC) (year 1 only)
Portland, Oregon

Objective: communities of color, low-income communities

Overview

OSPIRG works on policy development, legislative advocacy and on-the-ground organizing. Along with their partners, Unite Oregon and OLHC, OSPIRG aimed to organize grassroots participation in Coordinated Care Organizations (CCOs) in southern Oregon and increase the influence of consumers and focus on addressing social determinants of health (SDOH) in the CCOs.

Key activities

- Published press statements to illustrate potential negative impact of ACA repeal on consumers and state
- Engaged new Oregon Health Authority leadership to discuss next steps for the state's HST effort and the need for increased transparency and accountability for CCOs
- Organized community meetings on HST, Medicaid access and the threat of ACA repeal
- Attended meetings with stakeholders, such as the Community Advisory Councils (CACs) of local CCOs, the steering committee for Southern Oregon Health Equity, and the county Perinatal Task Force
- Conducted advocacy and education meetings with state legislators about HST, Medicaid access and health equity
- Monitored and provided feedback to the state's rollout of CCO 2.0
- Provided listening sessions and trainings for members of CACs to increase their advocacy skills

Outcomes and impacts

Consumer engagement

- Reached out to over 13,900 consumers
- Added over 1,200 consumers to base
- Recruited and trained over 340 new consumer leaders
- Established a new base of grassroots support for Unite Oregon in Josephine County

HST promotion

- Passed the state's first significant reform to the Medicaid CCO system since it was established
- Secured health care coverage for all Oregon children, many of whom were previously ineligible
- Gathered and processed information through a statewide consumer survey that collected over 200 responses
- Increased the number of consumer seats on CACs, and helped build the skillsets of consumers already serving on CACs and CCO boards
- Worked on housing advocacy and the first statewide rent stabilization law in the United States after noticing that housing was a top concern in the state and local health assessments

Lessons learned

- Legislative advocacy can take a couple of 'failed' rounds before succeeding
- Consider how to integrate grassroots organizing with policy change goals, and how to funnel grassroots energy into the right place

- Organizing Medicaid consumers is difficult, and *“It’s absolutely critical, but you have to figure out how to do that in a way that’s strategic and coordinated with other things that you’re doing to try to amplify what that work can actually mean, so that you can show that it’s really worth people’s time to do it, if nothing else.”* (Interview participant)
- Consumer testimony is very useful in moving policy-makers on health care
- Building relationships with existing CCOs, health systems, coalitions, and individuals across counties helps
- A single individual can totally define and drive small operations, so staff departures can represent a substantial change, potentially requiring significant adjustments for a grant-funded project

PENNSYLVANIA HEALTH ACCESS NETWORK (PHAN)
Southeast Asian Mutual Assistance Associations Coalition (SEAMACC) (year 2 only)
Philadelphia, Pennsylvania

Objective: communities of color, low-income communities, older adults

Overview

PHAN is Pennsylvania's main consumer-led health care organization. PHAN's goal was to organize consumers affected by the rollout of managed long-term services and supports in Pennsylvania's Medicaid program, with a focus on mobilizing seniors who are eligible for both Medicaid and Medicare.

Key activities

- Held conversations and meetings with policymakers
- Conducted listening and education sessions (e.g., community conversations) about the new Medicaid managed care program, Community Health Choices (CHC)
- Continued partnership with SEAMAAC with a focus on support and development of consumer friendly materials
- Conducted "Lift Up Your Voice!" trainings for potential consumer leaders
- Formed partnerships with community based organizations and religious groups to coordinate strategies
- Administered a "consumer experience survey" to understand experience with new CHC managed care plans. Facilitated workgroups and conducted webinars to engage consumers on various health care access topics (CHC and immigrant community workgroups, long-term care webinar series to present on a new expedited eligibility process for nursing home residents seeking to transition back home, Services My Way workgroup)

Outcomes and impacts

Consumer engagement

- Reached out to 2,800 consumers
- Added over 1,100 consumers to base
- Recruited and trained over 160 new consumer leaders

HST promotion

- Successfully advocated to the Office of Long-Term Living (OLTL), which is managing the rollout and program design of CHC, to build consumer engagement and grievance processes into the metrics for success for the new CHC implementation process
- Successfully advocated for and conducted observations of individual care planning sessions between consumers and CHC's service coordinator in order to advocate for consumers and provide feedback to CHC
- Successfully created and supported the Services My Way workgroup, a consumer-led committee of officials from OLTL, the CHC plans, the fiscal agent, and advocates to work on improving operations of, education about, and understanding of the full budget authority model of home and community based services
- Encouraged diverse consumer leaders to use personal experiences to advocate for and engage in HST
- Advocated to change protocols around arranging medical transportation for nursing facility residents, to minimize confusion and ensure quality and safety

- Discussed with Maximus, the state’s independent enrollment broker, the need to improve language assistance for limited English proficient consumers applying for long-term services or choosing/changing a CHC plan

Lessons learned

- Community organizing is a multi-year investment
- “Crack[ing] the code” to make HST simple is important
- Contacts made at events – both hosted and attended – lead to fruitful partnerships
- Well-focused local earned media placements can result in successful outreach
- Invest time in building relationships – both in person and on the phone

RHODE ISLAND ORGANIZING PROJECT (RIOP) Providence, Rhode Island

Objective: communities of color, low-income communities, older adults

Overview

RIOP works for social change through community organizing and empowerment. RIOP aimed to promote better health care outcomes through better care coordination, increased access to home and community-based services, and improved access to transportation for low-income seniors.

Key activities

- Sponsored house meetings for consumers to learn about the ACA, Medicaid and other health care issues
- Invited consumers to participate in public hearings to share their stories about the impact of increased bus fares on their lives
- Mentored consumer members of the Integrated Care Initiative (ICI) Implementation Council by helping them debrief the meetings, by sponsoring house meetings, and by taking action in the community on key issues
- Organized the “Lift Up Your Voice!” training to educate consumers about the health care system
- Sponsored trainings on how consumers can use their stories to get other people involved in health care, transportation and aging issues
- Continued work with allies to roll out the IP (Independent Provider) model for homecare workers, and conducted outreach in the community to identify homecare stories
- Prevented Medicaid co-pays in state’s FY2019 budget

Outcomes and impacts

Consumer engagement

- Reached out to over 1,300 consumers
- Added over 550 consumers to base
- Recruited and trained over 180 new consumer leaders

HST promotion

- Restored the state public transit authority’s (RIPTA) No Fare Bus Pass for seniors by having consumers provide testimonies and write support letters to public officials. The Governor put \$3.4 million for the No Fare Bus Pass in the state’s FY2020 budget
 - 18,000 people will benefit from continued funding of the No Fare Bus Pass Program (4 million rides)
- Participated in the RIPTA planning committee to find a sustainable solution to keeping transportation free for seniors and people with disabilities
- Worked closely with the RI Medicaid Director and EOHHS to rollout a new NEMT vendor, as well as recommended improvements to the system (call center, computer systems and driver dispatch system)
- Sixteen people were recruited to be on the 2019 Implementation Council (ICI)
- A new consumer oversight board was created for the non-emergency medical transportation (NEMT) system
- Built alliances with organizations that serve vulnerable adults dealing with homelessness, mental health issues, and disabilities, as well as the local branch of SEIU, the largest health care union in the US

Lessons learned

- Flexibility and willingness to try out new things are key
- Meeting consumers where they are (e.g., senior center, recovery facility) is critical for working with seniors
- House meetings are an effective format to identify new leaders, discuss with the community, and listen to their concerns
- One-on-one mentoring and role playing were the most successful leadership development tools
- Rallies and public hearings were helpful to identify potential leaders who can motivate other consumers

Appendix C – Evaluation methods

Table 1. Overview of evaluation activities

Activity	Goal	Participants
Grantee survey (baseline, midpoint, final)	Assess changes in the size of the consumer base, depth of consumer engagement, grantee capacity, relationship with decision-makers, and grantee perceptions of changes in decision-maker understanding	Baseline: 6 grantees Midpoint and final: 5 grantees
Stakeholder interviews (midpoint and final)	Deepen understanding of grantees' grassroots organizing efforts, successes, challenges and lessons learned	<ul style="list-style-type: none"> • 1-2 staff members from each grantee (midpoint and final) ; • 1 consumer per grantee (final) • 1 decision-maker or coalition member per grantee (final) • 24 total interviews, 28 individuals
Consumer survey (midpoint and final)	Understand activities consumers participated in; identify best practices for effective engagement and leadership development strategies from the consumers' perspective	Consumers from each state <ul style="list-style-type: none"> • 112 at midpoint • 72 at final • 184 total surveys completed
Review of grantees' quarterly reports and Centers' technical assistance tracking	Summarize key points about grantees' progress and impacts; understand program implementation activities such as types of technical assistance provided	Grantees, Center staff

Table 2. Data Collection Instruments

Data Collection Instrument	Time period administered
Grantee Quarterly Report Template	Quarterly, May 2017 – April 2019
Baseline Grantee Survey	May/June 2017
Midpoint Grantee Survey	April 2018
Final Grantee Survey	March/April 2019
Consumer Survey, Year 1	January / February 2018
Consumer Survey, Year 2	January / February 2019
Grantee Interview Guide, Midpoint	January 2018
Grantee Interview Guide, Final	February/March 2019
Consumer Interview Guide	February/March 2019
Decision-maker/Coalition Partner Interview Guide	February / March 2019