



Consumer Voices for Innovation 2.0 (CVI 2.0) Interim Report

OCTOBER 2020



INSTITUTE FOR
COMMUNITY
HEALTH



CENTER FOR CONSUMER ENGAGEMENT
in health innovation
A better way to better health. For everyone.

Consumer Voices for Innovation 2.0 (CVI 2.0) Interim Report

OCTOBER 2020

PREPARED FOR:

The Center for Consumer Engagement in Health Innovation

PREPARED BY:

Institute for Community Health

350 Main Street

Malden, MA 02148

www.icommunityhealth.org

TEAM:

Carolyn Fisher, PhD

Sofia Ladner, MPH

Leah Zallman, MD, MPH

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.

Table of Contents

EXECUTIVE SUMMARY	4
BACKGROUND	6
GRANT MAKING PROGRAM AND EVALUATION ACTIVITIES	7
Institute for Community Health: Evaluation activities	7
The Center: Program activities	8
GRANTEE ACTIVITIES AND OUTCOMES	9
Organizing in a time of chaos: Implications of 2020 crises	9
Internal organization capacity-building	12
Grassroots organizing	13
Increasing depth of engagement and consumer leadership development	15
Building relationships between organizations	17
Policy wins	19
Racial equity work	20
CONCLUSIONS AND LESSONS LEARNED	22
APPENDIX A: GRANTEE PROFILES	24
APPENDIX B: LOGIC MODEL	31
APPENDIX C: SURVEY DETAILED DATA	32
Consumer demographic survey	32
Grantee survey	33
APPENDIX D: DATA COLLECTION INSTRUMENTS	36

EXECUTIVE SUMMARY

The COVID-19 pandemic has catalyzed unprecedented challenges to health and economic security, fundamentally changing all aspects of life in the U.S. These challenges, combined with nationwide protests related to police violence and racial justice, have created an imperative to address the underlying social determinants of health (SDOH) - such as food insecurity, housing insecurity and transportation access- and the racial inequities that contribute to poor health. Despite this, there remains uncertainty about the best strategies to engage consumers in driving necessary changes for SDOH and racial justice in health.

Prior to the COVID-19 pandemic and related economic disruption and racial justice movements, recognizing the importance of consumer engagement in SDOH policies, the Center for Consumer Engagement in Health Innovation (the 'Center') launched the two-year Consumer Voices for Innovation 2.0 (CVI 2.0) grant program. This program, which started in May 2019, supports seven state health advocacy organizations to build an engaged base of consumers to advocate for policies and programs that expand how the health care sector addresses the SDOH. The program focuses on food security, housing security and non-emergency medical transportation (NEMT) for consumer communities that have been traditionally left out of policy conversations including: people from low-income communities, people of color, and/or older adults.

Each grantee receives funding, technical assistance (TA), and access to group learning opportunities from the Center. The Institute for Community Health is conducting a mixed methods evaluation incorporating learnings from surveys and interviews with grantees, a consumer survey, conversations with Center staff, and review of quarterly reports.

In the first year, grantees used a few key strategies to engage consumers.

Grantees built strong relationships and trust among local communities, addressed concrete needs, and digitally engaged consumers. When the pandemic hit the US in March of 2020, these organizations were already in a position to pivot rapidly to become vital resources for their communities. This rapid ability to pivot helped the grantees increase engagement amidst chaos: the number of consumers participating in activities at all levels of engagement (from interest to leadership) more than tripled.

CVI 2.0 provides several lessons for engaging consumers in SDOH advocacy. First, CVI 2.0 highlights that remote or distanced organizing through online platforms and other remote means of communication is a viable means of connecting with consumers, even among some low-income or disadvantaged communities for whom it was previously not considered viable. Second, dedicated funding, TA, and group learning opportunities can help grassroots organizers to mobilize a base of engaged consumers, build consumer leaders, and deepen



7,066
CONSUMERS
ADDED TO BASE

consumer engagement in SDOH policy. Indeed, during the first year of the grant, over 51,000 consumers were reached, over 7,000 were added to the base, and over 800 leaders were recruited and trained. Grantees more than doubled the number of organizations they worked with, from 51 to 107. Grantees noted that organizing for housing, food security or NEMT changes was facilitated by the fact that these issues resonated easily with both coalition partners and grassroots consumers. They also noted that some of the issues, particularly ones

related to Medicaid policy, included complexity that required significant investment in educating themselves and consumers.

Despite significant changes in the policy landscape due to the COVID-19 pandemic and related economic disruption and racial justice movement, CVI 2.0 showed that an engaged consumer base can help change policies. Grantees in six of the seven states influenced policy wins during the first year. Policy wins occurred in each SDOH focus area, with five in transportation, three in housing, two in food, and an additional five related to the COVID-19 pandemic.

51 Baseline → **107** Interim
Increase in number of
organizational relationships

Understanding how to engage vulnerable consumers in advocating for social needs policy change has never been more relevant than in 2020. The COVID-19 pandemic and related economic disruption and racial justice movements have highlighted the danger of creating systems that do not engage communities in developing solutions to underlying social needs; the CVI 2.0 program is well-positioned to identify how to support consumer voice in developing the long-lasting changes needed to address the underlying social and economic drivers of health.

BACKGROUND

The year 2020 has seen unprecedented challenges to health and economic security, fundamentally changing all aspects of life in the US. This year has seen a series of crises, with the COVID-19 pandemic and related shutdowns beginning in March 2020, followed by significant economic disruption and widespread unemployment, and in late May nationwide protests related to police violence and racial justice. Even before these crises, there had been increasing recognition of the importance of social determinants of health (SDOH) - such as food security, housing security and transportation access - in driving health and health disparities. The crises of 2020 brought into prominent focus the need to advocate for improvement in SDOHs, in particular focusing on underlying structural inequalities, particularly along racial lines. While removing the structural barriers that lead to these inequalities is the focus of much advocacy, there remains uncertainty about the best strategies for engaging affected consumers in advocating for changes.

From 2017-2019, Community Catalyst’s Center for Consumer Engagement in Health Innovation (hereafter, ‘the Center’) led an innovative and successful effort, the Consumer Voices for Innovation 1.0 program, to support grassroots organizing and base building in health system transformation.¹ In 2019, utilizing lessons learned from that effort, the Center launched the Consumer Voices for Innovation 2.0 (CVI 2.0) grant program. The goals of CVI 2.0 are to (1) support state efforts to build an engaged consumer base in order to permanently foster engagement in advocacy for SDOH, with a particular focus on communities of color, and (2) understand the most effective strategies for engagement in SDOH advocacy.

The program focuses on food security, housing security and transportation, with a specific lens on the non-emergency medical transportation (NEMT) benefit in the Medicaid program. Grantees have all embraced policy goals designed to increase the ability of the health system to address the SDOH (Appendix A). Over the long term, the goal is to foster consumer activism in SDOH advocacy, especially in low-income communities, communities of color, among people with disabilities, and/or in communities of older adults. During the first year, CVI 2.0 funded a total of 7 grantees and 6 subgrantees across seven states (Table 1). This interim evaluation report reflects learnings from the first year of the two-year project.

Table 1. Summary of Grantee Program Objectives	
Grantee (subgrantee)	Program Objectives
Alabama Arise (Bay Area Women Coalition)	Intensive grassroots organizing focused on a low-income African-American neighborhood in Mobile, Alabama to engage the community around food security and Medicaid’s ability to improve access to healthy foods.
Together Colorado (Center for Health Progress)	Organizing communities to address access, inefficiencies, and poor customer service in the state’s Medicaid NEMT program.

¹ Consumer Voices for Innovation: Grant Program Evaluation Final Report. Leah Zallman, Carolyn Fisher, Sofia Ladner, Kirstin Lindeman, Martina Todaro. <https://www.healthinnovation.org/resources/publications/consumer-voices-for-innovation-grant-program-evaluation-final-report>

Georgians for a Healthy Future (GHF) (The Arc Georgia)	Mobilizing communities across the state around the Medicaid NEMT benefit, with a particular focus on people with intellectual and developmental disabilities.
Maine People’s Resource Center (MPRC) (Maine Community Integration)	Grassroots organizing around the state’s Medicaid NEMT benefit, seeking to improve access and customer service particularly by engaging different stakeholder groups.
Massachusetts Senior Action Council (MSAC) (New England United For Justice)	Organizing among low-income seniors to improve access to Supplemental Nutrition Assistance Program (SNAP) benefits and to increase the ability of health plans to address food security.
Make the Road New York (MRNY)	Improve housing security through an integrated asthma CHW program, with a focus on increasing public investment in the program.
Pennsylvania Health Access Network (PHAN) (New Voices for Reproductive Justice)	Organizing consumers to improve access and customer service in the state’s Medicaid NEMT program, called the Medical Assistance Transportation Program (MATP), with a focus on rural and communities of color.

GRANT MAKING PROGRAM AND EVALUATION ACTIVITIES

Institute for Community Health: Evaluation activities

The Institute for Community Health (ICH) is 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 B). This framework reflects the Center’s approach to consumer engagement, understood as a pyramid of five levels of engagement.² These formative activities led to the following key evaluation questions:

- How many consumers (particularly from low-income communities, communities of color, people with disabilities 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: grantee surveys, consumer surveys, stakeholder interviews with grantees and review of grantees’ quarterly reports (Table 2). In order to understand how grantees adapted to the COVID-19 pandemic, ICH conducted an additional set of grantee interviews in late summer of 2020.

² Community Catalyst Pyramid of Engagement. <https://www.communitycatalyst.org/resources/tools/pyramid-of-engagement>

Table 2. Overview of Evaluation Activities*		
Activity	Goal	Participants
Grantee survey (baseline, interim)	Assess changes in the size of the consumer base, depth of consumer engagement, grantee capacity, and relationships with coalition partners	7 grantees at baseline and interim (14 total)
Grantee interviews	Deepen understanding of grantees' grassroots organizing efforts, successes, challenges and lessons learned	1-2 staff members from each grantee in early 2020 and late summer 2020 (14 interviews with 21 interviewees)
Consumer demographic survey	Understand the demographic characteristics of community members engaged in advocacy efforts	Consumers from each state at baseline and interim (95 total)
Quarterly reports	Build familiarity with grantees' activities, goals, successes and challenges	Quarterly reports from each state (28 total)

*see Appendices C and D for detailed data and instruments

The Center: Program activities

Funding: The Center provided \$700,000 dollars to the grantees in the first year of the program (\$100,000 per grantee).

One-On-One Technical Assistance (TA): The Center's state advocacy managers (SAMs), policy analysts, communication staff and mentors provided customized TA to grantees. 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. Specific topics addressed varied widely according to the specific needs of the grantee.

Grantees highlighted TA in some areas as particularly helpful, including policy analysis and advocacy, and coalition and stakeholder alliances (connecting with other organizations). They also highlighted the importance of having an organization, like the Center, that is very accessible and responsive to TA requests. At the same time, they noted that they were sometimes unsure about what type of TA to request, and that it was helpful when the Center proactively suggested ways in which they could help.

Group Learning Opportunities: The Center offered multiple group learning opportunities for grantees and consumer leaders. Regularly scheduled learning community calls focused on a variety of topics, such as sustainability, effective consumer advocacy strategies, the impact of managed care on individuals with intellectual and developmental disabilities, using academic research in policy advocacy, and federal and state policy changes in light of the COVID-19 pandemic. Grantees also participated in a Partner Meeting in November 2019 in Washington, DC where they heard from national speakers, participated in a wide variety of workshops and networked with their colleagues. Grantees brought consumer leaders to this

meeting, providing the consumers with an opportunity to build their leadership skills and share their experience by serving as speakers on workshop panels. Grantees noted that formal learning opportunities were effective in communicating large amounts of information. Grantees suggested that informal opportunities to connect with other grantees would be valuable as well.

GRANTEE ACTIVITIES AND OUTCOMES

Organizing in a time of chaos: Implications of 2020 crises

The COVID-19 pandemic and related economic disruption and racial justice movements ushered in an unprecedented time for organizing. These crises created a series of unanticipated challenges, but also some surprising opportunities. In response, all grantees reoriented their work, often cancelling or postponing planned activities, and all re-prioritizing their work to adapt to the new reality. The main strategies that grantees used to address the crisis were: focusing more on meeting consumer needs; adapting to remote work and organizing; and shifting policy goals.

Figure 1. Main strategies used to address the crisis



Focusing more on meeting consumer needs: A key way in which grantees pivoted their work was to focus on helping fill the gaps in increased concrete needs faced by their priority communities. Some grantees focused on food – two did wellness checks with members, another began assisting people with SNAP applications, and three others became involved in direct food distribution. In two cases these initiatives were led by consumer leaders. One grantee launched a state-wide digital platform to help consumers connect to social services - from this platform they were able to add people to their base. Some grantees working on NEMT also focused on concrete pandemic-related needs by advocating for infection safety measures in transportation such as making sure drivers are wearing masks. Early on, one grantee found that their members were overwhelmed by the crisis to the extent that they struggled to engage with the organization. Other grantees, however, found that members were seeing them as crucial advocates for their needs during the crisis.

You can't have a conversation with anyone about anything that does not somehow connect to COVID-19.

We're just working on new ways of making sure people feel connected, even though they're not in person, and make sure they still can see each other virtually and can still feel like we're out there supporting.

Adapting to remote work and organizing: The pandemic caused all grantees to shift away from in-person activities, both within the organizations and in their externally facing work. Several grantees perceived challenges with getting their population on digital platforms and responded in innovative ways. A few grantees held large digital events (e.g., on Facebook Live) and found these were far more heavily attended than anticipated. Other grantees that work with rural populations

noted lack of internet access to be a challenge for engaging with their population, resulting in postponement of activities; grantees identified some solutions to the internet challenge such as drive-in meetings, communicating via text messaging, using dial-in conference calling, and even old-fashioned phone trees instead of Zoom or other high-tech methods. Another grantee used funds and found donations to purchase and distribute tablets to members without access to the internet, along with a multi-month subscription to internet access. A third grantee developed new strategies to support group discussions and collective decision making through Zoom. Finally, a grantee working with organizers and consumers with disabilities invested significant time helping organizers access digital platforms and worked on mechanisms to increase accessibility.

Grantees found these efforts paid off: four grantees reported an increase in engagement once they shifted to online/digital engagement activities due to a decrease in the barriers presented by traveling and other time limitations. All grantees reported a positive experience with getting staff on board with remote work and adopting new technologies. One grantee stated: "I think we are figuring out how to not get burned out while staying focused on our goals...in some ways it's helped grow the momentum on this work in particular." A few grantees already had staff working remotely across their state before the pandemic hit; they already had systems for remote work in place, including workplace cultural norms and working expectations. This made the transition in response to the pandemic smoother.

We've actually seen an uptick in people participating because they want more ways in which they can be engaged to overcome that isolation, and organizing presents a really unique opportunity because not only is it something -- it's an educational opportunity, but it's also an opportunity to actually be able to do something and to be invited into something bigger. So people have seemed really hungry for those kinds of experiences.

Shifting policy goals: The policy goals of all grantees changed in response to the new reality of the pandemic. Due to the early adjournment of their state legislatures, two grantees shifted their advocacy priorities away from legislation that was newly “dead in the water.” Two other grantees maintained their focus on their original priorities, but found that they were forced to slow down their work as their partners were redeployed to work on pandemic-related issues. One grantee carved out a new role with policymakers in assisting with communication to their constituent communities, thereby strengthening these relationships. Several interviewees made the point that their SDOH topics felt even more urgent now than previously, and one commented that more radical solutions were newly “thinkable” in the public mind due to the crisis of the pandemic.

We've had to educate ourselves so that we can educate them. You can find somebody who is sympathetic to solving this problem, or has had bad experiences about the system, but still immediately has questions that are all very straightforward: Who gets Medicaid transportation? How much does it cost? Why's it set up this way? You know, where does my ride come from? For them to actually have meaningful answers, it requires a lot of training.

Two grantees pivoted their NEMT-related policy work to apply pressure on their state to provide continued access to rides during the pandemic, and safety for riders and drivers through government-mandated continued use of personal protective equipment and social distancing efforts. Two grantees focusing on housing found that advocacy for housing felt more urgent, even though their original housing policy focus was now less urgent than focusing on eviction moratoriums. Two grantees discussed not changing their overarching policy agenda, but will be looking for opportunities to make positive change on their topics during the pandemic, for example by adding on telehealth to their NEMT campaign.

Overall, the grantees that showed the most flexibility were the ones that were able to stay the most active during the pandemic – shifting their strategies and tactics allowed grantees to maintain or increase their relevance among their constituents and their policymakers of focus.

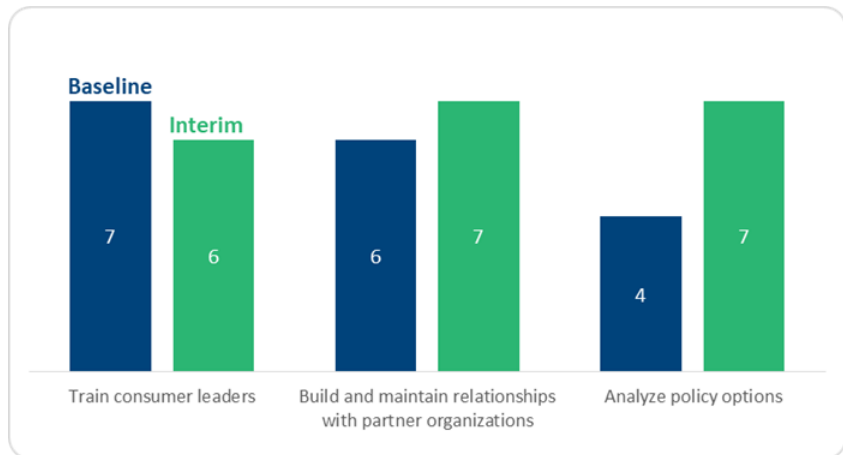
Internal organization capacity-building

During the first year, grantees built capacity in a variety of areas (Figure 2). In large part because understanding social needs and healthcare policy was so complex, grantees focused much of their effort on learning about the issues and the policy environment. For example, several grantees focused on Medicaid NEMT, which required understanding complex Medicaid policies.

Given the complicated nature of the policy and issues, it is unsurprising that grantees' reports of their own capacity to "analyze policy options" showed the largest increase on the survey. A second area of focus was building connections with other organizations; while *most* grantees reported strong to very strong capacity to build and maintain relationships with these other organizations at baseline, by the end of the first year, *all* grantees reported having strong or very strong capacity in this area. Building and maintaining relationships was seen as an important part of sustainability for organizations. Finally, grantees reported building internal infrastructure to make connections between the issues, such as between their housing campaigns and their health campaigns. For example, one grantee newly created a series of meetings between their internal organization's housing committee and the health committee.

Across most areas, grantees rated their own capacity as relatively high at baseline (see Appendix C for detailed capacity results) – possibly reflecting a social desirability bias related to being asked to report one's own ability to perform to a funder. Yet, despite starting high, most categories did show some increase. The only capacity for which grantees reported a decrease was the capacity to train consumer leaders. Interview data suggest some reasons for this decrease. First, several grantees were working with new populations, and began working with these populations slowly in order to focus on relationships and trust building. Second, several grantees found that their policy goals were complicated, without an obvious "ask" around which they could orient their leadership building. For both reasons, grantees focused less on building leadership, instead concentrating on the preliminary steps of relationship building and internal organizational education and capacity building.

Figure 2. Number of Grantees Reporting "Strong" to "Very Strong" Capacity to Conduct Activities



Grassroots organizing

Increasing the size of the consumer base, particularly for priority communities, was a key goal of this program. Across the entire first year, grantees reported making contact with a total of 51,213 new people. As a result of this outreach, 7,066 consumers were added to the base (i.e., grantees obtained contact information and put that information in their database). The program was successful in reaching the priority communities. Among consumers responding to the consumer survey over two time points (total responses n=95), 94% were a member of at least one of these priority communities: 71% were people of color, 32% were disabled, 23% were caregivers for a person with a disability, and 26% were 65+ years old. Forty-three percent had very low incomes, defined as having vulnerability in at least one of the following domains of social determinants of health: food insecurity (22%), homeless or unstably housed (21%), transportation needs (20%), and/or at risk of losing utilities such as electric, gas, water or oil (9%).

51,213
CONSUMERS
REACHED

7,066
CONSUMERS
ADDED TO BASE

During this first year of the grant, grantees focused much of their effort on outreach. Similar to grantees in CVI 1.0, grantees built trust and addressed concrete needs as strategies to build their bases. In addition, a new strategy emerged – grantees used digital/survey engagement (even before the COVID-19 pandemic) and found that to be an effective strategy. To build trust, grantees worked through existing member relationships in priority communities and fostered relationships with partner community organizations that already had the trust of the priority communities. Grantees also built trust and added new people to their base through addressing concrete needs of priority communities. For example, one grantee organized activities like food distribution and neighborhood cleaning events to connect with the community. This grantee noted that both the process of working with communities on projects and the outcomes of these projects helped engage community members. Another grantee employed community health workers that visited the homes of patients with asthma. While addressing their asthma concerns, these health workers also completed housing assessments and signed up interested individuals to learn more about advocacy efforts. Finally, even before the COVID-19 pandemic increased focus on remote strategies for organizing, grantees were adding to their base through digital

Figure 3. Strategies to build an engaged consumer base for SDOH



engagement by using techniques like building Facebook groups and online survey distribution.

A key factor that supported these goals was the fact that all of the SDOHs addressed by the grantees had resonance with their priority communities. At the same time, grantees faced challenges in building their base, particularly around NEMT. Grantees noted that this was a new and somewhat complicated policy issue for them to address. Grantees needed education on NEMT policy themselves in order to, for example, learn about how broker systems worked and identify an advocacy goal. Some also noted that in the absence of a clear advocacy goal, there were difficulties engaging communities. As one grantee noted:

“Some of the challenges around the grassroots work – you know, people come to the meeting and they’re engaged but the nature of this policy work is it’s slow moving itself and because it’s a new reform that Medicaid is implementing. Medicaid has had its own glitches internally so it’s not been as clear cut as, “okay, community, here’s a distinct clear-cut action you can take right now.” It’s not like some of our other things. So keeping folks engaged... along the way, yeah, that has been a little bit of a challenge for us.”

When the pandemic hit, grantees’ priorities shifted dramatically. Because of both this shift in priorities and the need for social distancing, grantees halted many traditional outreach and recruitment activities, including door knocking and tabling. As described above, some grantees turned to downstream activities during the pandemic to address their members’ and community’s needs. Nevertheless, through efforts such as food and other aid distribution, many grantees recruited new members to their programs.

True community organizing must move at the pace of the community. A key lesson we learned is that community leaders are passionate and engaged. They work in their communities among family and friends. Therefore, we had to facilitate processes, resources and build relationships to motivate and inspire leaders to advocate outside those comfort zones.

A myriad of different methods to communicate were used by grantees. For internal work, grantees reported using Zoom and Slack. For communicating with members and communities, grantees discussed needing to use different methods for different populations. While the list of communication platforms is never-ending, some of the most common methods that grantees used to communicate externally are: Zoom, social media platforms (Facebook Live, WhatsApp, and Twitter), Hustle (a digital organizing platform), UberConference, and phones (dial-in conference calls, phone banking, and traditional phone tree methods).

Pivoting their work also meant finding new ways to communicate and keep members engaged. One grantee moved away from the face-to-face events they would normally have run, and began conducting weekly town halls instead. This grantee described how the town halls, run via Zoom, allowed them to split into break out rooms where people had space to share personal issues, helping their mission to

build community. A few grantees discussed relying on their existing members more heavily to organize and help with outreach – thereby building leadership among these existing members. These new approaches lowered barriers to participation for certain populations; for example, removing the need to travel for far-flung community members or consumers with disabilities that have difficulty leaving the house. This was not universally the case – difficulties engaging with these new modes of communication appeared to be greater for older populations and more rural communities.

Overall, grantees displayed wide optimism when discussing their grassroots organizing efforts during the pandemic, observing that during times of crisis, people want to be more involved and want to do something to help in their communities.

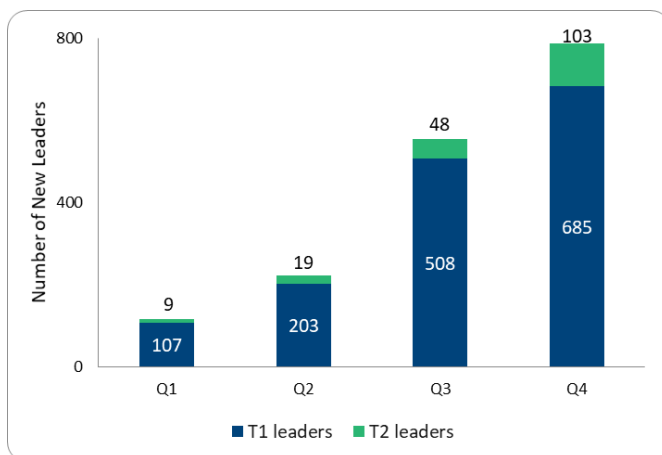
Increasing depth of engagement and consumer leadership development

The Center understands engagement in five categories of deepening engagement from awareness, interest, participation, commitment to leadership. In addition to growing the size of the consumer base, the evaluation assessed the extent to which grantees increased the numbers of consumers at every stage of engagement ('depth of engagement'). We found that depth of engagement increased across all engagement levels we examined: for example, the number of consumers participating in activities consistent with interest increased from 1,300 to 7,080. In fact, engagement more than tripled for all levels examined.



Recognizing that leaders are often in different stages of development, the Center understands consumer leaders in two tiers. Tier 1 leaders may engage in leadership activities but not do so regularly – for example, they may speak in person with a decision-maker, share a personal health care story with the media or elected official, or attend a training or workshop. Tier 2 leaders demonstrate continuous engagement in leadership activities through serving on groups (e.g., boards, committees, public workgroups or regional partnerships), committing to training others (attending a train the trainer workshop or training people in their communities) or regularly serving as a spokesperson. The program increased

Figure 4. Cumulative number of new leaders



the numbers of consumer leaders in both tiers: 685 Tier 1 and 103 Tier 2 consumer leaders were built during this year (Figure 4).

Before the pandemic, grantees were using several strategies to encourage consumers to more deeply engage and to build consumer leaders. Some built off of their base-building efforts. For example, one grantee identified potential leaders by asking online survey respondents if they were interested in sharing stories. This grantee then invited those interested consumers to join community conversations and followed up with them individually, finding this method to be effective. Another grantee organized quarterly meetings to more deeply engage its base and used these meetings to identify potential leaders. The leaders were then invited to meet with decision makers to share stories. Finally, one grantee provided a small stipend to leaders, describing their leaders as “the primary mechanism through which the project team does outreach; and their social and professional networks have added value to the work of the project team.”

We’ve used a lot of our social media tools available to connect with people online, digitally. And then a big move has been getting them offline, in-person, to come out to these meetings, right. And once they come out to the meetings, it’s about letting them feel listened-to.

Some grantees noticed an increase in participation and engagement from their members and leaders as a result of the pandemic. One grantee discussed how one young leader in particular took charge of food and supply distribution for elderly community members. Another grantee discussed how they traditionally would develop leaders through their community health worker (CHW) certification program. When the pandemic hit and CHWs weren’t allowed to do their traditional in-person work in hospitals and homes, the grantee shifted CHW work to help with the state’s COVID-19 contact tracing. Another grantee noted that their new network to provide aid across their state pushed volunteers to be increasingly engaged by taking on leadership roles to coordinate supplies. They described it as “...probably the most successful decentralized leadership structure we’ve ever had.” Finally, one grantee discussed using a phone tree method where everyone in the community had a role in getting information out to their network. Through this method, their number of leaders doubled, and the grantee stated:

“Our organizing team made an incredible pivot right after our statewide shelter-in-place order. Over the past 6 months, they have been able to support our grassroots leaders and build a group of new folks that now are super dedicated, people who now are doing classic organizing, but almost entirely over the phone. This phone outreach has really cultivated more folks from a broader pool to become community leaders doing that outreach.”

Grantees also noted a series of challenges for leadership development. The most common challenge to leadership development was the length of the process needed to build leaders. The length of time required was in part due to the limited time and flexibility of leaders, whose primary responsibilities are to their work, family and community. As one grantee

noted: “they are committed and do what they can and yet they have to live life too and provide and work and all those things.” This challenge was exacerbated during the pandemic, although as noted above, it was counterbalanced by an increased energy and desire among consumers to make a contribution to their communities. Grantees also noted that the time and effort invested was worthwhile as the benefits were significant. As one grantee noted “that’s kind of how I approach organizing is that you have to go slow to go far.”

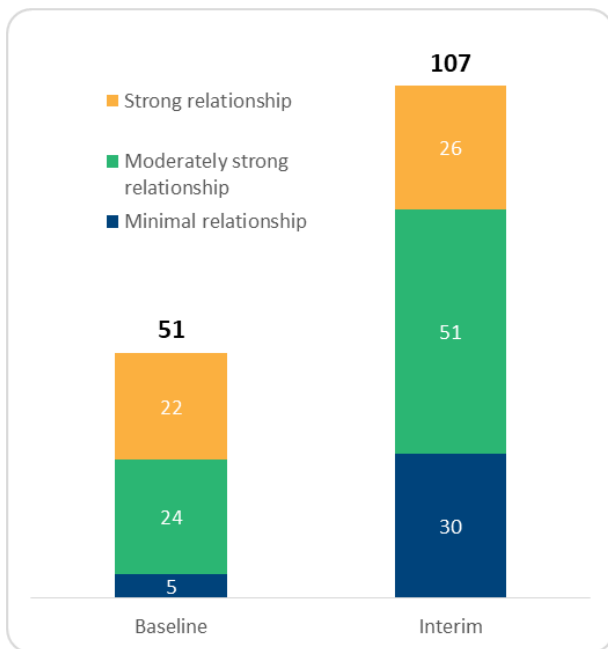
Two additional challenges for leadership development arose. Two grantees were working with communities in far-flung geographies, making it challenging to bring leaders together and to connect with potential leaders. Three grantees were working with new populations, all of which were communities that had histories of being treated poorly (undocumented immigrants, consumers with intellectual disabilities and Spanish-speaking immigrant communities) and therefore have a tendency to mistrust newcomers.

This type of work where you’re actually deeply diving into the community, building what the Center calls tier one, tier two leaders, building engagement for folks most impacted actually is long-term change work...[It] is a slower process than if we were just to go...and advocate at the capitol...by ourselves. And so for me the benefits pay way more than to do it faster. It’s a slow intentional work.

Building relationships between organizations

The Center identified that advocating for SDOH needs would require advancing the number and strength of relationships between grantees and other organizations, including their subgrantees and coalition partners. These partnerships were seen as an essential aspect of this project - they helped build support for advocacy work and provided the opportunity to share resources among groups with similar goals. With regard to coalition partners, CVI 2.0 was successful in increasing both the total number of grantees’ relationships and the number of moderately strong and strong relationships from baseline to interim (Figure 5). Grantees noted that connecting with other organizations was facilitated by the fact that their issue - whether housing, food security or NEMT - resonated easily with both coalition partners and grassroots consumers. Many grantees described learning important lessons from other organizations and coalitions. These relationships provided grantees with the opportunity to bring new vulnerable groups to the table, build their base, and develop new consumer leaders.

Figure 5. Number of organizational relationships, by strength category



Subgrantee relationships were highly encouraged by the Center; the Center viewed these relationships as ones that would expand consumer networks and enable grantees to work more directly with affected consumers. For some grantees, these relationships were new, and some subgrantees were relatively fragile organizations with little organizational infrastructure, small operating budgets and few staff members. Thus, these subgrantee relationships were understood to hold some risk at the outset of the grant. Given this context, some instability in these relationships was expected to be inherent to the process. Despite this risk, four grantees described relationships with their subgrantees that grew in strength and were essential to expanding their work on this project. In general, these relationships included grantees with strength in state-wide

organizing, who lacked experience with on-the-ground community organizing in the priority communities. For example, one subgrantee brought specific experience advocating for people with intellectual and developmental disabilities, and another helped build the grantees' relationship and credibility with immigrant-owned transportation companies. In fact, one grantee had long shared office space with their subgrantee, but noted that this grant allowed them to work together and deepen their connection in a way that had not occurred before.

Grantees noted that sharing resources (e.g., workspace) and approaching the grant as equal partners were strategies that supported success. In the case of one grantee, it was the strength of the relationship that allowed the project to continue after the grantee organization made an institutional decision to pivot their focus away from the SDOH of focus – because the relationship was strong, the subgrantee was in a position to take over as the main grantee for the remainder of the grant period.

As described above, one risk in furthering new relationships through subgrantee relationships with relatively small and new organizations is that relationships may be tenuous. Indeed, two subgrantee relationships will not continue in the second year. One subgrantee underwent a number of transitions, and only started working on the project in the third quarter, leading to the decision to move forward with a different subgrantee in the second year.

In order to influence policies, grantees also focused on building relationships with advocacy targets. Although most grantees reported that it was more difficult to contact policy makers after the pandemic began, one reported their relationship was improved by being able to engage positively with the policy maker, for example by thanking them for a job well done,

rather than continuously noting opportunities for improvement. A second grantee stepped up to fill a gap in the state’s communications with their constituent community, and noted that this led to the more positive relationships with the state.

There were two notable changes in relationship building with policy makers. Two grantees learned that private sector targets - such as vendors for NEMT contracts and health networks – were more motivated to make changes than government entities (e.g., Medicaid). This motivation was derived from private sector entities being driven, at least in part, by incentives and profit. Thus, these grantees shifted their targets to private sector entities and found that they were able to make more progress with private entities than with governmental agencies. Second, because legislative sessions were postponed or adjourned early due to the COVID-19 pandemic, grantees pivoted to administrative instead of legislative targets.

Policy wins

Grantees in six of seven states influenced policy wins during the first year. Policy wins occurred in each SDOH focus area, with five in transportation, four in food security, and three in housing. Four of these SDOH wins were related to the COVID-19 pandemic. For example, grantees were able to convince two states to issue guidance regarding COVID-19-related safety procedures for NEMT; and in two states moratoriums on eviction and rental relief assistance funds were allocated in response to grantee advocacy. In addition, in response to emerging needs due to the COVID-19 pandemic, grantees also worked on four COVID-19 policy campaigns that led to changes. As an example, in response to community input, one grantee grew their CHW program by working with a major hospital system and the state health department to include CHWs in their contact tracing program. This grantee also convinced the health system to not require home visits by CHWs during the pandemic; this advocacy was informed by concerns from patients and CHWs. Grantees also advocated for policy change in other areas, achieving four wins. This included the creation of a bed bug policy, including assurances of continuation of services and pest management services for recipients of Medicaid waiver services.

Policy wins by category:

- 5 Transportation**
- 4 Food security**
- 3 Housing**
- 4 COVID-19 related**
- 4 Other**

...it's not a kind of campaign where you go in and you pretty much know "Alright, here's the policy we want. Let's build a coalition, figure out who the decision makers are, pressure swing votes, get this law passed." It's a lot more back and forth. It's a lot more like, "oh, wow, like, didn't even know this was broken or why does it work this way? We've got to go talk to more people."

The majority of these changes were at the state level, with eight administrative and five legislative changes, and one was a local policy change. Four were at the health system

level, all of which were COVID-19 related and in one state. This reflected the influence of one of the grantees at the local health system level.

These policy wins were achieved despite the fact that many of the grantees had never or rarely interacted with SDOH policies prior to the CVI 2.0 program. Grantees realized during the first year that the policy work was more complicated than anticipated - in particular Medicaid policy. This led grantees to spend extra time teaching community members about the complexity of the policy environment, and becoming experts themselves. For example, several grantees expressed this difficulty with regards to NEMT, which required investing time to learn about the complexities of these policies and how they compare to those of other states through an iterative process.

Overall, grantees experienced challenges understanding the policy behind the program goals, but all grantees made significant progress during the last year, and most are now in a position to make connections between the policy and consumer experience. Grantees viewed being in a position to bring relevant consumer experience to the policy work as a critical step towards advancing the work.

I find myself, in my role with lawmakers and coalition partners, talking more and more about the stories that we're hearing on the ground. So I think that's the best example. It's no longer me just being the policy work.

So...it turns out Medicaid transportation is really complicated, as are all things in Medicaid and so just trying to understand the nuances and that kind of policy detail at a level where we feel competent to talk about them with decision makers... for a lot of us as advocates, we want to be expert in the issues that we're speaking to and because Medicaid transportation is just kind of a big, unwieldy beast in and of itself, it's hard to get your arms wrapped around it really quickly.

Racial equity work

The COVID-19 pandemic and related economic disruption and racial justice movements increased national awareness of the impact of racial inequity for communities of color. From its inception (prior to these events), CVI 2.0 aimed to increase the capacity for community organizing among communities of color. To achieve these goals, the Center selected some grantees that have long been deeply embedded in communities of color and other grantees that were not already working significantly with these communities, but engaged subgrantees that were deeply engaged with the communities. Given this context, grantees were at a variety of different places with regards to their organizing around racial

equity. When describing their base, some organizations described their base as already largely made up of people of color. Others were just getting started with their organizational goals of working more deeply with communities of color, with over half reporting that they started to work newly or more deeply with specific communities of color. Although these grantees were newer to these populations and not yet deeply engaged working with communities of color, they considered that the work they were doing on SDOH would benefit communities of color, because these issues disproportionately affect those communities. All grantees considered racial equity to be closely aligned with other, related dimensions of inequality, especially including income, geography, and language, and tended to focus on these other dimensions of inequality in describing their programs.

Racial equity has been implicit in our work since the beginning, but we weren't always super explicit about it and kind of outward facing about it. So the intent was really to kind of state it for ourselves and build agreement internally and then make it very explicit externally. We had started that process and then COVID hit and kind of the uprisings for racial justice began. It definitely added some urgency to the work that we were already doing.

To support the goals of working with communities of color, grantees utilized multiple strategies. First, several grantees partnered with subgrantees that had significant engagement with these communities. Two grantees hired new staff to conduct Spanish-language outreach. Finally, two organizations made changes to their policies to more explicitly and intentionally focus on racial equity. As one grantee described:

“Our members actually select the issues that become our issue agenda for a given year. The board has one responsibility and that's to determine whether issues that the member groups propose [meet our criteria] ...in that proposing process we added criteria ... you need to tell us what impact it would have in terms of advancing racial equity.”

Although CVI 2.0 had racial equity as a goal of the program prior to the COVID-19 pandemic and related economic crisis and racial justice movement, racial equity takes time to build. As grantees continue to focus on racial equity in the second year, increasing support for the leadership growth of consumers of color is an opportunity that could be pursued in Year 2. In addition, explicit focus on racial equity in TA and learning opportunities may advance racial equity goals of the program.

It's the water we're swimming in that subtexts pretty much all politics in America right now is racial equity... even when you're not talking about that explicitly, you really are sort of talking about it.

CONCLUSIONS AND LESSONS LEARNED

The COVID-19 pandemic and resulting economic disruption and racial justice movement has forced organizations to respond to historical changes in our society. This three-fold crisis has highlighted the critical importance of addressing social needs as a strategy for improving health. The CVI 2.0 program provides key lessons for engaging consumers in advocating for policies that address the needs of vulnerable populations, particularly in a time of chaos. These lessons will thus remain relevant for organizers long after we pass this historical moment in time.

First, the program highlights that a critical skill for advocacy organizations is to remain flexible so as to maintain and increase their relevance to members and base communities. Successful organizations were able to address their members' immediate needs and shift their advocacy goals accordingly. Perhaps one of the most exciting lessons from this time is the idea that remote or distanced organizing through online platforms and other means of communication is a viable means of maintaining and advancing contact with consumers, even among low-income or disadvantaged communities for whom it was previously not considered a feasible strategy. The fact that technology is a smaller-than-anticipated barrier for some populations holds interesting future implications.

Key Lessons:

1. Remote organizing is a viable means of contact with disadvantaged communities for whom it was previously not considered a feasible strategy.
2. Dedicated funding, technical assistance and group learning can lead to an engaged consumer base focused on social needs, even during a time of multiple national crises.
3. The engaged base can lead to policy wins for food, housing, and transportation.

Second, the program demonstrated that dedicated funding, technical assistance, and group learning opportunities can lead to an engaged consumer base focused on social needs, even during a time of multiple national crises. Through this program, 7,066 new consumers were added to the base and the level of participation in activities at every level of engagement increased between 4 and 6 times. Grantees accomplished these successes by focusing on building

trusting relationships, addressing concrete consumer needs, engaging consumers through digital means, partnering with organizations that are deeply embedded in communities of color, and more than doubling the number of relationships with partner organizations. This allowed them to work with communities they had not previously worked with, and more deeply engage communities of color.

Finally, a program like CVI 2.0 can lead to policy changes that improve how social needs are met. Grantees in six of seven states influenced policy wins during the first year. Policy wins occurred in each SDOH focus area, with five in transportation, four in food security, three in housing, four related to the COVID-19 pandemic, and four other related wins.

The second year of CVI 2.0 will be an opportunity to build upon the findings presented here, with the ultimate aim of creating an understanding of how best to support consumer advocacy organizations in engaging consumers and working for relevant policy change in

rapidly-changing conditions. Understanding how to engage vulnerable consumers in advocating for social needs policy change has never been more relevant than in 2020. The COVID-19 pandemic and related economic crises and racial justice movements have highlighted the danger of creating systems that do not engage communities in developing solutions to underlying social needs; the CVI 2.0 program is well-poised to identify how to support consumer voice in developing the long-lasting changes needed to address the underlying social and economic drivers of health.

APPENDIX A: GRANTEE PROFILES

ALABAMA ARISE Montgomery, Alabama Target SDOH: food insecurity

Overview

Alabama Arise is a statewide organization that works to promote state policies that improve the lives of people in Alabama. In this project, they worked with a grassroots organization in Mobile, AL, particularly in the neighborhood of Trinity Gardens, to engage the community in organizing activities around food insecurity and Medicaid's policy influence on it.

Key activities

- Engaged Trinity Gardens community members through meetings, organizing events, and activities to build ongoing relationships and new leaders
- Trained community leaders on state policy issues, including Medicaid and Advocacy 101 sessions, to build knowledge

Outcomes and impacts

Consumer engagement

- Reached over 2,000 consumers
- Added over 100 consumers to base
- Built 40 Tier 1 grassroots leaders and 2 Tier 2 grassroots leaders

Lessons learned

- Community leaders have different comfort levels with policy issues related to food insecurity, and therefore the grantee had to focus some time on training.
- Consumer engagement can influence Medicaid processes. For example, in response to consumer input, key leadership in the Alabama Medicaid office acknowledged the need to change their Quality Improvement Projects (QIP) process.
- "True community organizing must move at the pace of the community. A key lesson we learned is that community leaders are passionate and engaged. They work in their communities among family and friends. Therefore, we had to facilitate processes, resources and build relationships to motivate and inspire leaders to advocate outside those comfort zones." (Q4 report)
- The best way to engage community members is through actionable work and activities.

COVID-19 pivot work

- Produced a comprehensive guide and published it on their website to help people access resources during COVID-19.
- Increased their focus on rapid response to COVID-19, such as helping people access unemployment insurance and pandemic EBT.
- Shifted their focus to administrative policies after the early adjournment of their legislature.

TOGETHER COLORADO & CENTER FOR HEALTH PROGRESS

Denver, Colorado

Target SDOH: non-emergency medical transportation

Overview

Together Colorado and Center for Health Progress worked closely on their project to address Medicaid non-emergency medical transportation (NEMT) in their state. The grantees focused their efforts on building their base through digital organizing, as well as meeting regularly with government decision-makers to influence Medicaid NEMT contracts in the state.

Key activities

- Although distribution was delayed due to impacts of COVID-19, they created an NEMT patient satisfaction survey
- Led organizing efforts in the Person Centered Transportation Coalition (PCTC)
- Through pre-COVID-19 digital organizing efforts, they created an online community for users and others affected by NEMT services (launched in February, 2020)
- Re-focused policy efforts on holding the manager of Medicaid NEMT services in Colorado (IntelliRide) accountable for their state contract by having meetings with the Department of Health Care Policy and Financing (HCPF) and other decision makers.

Outcomes and impacts

Consumer engagement

- Reached over 22,000 consumers
- Added over 260 consumers to base
- Built 4 Tier 1 grassroots leaders

COVID-19 pivot work

- Both grantees shifted their work entirely to COVID-19 response-related issues, while keeping a hold on their organizing goals. Their latest policy work is on making sure that NEMT services are accessible and safe to use during the pandemic.
- Due to their complete shift to digital organizing, grantees saw an increase in engagement due to eliminated travel barriers
- Grantees have also been checking in with members and making sure their basic needs are met

GEORGIANS FOR A HEALTHY FUTURE & THE ARC GEORGIA

Atlanta, Georgia

Target SDOH: non-emergency medical transportation

Overview

Georgians for a Healthy Future (GHF) is an organization that mobilizes around health policy efforts for the state of Georgia. Along with their partner, The Arc Georgia, GHF targeted their grassroots organizing efforts to people with intellectual and developmental disabilities. They built their knowledge and organizing around non-emergency medical transportation (NEMT) for marginalized groups.

Key activities

- Disseminated a rider survey for NEMT users
- Trained Grassroots Connectors (GC) to provide them with tools to continue their NEMT grassroots efforts
- Hosted meetings to discuss Georgia's advocacy and political landscape related to transportation, as well as advance their campaigns
- Completed a Health Transportation Shortage Index (HTSI) data analysis to identify transportation shortage areas in the state, and highlight areas for improvement
- Published a fact sheet about NEMT as a specific issue in the state

Outcomes and impacts

Consumer engagement

- Reached over 4900 consumers
- Added over 110 consumers to base
- Built 25 Tier 1 grassroots leaders and 14 Tier 2 grassroots leaders

Lessons learned

- GHF had to spend more time than planned educating Grassroots Connectors on state policy in relation to NEMT
- They needed to adapt outreach strategies after seeing an initial low response rate to their NEMT rider survey

COVID-19 pivot work

- Worked on having deeper knowledge on the new policy opportunity regarding telehealth services
- The shift to virtual coalition meetings increased accessibility, especially for people with intellectual and developmental disabilities

MASSACHUSETTS SENIOR ACTION COUNCIL

Quincy, Massachusetts

Target SDOH: food insecurity

Overview

The Massachusetts Senior Action Council (MSAC) is a grassroots, senior-led organization with a long history of addressing community issues in the state. In this program, MSAC has worked to deepen engagement with its members and advance efforts around food insecurity issues among low-income seniors.

Key activities

- Provided input to integrate the SNAP application into the MassHealth application for seniors (65+) as a “SNAP sign-off page” to streamline the application process
- Community outreach and education efforts, including presentations at senior housing developments and senior centers
- Continuous strategy meetings with members to keep their base engaged and build grassroots leaders
- Led days of action and lobbying activities at the State House for their members to meet with decision makers

Outcomes and impacts

Consumer engagement

- Reached over 630 consumers
- Added over 320 consumers to base
- Built 161 Tier 1 grassroots leaders and 15 Tier 2 grassroots leaders

COVID-19 pivot work

- Seamlessly transitioned all their discussions, meetings, and even direct consumer-policy maker interactions to a virtual platform
- Have not changed their overarching agenda, yet the pandemic has provided new opportunities to make permanent some of the temporary policies that were implemented
- Many of their activities, especially at the beginning of the pandemic, focused on providing basic needs to their members and community

MAINE PEOPLE'S RESOURCE CENTER

Portland, Maine

Target SDOH: non-emergency medical transportation (NEMT)

Overview

Maine People's Resource Center (MPRC) is a widely recognized organization that works for social change by engaging the community. MPRC focused their organizing in this program on the state's Medicaid NEMT system improvements by engaging communities.

Key activities

- Conducted policy work research, culminating in a report summarizing Maine's Medicaid transportation system comparing models in other states
- Engaged and connected with immigrant owners of transportation companies, as well as other interest groups, to grow their base and get their feedback
- Grew their base through door-knocking and tabling at polling locations, food pantries and senior living facilities
- They grew their coalition by building their relationships with other organizations in the state with similar big-picture interests
- Trained volunteers on the importance of transportation for health outcomes

Outcomes and impacts

Consumer engagement

- Reached over 7,300 consumers
- Added over 4,700 consumers to base
- Built 53 Tier 1 grassroots leaders and 29 Tier 2 grassroots leaders

Lessons learned

- The state's Medicaid NEMT system is very complicated, and MRPC spent a good amount of time educating themselves on its complexities
- They do not need to have a new state law passed to see the changes they want to see

COVID-19 pivot work

- Launched a massive mutual aid network during the early stages of the pandemic to connect Maine residents to resources for basic needs. This has helped them grow their base and build community leaders.
- Shifted their policy focus to administrative policies due to the early adjournment of the legislature
- Focused on collecting stories from members about the impacts of the pandemic
- "The COVID crisis has definitely highlighted the need for supports and services targeted at the social determinants of health, from housing to food security to the volunteer delivery services that solve transportation issues." (*quarterly report*)

MAKE THE ROAD NEW YORK (MRNY)

New York City, New York

Target SDOH: housing

Overview

MRNY has focused their CVI 2.0 project on their continuing work with community health workers (CHWs) by centering CHW efforts on asthma and housing. Their asthma CHW program not only continues to support the health of community members, but also has an integrated screening system to detect asthma- and housing-related health concerns. MRNY's project aimed to connect their CHW's health care work with housing advocacy work.

Key activities

- Created a CHW screening tool to connect community members to housing services
- Worked closely with the Performance Provider System (PPS) to adapt their CHW model and get input in their activities
- Trained CHWs on social determinants of health and the relationship to their work, as well as other topics like Delivery System Reform and Incentive Payment (DSRIP) program
- Created a new database that launched in February 2020 to better track CHW activities and facilitate the referral process
- Led multiple meetings with housing leaders in different boroughs to collect stories and engage the community in different parts of their campaign
- Facilitated attendance by members at several events in connection with this project

Outcomes and impacts

Consumer engagement

- Reached over 760 consumers
- Added over 600 consumers to base
- Built 122 Tier 1 grassroots leaders and 22 Tier 2 grassroots leaders

COVID-19 pivot work

- Transitioned to a fully remote work model (except their food pantry)– checked in with members on the phone, organized Zoom and Facebook Live events, and trained consumers via Zoom and WhatsApp
- Constantly communicated COVID-19-related news to members via robo calls
- Shifted their policy campaigns to address COVID-19-related needs in their communities, from making sure community members had the most basic needs met to playing a critical role in providing feedback to government agencies to fine-tune their relief programs
- Three policy-level wins during this time period: a state level moratorium on evictions to protect renters, legalization of e-bikes to protect delivery workers, and ensured access to no-cost COVID-19 testing and treatment to immigrants on emergency Medicaid

PENNSYLVANIA HEALTH ACCESS NETWORK

Philadelphia, Pennsylvania

Target SDOH: non-emergency medical transportation

Overview

Pennsylvania Health Access Network (PHAN) is Pennsylvania's main consumer-led health advocacy organization. During this project, PHAN organized consumers to advocate around the state's Medical Assistance Transportation Program (MATP), focusing efforts on rural communities and communities of color.

Key activities

- Held multiple presentations and conference calls for consumers and advocates to spread knowledge about MATP and get feedback on their experiences
- Distributed and collected a 2-page survey in English and Spanish to gauge consumer awareness and use of MATP
- Collected stories from survey respondents who were interested in sharing them
- Held ongoing calls with the Transportation Alliance and other small stakeholder groups to further relationships with other organizations

Outcomes and impacts

Consumer engagement

- Reached over 12,000 consumers
- Added over 840 consumers to base
- Built 280 Tier 1 grassroots leaders and 1 Tier 2 grassroots leader

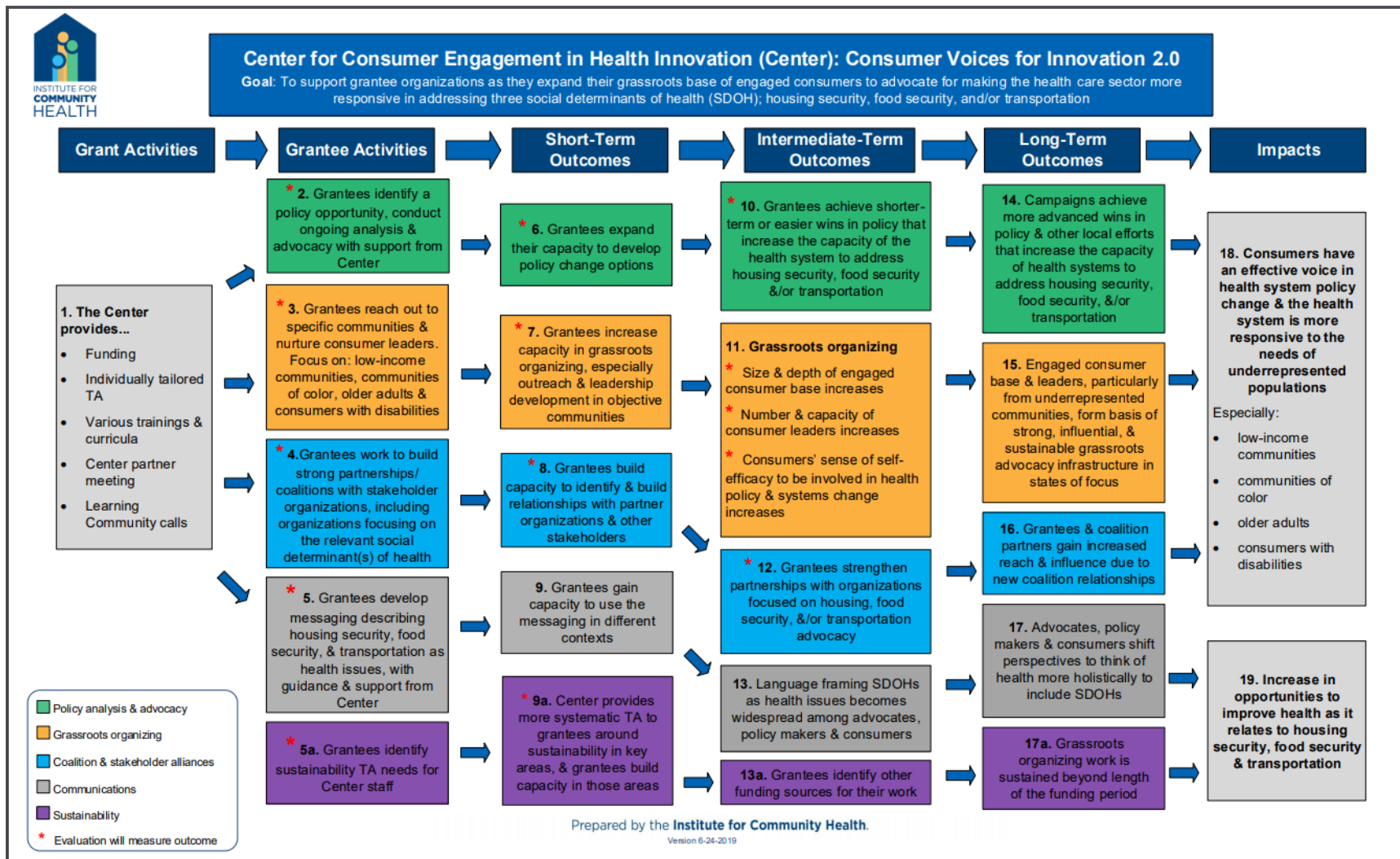
Lessons learned

- Through feedback from different partners across the state, PHAN saw a need to focus their project on a priority community to better direct their advocacy work: now will focus on immigrant and Spanish-speaking communities

COVID-19 pivot work

- Distributed guidance on using NEMT services during the pandemic
- Postponed addressing system improvements and expanding access as a policy area, and shifted priorities to advocating for rider safety and overall access
- Moved all meetings and engagement to virtual platforms, and noted that it has expanded their reach

APPENDIX B: LOGIC MODEL



APPENDIX C: SURVEY DETAILED DATA

Consumer demographic survey

Age		
	Baseline (n=53)	Interim (n=42)
≤ 34 years old	9 (17%)	10 (24%)
35 to 64 years old	25 (47%)	23 (55%)
65+ years old	18 (34%)	7 (16%)
I don't want to answer	1 (2%)	2 (5%)

Identify as a person with a disability?		
	Baseline (n=52)	Interim (n=42)
Yes	19 (36%)	11 (26%)
No	31 (60%)	29 (69%)
I don't want to answer	2 (4%)	2 (5%)

Caregiver for a person with a disability?		
	Baseline (n=52)	Interim (n=41)
Yes	13 (25%)	9 (22%)
No	38 (73%)	31 (76%)
I don't want to answer	1 (2%)	1 (2%)

Race/ethnicity*		
	Baseline (n=53)	Interim (n=42)
Black or African American	23 (43%)	14 (33%)
Hispanic/Latino	19 (36%)	13 (31%)
White	12 (23%)	14 (33%)
Other**	6 (12%)	2 (4%)
I don't want to answer	1 (2%)	1 (2%)

*Respondents were allowed to choose more than one answer

**Other includes: American Indian or Alaskan Native, Asian, and Native Hawaiian or Other Pacific Islander, Other

Social Determinants of Health (SDOH) – Frequency of SDOHs*		
	Baseline (n=53)	Interim (n=42)
We worried whether our food would run out before we got money to buy more	10 (19%)	10 (24%)
We worried about losing housing or we were homeless	9 (17%)	12 (29%)
We had to go without healthcare or medications because we didn't have transportation to the doctor or pharmacy	10 (19%)	10 (24%)
The electric, gas, water or oil company threatened to shut off services where we live	1 (2%)	8 (19%)
None of the above	27 (51%)	19 (45%)
I don't want to answer	5 (9%)	3 (7%)

*Respondents were allowed to choose more than one answer

Social Determinants of Health (SDOH)- Number of SDOHs per Respondent		
	Baseline (n=53)	Interim (n=42)
None	33 (62%)	22 (52%)
One	15 (28%)	8 (19%)
Two	4 (7%)	6 (14%)
Three	1 (2%)	4 (9%)
Four	1 (2%)	2 (5%)

Grantee survey

Depth of Consumer Engagement		
<i>Please estimate the number of people in the past year who...</i>	Baseline	Interim
Interest	1,300	336,316
signed up to receive more information about making the healthcare system more responsive to the social determinant(s) of health you are focusing on	1,300	7,088
Engaged in some way with your campaign on social media (liked or followed your Facebook page, followed you on Twitter, etc.)*	-	329,228
Participation	911	5,319
attended an event such as a rally, community forum or other public event (including events that honored physical distancing protocols) related to expanding the ability of the healthcare system to address the social determinant(s) of health you are focusing on	353	2,999
provided a personal health care story to your organization related to the social determinant(s) of health you are focusing on	90	886
contacted a decision-maker (e.g., by email, letter, post-card, or phone call) about making the healthcare system more responsive to the social determinant(s) of health you are focusing on	468	1,434
Commitment	281	1,495
shared a personal health care story with the media or legislators about making the healthcare system more responsive to the social determinant(s) of health you are focusing on	15	111
attended a training or workshop related to making the healthcare system more responsive to the social determinant(s) of health you are focusing on	254	1,268
spoke in person (e.g., at a lobby day, through testifying at a hearing, or attending a meeting with a decision-maker) about an issue related to making the healthcare system more responsive to the social determinant(s) of health you are focusing on	12	116
Leadership	70	264
attended a train-the-trainer training or trained individuals in the community about issues related to making the healthcare system more responsive to social determinant(s) of health	40	168
regularly served as a spokesperson for making the healthcare system more responsive to social determinant(s) of health	19	78
served on boards, committees, public workgroups, or regional partnerships relevant to making the healthcare system more responsive to social determinant(s) of health	11	18

*New indicator (not administered in baseline)

Capacity Assessment*					
	Timepoint	Little Capacity	Some Capacity	Strong Capacity	Very Strong Capacity
Mobilize a strong grassroots base of support for policy change related to the social determinant(s) of health you are focusing on	Baseline	0	1 (14%)	3 (43%)	3 (43%)
	Interim	0	0	4 (57%)	3 (43%)
Train consumer leaders in advocacy for policy change related to the social determinant(s) of health you are focusing on	Baseline	0	0	3 (43%)	4 (57%)
	Interim	0	1 (14%)	3 (43%)	3 (43%)
Build and maintain relationships with partner organizations for advocating for policy change related to the social determinant(s) of health you are focusing on	Baseline	0	1 (14%)	1 (14%)	5 (71%)
	Interim	0	0	3 (43%)	4 (57%)
Effectively analyze policy options for the social determinant(s) of health you are focusing on	Baseline	0	3 (43%)	1 (14%)	3 (43%)
	Interim	0	0	3 (43%)	4 (57%)
Influence policy around the social determinant(s) of health you are focusing on	Baseline	0	2 (29%)	3 (42%)	2 (29%)
	Interim	0	1 (14%)	4 (57%)	2 (29%)
Effectively use messaging about housing security, food security and/or transportation as health issues	Baseline	0	2 (29%)	2 (29%)	3 (42%)
	Interim	0	1 (14%)	2 (29%)	4 (57%)
Develop a continuous funding stream to continue to support consumer advocacy in policy change related to SDOH generally, and/or the social determinant(s) of health you are focusing on	Baseline	2 (29%)	3 (42%)	2 (29%)	0
	Interim	0	5 (71%)	2 (29%)	0

*'No capacity' was a response option, however no grantee selected this option.

Engagement with Partners (sum of all grantees)		
	Baseline	Interim
Not counting your sub-grantees, how many partner organizations focused on housing security, food security and/or transportation advocacy do you currently work with (i.e., participate in meetings or activities with)?	80	113

Strength of Relationship with Each Partner (sum of all grantees)		
	Baseline	Interim
Minimal Relationship	5 (10%)	30 (28%)
Moderately Strong Relationship	24 (47%)	51 (48%)
Strong Relationship	22 (43%)	26 (24%)
Total	51	107

APPENDIX D: DATA COLLECTION INSTRUMENTS

[Data collection instruments](#)