THE PATH TO VICTORY:

The Role of Grassroots Organizing in Health Policy Change

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

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INTRODUCTION

The Center for Consumer Engagement in Health Innovation's Consumer Voices for Innovation 2.0 Grant Program (CVI 2.0) builds on our previous work demonstrating the power of grassroots organizing to achieve health policy change. The original CVI grant program ended after two years on March 1, 2019, and was focused on leveraging grassroots organizing strategies to bring a meaningful consumer voice to health policy decisions. CVI 2.0 (also a two-year grant program) began May 1, 2019, and is designed to build an engaged base of consumers to advocate for policies and programs that improve the ability of the health system to address the social and economic drivers of health – specifically, housing security, food security and transportation.

The CVI 2.0 program required that our advocacy partner organizations spend at least two-thirds of the grant funds directly on organizing. As such, the organizations selected for CVI 2.0 had previously demonstrated a clear record of accomplishment in implementing grassroots organizing strategies including both base building and leadership development activities among consumers with complex health and social needs. We asked the CVI 2.0 organizations to focus in particular on outreach to communities of color, low-income communities, older adults, and/or people with disabilities. Additionally, because the Center seeks to expand resources and capacity within communities of color specifically, we sought to give a majority of the CVI 2.0 grants to organization[1] or to projects that sub-granted at least 20 percent of their grant to an OOC.

It should be noted that the COVID-19 pandemic hit at the end of the first year of the grant, and like so many others, the CVI 2.0 organizations had to rapidly adapt to the new environment and pivot their efforts accordingly. Given that these were grassroots organizing grants, the pandemic was particularly challenging. Organizing is all about building relationships, and advocates had to identify ways to do this while still complying with physical distancing protocols. This was especially difficult for groups that have developed momentum and leadership opportunities primarily by communicating with their base through in-person events and trainings. Despite these significant challenges, and even though the grant period is not yet over, these advocates have already achieved significant policy victories that have had immediate, positive and lasting impacts on communities.

In one way or another, the victories achieved by the CVI 2.0 cohort build on years, and in some cases decades, of grassroots activism. These organizations developed the infrastructure necessary to pursue policy goals over time, then broke through to achieve their specified goals after sustained momentum. In some cases, external influences like COVID-19 actually created an opportunity that advocates were ready to take advantage of. In others, years of patient work resulted in breakthroughs. In either case, these organizations have been able to achieve impactful policy victories by obtaining consistent funding and support to focus on base building and leadership development. What we describe below are a few of their policy victories and how grassroots organizing played a role in achieving them.

[1] Community Catalyst defines an organization of color (OOC) as follows:

1a. Constituents are comprised mainly of the following identities: ***Black, Indigenous, Hispanic, Latino/a/e/X, Arab/Arab American, Southeast Asian, Asian, Asian Pacific Islander, Native Hawaiian, Desi and/or immigrant communities, and/or any other identities of color not listed.***

OR

1b. The organization is primarily focused on improving the lives of the communities listed above and their families, and this is reflected in the organization's mission, goals, and program activities

AND

2a. A majority (75%) of staff members identify as members of the above listed communities

OR

2b. A majority (75%) of Leadership (board members and executive director) identify as members of the above listed communities.

CONSUMER ENGAGEMENT AND POLICY CHANGE

The Center has long advocated for meaningful consumer engagement in health systems. Ensuring that consumers have a voice at the table when health plans and provider systems develop policies helps to ensure that the needs of consumers are addressed. Alabama Arise has demonstrated the effectiveness of consumer engagement by developing consumer leaders, placing them in key positions and supporting them in effecting policy change. The Alabama Integrated Care Network (ICN), for example, is a competitively bid, integrated network that provides enhanced case management, education and outreach services to Medicaid long-term care recipients in both Home and Community-Based Services (HCBS) and institutional settings. The ICN's Consumer Advocacy Committee (CAC) and board include grassroots consumer advocates that Alabama Arise has identified, trained, and supported over a period of years. In 2019 and 2020, we began to see the impact of this leadership development strategy on policy change.

For instance, at the recommendation of the CAC, the State of Alabama created a "one-out-one-in" policy revision to make more Medicaid Home and Community-Based Services (HCBS) slots available to consumers each year. Previously, when an HCBS slot opened up in Alabama, the state would not make that slot available until the beginning of the following fiscal year. As a practical matter, this meant around 1,600 slots went unused for a portion of every year. The ICN Board credits consumer advocates with raising this issue, which the ICN then pushed the state to revise. This change in policy went into effect October 2019 and has expanded utilized HCBS slots in Alabama by hundreds per year.

Consumer engagement through the ICN also led to the state adopting a new policy around bed bug eradication for individuals receiving HCBS. Prior to this policy change, an estimated 20 people per month in Alabama were losing services due to the presence of bed bugs in their homes. As the CAC began raising this issue, Arise and the ICN began pressuring the state to collect data on the practice and then make policy changes to prevent consumers from losing services. In July 2020 the state issued new guidance around bed bugs, prohibiting the practice of discontinuing HCBS services and requiring pest management services to eradicate bed bugs where necessary. This policy change will mean that more than 200 people per year will now maintain their HCBS in Alabama.

ABOUT OUR PARTNERS

ALABAMA ARISE

Alabama Arise is a statewide non-profit, non-partisan coalition of congregations, organizations and individuals united in their belief that people in poverty are suffering because of state policy decisions. Through Arise, groups and individuals join together to promote policies to improve the lives of Alabamians with low incomes. Arise provides a structure in which Alabamians can engage in public debates to promote the common good.

CENTER FOR HEALTH PROGRESS & TOGETHER COLORADO

Since 1997, Center for Health Progress has been working to create opportunities and eliminate barriers to health equity for Coloradans. They have worked alongside some of Colorado's most influential leaders, and helped Colorado make big steps toward ensuring that the health care system works for everyone. Together Colorado (formerly Metro Organizations for People) has been organizing since 1979 to build and solidify lasting power in the state of Colorado. The organization spans 220 congregations, schools, and faith leaders across the state. Together Colorado is a member of the national network, Faith in Action, and is comprised of people of various faith traditions organizing to create a better world; one that values, uplifts and protects the humanity and human dignity of every person.

MAINTAINING EFFECTIVE CHW PROGRAMS

Make the Road New York (MRNY) has an established Community Health Worker (CHW) training program that provides primarily immigrants and low-income people of color with the skills needed to become CHWs in New York City. The original goal of MRNY's CVI 2.0 project was to convince city elected officials to provide sustained funding for a CHW pilot program focused on improving the health of families with asthma. In collaboration with the CHWs themselves, the advocates were already talking to the New York City Council about how to fund a CHW program when the pandemic began in the heart of the MRNY base in New York City. Recognizing the budget implications of the pandemic, MRNY broadened its search for CHW funding and pivoted to advocating to ensure that other funding made available during the pandemic, such as through the state's contact tracing initiative, incorporates hiring CHWs.

In addition to expanding and strengthening the CHW program, at the start of the pandemic MRNY, with crucial input from CHWs, worked with the New York City Health+Hospitals system to transition its CHW asthma project to a remote program rather than an in-person program. This crucial change directly helped to maintain the safety and health of CHWs and their patients, almost all of whom are from immigrant backgrounds.

HOUSING SECURITY IN THE PANDEMIC

Early in the pandemic, the threat of future evictions emerged as an advocacy issue for many organizations, as millions of people lost their jobs and would shortly no longer be able to pay their rent. Both MRNY and the Maine People's Alliance (MPA) secured a moratorium on evictions in their respective states, moratoria which disproportionally benefited immigrants and low-income people of color. Grassroots memberships of both organizations pushed for these housing protections loudly and publicly, and as the pandemic wore on and moratoria began to expire, maintained that pressure. As a result of these efforts, the governors of both New York and Maine extended their state moratoria on evictions.[2] In addition, both states created rental assistance programs for people unable to pay their rent. New York has thus far allocated $100 million to its rent relief fund, while

[2] As of this writing, the Maine moratorium is ongoing. In New York the moratorium has been extended to January 2021.

MAINE PEOPLE'S ALLIANCE

Over the past three decades, Maine People's Alliance (MPA) has worked to build a powerful statewide grassroots movement for progressive social change, serving as a leader in state campaigns for expanded health care access, toxics use reduction, affordable housing, universal home care, clean elections reform, racial justice, immigrant rights, a higher minimum wage and tax fairness. With more than 32,000 members across Maine, MPA is the state's largest community action organization.

MASSACHUSETTS SENIOR ACTION COUNCIL

The Massachusetts Senior Action Council (MSAC) is a statewide, grassroots, senior-led organization that empowers its members, largely low-income and people of color, to use their own voices to address key public policy and community issues that affect their health and well-being. MSAC's base includes thousands of seniors across the Commonwealth who have participated in public meetings, rallies, government hearings, and direct actions. MSAC has over 1,100 members, 30 affiliated groups, and six active chapters across the Commonwealth.

MaineHousing, after sustained advocacy by MPA's grassroots base and coalition, created a $5 million COVID-19 Rent Relief Program. Advocates continue to push for additional dollars for the rental assistance fund in both states as well as further extensions on the eviction moratoria.

FOOD SECURITY FOR SENIORS

The Massachusetts Senior Action Council (MSAC) focused on food security in their CVI 2.0 project, with the goal of increasing Supplemental Nutrition Assistance Program (SNAP) benefits for seniors and streamlining the application process. More than 200,000 Massachusetts seniors are eligible for SNAP benefits, and half of them are already enrolled in MassHealth (the state's Medicaid program). However, seniors must complete long, complex applications for each program separately, often providing the same information and documentation each time. MSAC members directly engaged with policy and decision makers to advocate for a synthesized and simplified application process for both programs.

Over several months, grassroots advocates attended one-on-one meetings with the directors of MassHealth, the Executive Office of Elder Affairs (EOEA), the Department of Transitional Assistance (DTA), and the Executive Office of Health and Human Services (EOHHS). Additionally, MSAC members showed up in force for several "days of action" at the statehouse, engaging state lawmakers during session on these issues. As a result, on March 1, 2020 the state published the first MassHealth application for seniors (new enrollees only) that included a streamlined application for SNAP benefits. MSAC also received a commitment to extend the integrated application to current enrollees for recertification and later for Medicare Savings Program applicants. Additionally, the governor included $1 million in the proposed FY 21 budget for a unified system of applications with a goal of creating a "no wrong door" application approach for SNAP, MassHealth, and other benefit programs in Massachusetts.

TRANSPORTATION ACCESS

The majority of work that MSAC champions is designed to have a statewide impact. However, because there are regional chapters throughout the state, opportunities for change can also occur locally, as was the case in Springfield, MA. MSAC held a rally at City Hall to protest the cost of meals at and transportation to the new Raymond A. Jordan Senior Center at

MAKE THE ROAD NEW YORK

Make the Road New York (MRNY) builds the power of immigrant and working class communities to achieve dignity and justice. They have 23,000+ members across New York City, Long Island, and Westchester County who lead multiple organizing committees across their issues and program areas. Members take on leadership roles in campaigns, determine priorities, and elect the representatives who comprise most of MRNY's Board of Directors. The vast majority of MRNY staff come from the communities they represent.

PENNSYLVANIA HEALTH ACCESS NETWORK

Pennsylvania Health Access Network (PHAN) is Pennsylvania's only statewide consumer-driven organization working to expand and protect access to high-quality, equitable, affordable healthcare for all Pennsylvanians. Since 2007, PHAN has brought together health care consumers and community organizations across the state to advocate for expanded access to health care in Pennsylvania. To achieve this, PHAN blends coalition-building and policy advocacy with a unique model of community health organizing that focuses on supporting and empowering consumers to get the treatment they need and become advocates for better healthcare in their local communities and statewide.

Blunt Park, which consolidated four neighborhood centers into a single senior center--and ended up being far away from many seniors' homes. After a protracted and very public battle with the city's mayor over affordable transportation to the Jordan Center, the mayor announced free shuttle service door-to-door, three times a week, which had an immediate and positive impact on the community, a large percentage of whom are people of color.

The Pennsylvania Health Access Network (PHAN) focused their CVI 2.0 work on the state's interest in adopting a transportation broker model for its Non-Emergency Medical Transportation service. The Medicaid-funded Non-Emergency Medical Transportation (NEMT) benefit, which has been part of Medicaid since the program was founded in 1965, provides transportation for Medicaid beneficiaries to and from medically necessary appointments and services. This service is vital as many Medicaid beneficiaries with complex health and social needs struggle to find safe and reliable transportation to non-emergency medical appointments.

PHAN feared that moving to a statewide broker model for NEMT services on a rapid timeline, which is what the state was pursuing, could have resulted in significant deterioration in customer service, something common to broker model programs in other states. Advocates mobilized both users of the NEMT service and a broad coalition to successfully pressure the state to pause pursuing the broker model and instead required a "stop and study" period. After an initial six-month suspension, the advocates were able to win a second 18-month delay, again by engaging users of the service to put pressure on policy makers. After the pandemic began, advocates pivoted and pushed the state to make the NEMT service safer for both riders and drivers. In direct response to concerns from consumers organized by PHAN, the Office of Medical Assistance Programs updated guidance for NEMT and COVID-19, requiring standards for keeping patients safe while being transported.

In Colorado, the Center for Health Progress (CHP) and Together Colorado (TC) also focused on improving NEMT, and when the pandemic hit, consumers and drivers alike raised concerns about the lack of COVID-related safety guidance. Even as NEMT was deemed an essential service, standards regarding Personal Protective Equipment (PPE) and sanitation were confusing or non-existent. By engaging their grassroots base, CHP and TC convinced the state to issue statewide protocols for NEMT drivers to prevent the spread of COVID-19. These protocols have been important in keeping drivers and riders – many of whom have complex health conditions – safer during the pandemic.

ORGANIZING: THE PATH TO VICTORY

The overarching goal of the CVI 2.0 program is to help organizations build and grow their base of engaged consumers so they can permanently strengthen organizational capacity, foster consumer activism in health advocacy over the long term, and win consumer-friendly policy change. Even within the context of an emergent global pandemic that prevented in-person organizing and disrupted every aspect of operations, the CVI 2.0 organizations have still achieved impressive policy victories. These victories span a variety of issues, and encompass a variety of approaches. Some victories were the result of mass mobilizations, while others were the products of patient behind-the-scenes advocacy by grassroots leaders. The common denominator, however, is organizing. Each of these victories was made possible by the engagement of ordinary people in the policy-making process. For funders and advocates seeking to impact health policy, the CVI 2.0 program demonstrates the efficacy of a grassroots organizing approach. We fully anticipate additional grassroots-driven policy victories in the remaining nine months of the grant program.

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