



WHERE THE MAGIC HAPPENS:

*A Guide to Grassroots Organizing for
Consumer-Driven Delivery Reform*





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INTRODUCTION

Much work remains for consumer advocates to defend and realize the health insurance coverage vision embodied in the Affordable Care Act (ACA), not to mention the defense of the Medicaid and Medicare programs. At the same time, however, increasing energy and resources are being directed toward another aspect of the ACA – how we deliver and pay for health care. The bulk of attention to these delivery reform issues has thus far come from providers and payers, both public and private. However, consumer advocates are coming to the table in ever-larger numbers as they recognize that delivery reform initiatives will have a critical impact on access, quality and affordability. The mission of the Center for Consumer Engagement in Health Innovation (the Center) is to bring the consumer experience to the forefront of delivery reform efforts.

One of the challenges consumer advocates face in doing this, however, is organizing consumers around delivery reform initiatives, many of which are highly complex and technical. As an organizer seeking to bring a powerful and organized group of grassroots consumers into the conversation about delivery reform, you face a series of thorny questions. To which populations of consumers do you reach out? Where do you find them? How do you talk to consumers about these complex issues? What key points do you listen for? What organizing tactics do you use? What are the most promising opportunities for consumers to participate in and influence delivery system reform initiatives?

This guide is an attempt to answer those questions, and is based largely on what we have learned from a group of our state-based partners who have been organizing around delivery reform issues for the past several years. We have learned from both the successes and the struggles of our partners, and no doubt what we've learned is a work in progress. As the future of consumer-based health care advocacy moves into the delivery reform space, however, we

believe that even these preliminary findings form a reasonably coherent picture that other advocates can use to organize around these challenging issues.

We assume throughout this guide that readers are familiar with the basics of delivery reform initiatives (for more on delivery reform, see the [Center’s Policy Platform](#)), as well as with the basics of grassroots organizing (for more on organizing, see the [Community Catalyst Grassroots Organizing Guide](#)). What we seek to do here is to apply the basics of grassroots organizing to delivery reform issues and to the populations most affected by those issues.

Without our state-based partners, the Center would not be able to present any of this information. We want to extend our thanks to all of our state-based partners, and particularly our partners in the Center’s [Consumer Voices for Innovation grant program](#): the [Maryland Citizens’ Health Initiative](#), [TakeAction Minnesota](#), [Make the Road New York](#), [Oregon State Public Interest Research Group](#), [Unite Oregon](#), the [Pennsylvania Health Access Network](#) and the [Rhode Island Organizing Project](#). We would also like to express our gratitude to [The Atlantic Philanthropies](#) and [The John A. Hartford Foundation](#), who made this work possible with their financial support.

“When you’re in
the room with
them – that’s
where the magic
happens.”

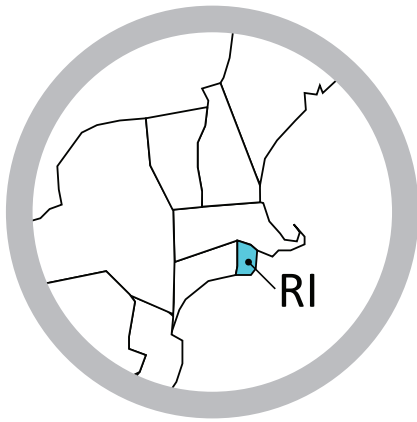


Photo courtesy of Boston Center for Independent Living

START BY LISTENING

To date, much of the delivery reform advocacy in which consumer advocates have engaged has been reactive rather than proactive. For example, a state may announce that it has decided to move all beneficiaries receiving LTSS (long-term services and supports) into a managed care program. Advocates then respond to this proposal by commenting on waiver applications, creating coalitions interested in the issue and building a base of consumers who would be affected by this change. This is important advocacy work, and advocates must continue to respond to these kinds of proposals. However, given that the goal of delivery reform is to move our health care system toward a more person-centered framework, a better model would be to ask consumers what would improve the health care system or, more meaningfully, their health, develop a policy agenda that addresses those issues and then strenuously seek to advance it. State-based advocates are beginning to move in this direction.

Most often, however, advocates are in the challenging position of having to be simultaneously reactive and proactive. States, providers and payers are putting forward delivery reform proposals, and advocates must engage, evaluate and try to ensure that these delivery reform initiatives be made as consumer-centered as possible. At the same time, advocates must be listening to the consumers they're organizing to understand their concerns about delivery reform initiatives and put forward a proactive agenda that addresses the real concerns of ordinary people. Our goal in writing this guide is to provide organizing suggestions that can be used in *both reactive and proactive contexts*. Regardless of the context, all successful organizing efforts begin with listening.



Best Practice Spotlight:

RHODE ISLAND ORGANIZING PROJECT (RIOP)

Reactive and Proactive Organizing Around Delivery Reform

RIOP organizers began talking with low-income older adults in Rhode Island in 2015 about their health care needs. What they heard about instead were the problems older adults were experiencing with transportation. From problems that Medicaid enrollees had with the state's Non-Emergency Medical Transportation broker to an increase in the bus fare for older adults using the state's public transit system, transportation loomed large for low-income older adults in Rhode Island. Indeed, these transportation problems were undermining the goals of the state's health reform efforts. Consumers struggled to get to their medical appointments because they lacked reliable, affordable transportation. They also couldn't get to a local food pantry, and they suffered from worse isolation and depression because the lack of transportation options prevented them from engaging in their community. The RIOP organizers listened to these consumers and, instead of organizing around the state's demonstration program for dually-eligible individuals as they'd originally intended, they organized around the need for affordable, reliable transportation. Over the course of a two-year campaign, the older adults RIOP organized worked with the state legislature to [preserve Rhode Island's No-Fare Bus Pass Program](#) for 13,500 low-income elderly and disabled riders. In addition to winning a great victory and improving the lives of older adults in Rhode Island, this campaign was an excellent example of proactive organizing. Advocates talked to people, heard about their concerns, and shifted their organizing focus. However, the advocates then made sure that this proactive organizing did double duty.

Because the population needing transportation services – low-income older adults and disabled individuals – was the same population targeted by the state's dual eligible demonstration, organizers were able, over the course of the bus fare campaign, to identify potential leaders who would be good candidates to serve on the state's [newly developed multi-stakeholder advisory council](#). In other words, advocates let their proactive organizing campaign around transportation do the heavy lifting of their organizing goal to identify and train consumer activists around a complex delivery reform issue. In this way, organizers in Rhode Island were able to simultaneously move forward on an agenda that was important to older adults, and to respond to a state proposal in a way that elevated the consumer voice.



Photo courtesy of Make the Road New York

WHO DO YOU LISTEN TO?

As is the case in any organizing campaign, you want to narrow the universe of people to whom you're talking to make your work more manageable. Most campaigns begin by applying a geographic lens. Grassroots organizing must always happen locally, but a geographic lens is particularly important in organizing around delivery reform issues because health conditions and disparities vary so significantly from community to community. You might focus on a specific city or town, or region of the state or even a particular neighborhood. Once you define your geographic focus, we recommend that you then layer some demographic strategies over that, focusing on key populations of interest. Some campaigns will lend themselves to reversing this process – demography first, then geography. But in either case, you should try to narrow your focus in both ways.

While almost anyone who has ever been a patient, or cared for someone who was a patient, has a story to tell about problems with our health care system, we have found that the consumers who have particularly valuable insights into delivery reform issues, and who are most likely to be motivated to effect change around these issues, are individuals who have a lot of interactions with the health care system. These people tend to know the system well *and* to be acutely aware of the system's weaknesses and inadequacies through their own long experience. The people most likely to interact with the health care system regularly are people with chronic health conditions, such as asthma, diabetes,

“The fact that health care was such a hot topic in 2017 both helped and hurt. It helped because it was easy to find people who wanted to talk about health care. But it was harder to interest people in the delivery reform issues. I had to learn how to piggy back onto the existing energy and do the slow work of finding the right people with the right stories.”

hypertension, renal disease, congestive heart failure and chronic obstructive pulmonary disease. In addition, people with dementia, chronic behavioral health conditions and people with disabilities interact with the health care system regularly. In thinking about these populations, be sure to include the caregivers of these individuals, who are vitally important voices for improving health care policies and programs. This could include, for example, the parents of children with asthma, the family members who look after someone with chronic mental illness, or the caregivers of older adults with dementia.

These populations are like the so-called “canaries in the coal mine.” When something goes wrong with the health care system, they are often the first to feel it. They are also often the first to notice the benefits of an intervention designed to correct care delivery problems. The organizing approach we recommend in this guide focuses on these populations, but can certainly be used by other groups of people who might use the health system less, but who are, nevertheless, ill-served and may experience health disparities.

How might you approach identifying and reaching out to these “canaries in the coal mine?” We recommend you look at several different populations. The most important thing is to approach all of these populations and/or organizations [respectfully](#), as is the first rule in any kind of organizing. *Always begin by listening.* Look for opportunities to build partnerships, and where appropriate, to share funding with organizations working with you.



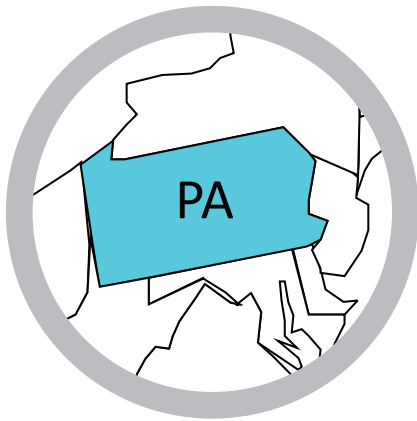
Best Practice Spotlight:

MAKING YOUR WORK ACCESSIBLE TO PEOPLE WITH DISABILITIES

Making sure your events, meetings and communications are accessible to people with disabilities is essential whether you’re reaching out to that specific population or not. For example, hosting an event after 11:00 a.m. is better for people who use personal care attendants. You should have food at your events, but make sure it isn’t all in packaging that would be difficult for someone with motor coordination challenges to open. Use ASL (American Sign Language) interpreters and/or closed captioning, as appropriate. Make sure the facility is accessible to wheelchairs and the room has enough space for wheelchairs to navigate. Be sure to have large print documents available and/or place your documents on thumb drives for those who use computer assistive technology. Make sure you have a good sound system, even if you think the room doesn’t need it. Use [People First Language](#) when describing people with disabilities, so as to emphasize the person and not the disability. For more tips on making your work accessible in every way, this [guide](#) from [Showing Up for Racial Justice](#) provides helpful information.

OLDER ADULTS

As people age they are more likely to develop chronic health conditions, so talking with older adults is a good way to identify consumers who will know a lot about what is wrong with our health care system. Promising strategies for reaching older adults include forging connections with the Resident Service Coordinators at senior housing developments and making presentations to the people who live there. Assisted living facilities, senior centers, faith communities, Meals on Wheels and other meal delivery programs are also good ways to reach this population. Some advocates have also reached out to local Area Agency on Aging Medicare benefit counseling programs to connect with older adults.



Best Practice Spotlight:

PENNSYLVANIA HEALTH ACCESS NETWORK (PHAN)

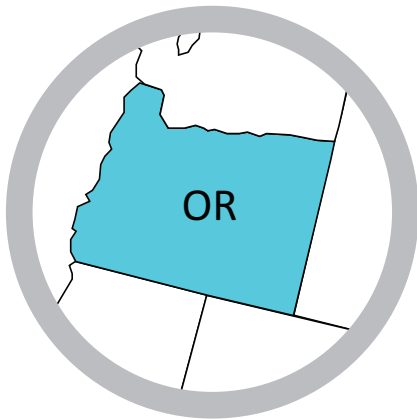
Using Paid and Earned Media

Advocates at PHAN are organizing older adults who are affected by Pennsylvania's shift to a managed care long-term services and supports program. The state of Pennsylvania began implementation of the program in the greater Pittsburgh area in 2018, so PHAN advocates started organizing in early 2017. Their challenge was to reach the older adults who would be affected by this change. They used a number of innovative tactics, but one of their most successful was advertising in a local newspaper called the [*Pittsburgh Senior News*](#). The *Senior News* is a free monthly paper that is widely read by older adults in three Pittsburgh-area counties. Advocates ran a simple, one-eighth-page ad ([see Appendix A](#)). The ad relied heavily on visuals. For example, instead of talking about Medicare and Medicaid, it showed pictures of Medicare and Medicaid cards. Instead of referring to housing, transportation and food security, it showed pictures of a home, a car and a dinner plate. Perhaps most importantly, the ad included the name and phone number of the organizer. The advocates reported they got dozens of calls right away, and through the individuals who called, the advocates were also able to connect with their friends and families.

PHAN also used earned media to bring attention to their organizing effort. Advocates learned that many media outlets saw delivery-reform-related stories not as political issues, but as public service issues. Consequently, advocates had a much easier time controlling the message of earned media stories in hyper-local outlets like *Senior News*, as well as local radio stations and public access cable channels.

LOW-INCOME COMMUNITIES

Many low-income communities have disproportionate rates of poor health outcomes. The voices of low-income communities of color in particular are critically important to efforts to identify and address problems in our health care system. Get to know the trusted voices in these communities, including community centers, places of worship, clinics and schools.

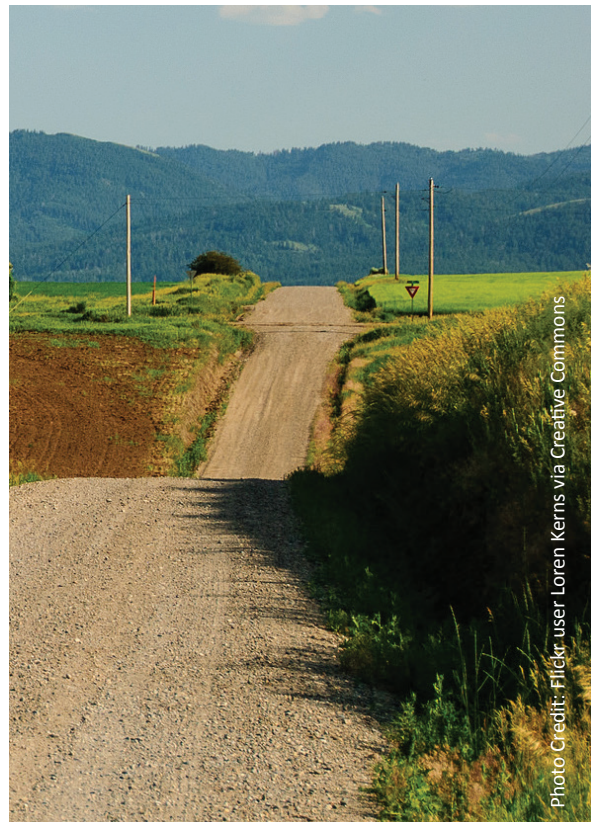


Best Practice Spotlight:

UNITE OREGON

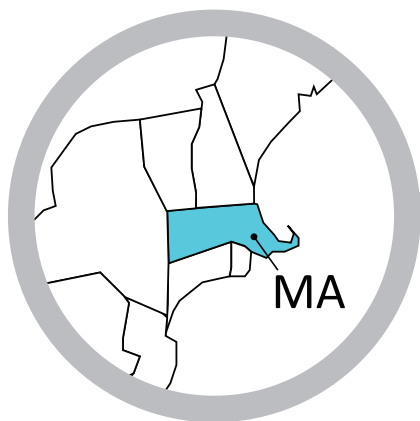
Reaching People in Rural Areas

In building a base of consumers they could place on the consumer advisory councils and governing boards of [Oregon's Coordinated Care Organizations](#), organizers at Unite Oregon sought ways to reach rural populations, a notoriously difficult task in any organizing work. Several rural communities had one day per week when residents could sign up for WIC (Women, Infants and Children) benefits, which provide nutritious food support to low-income families. The Unite Oregon organizer began showing up for these WIC signup days, and found it to be a great opportunity to reach consumers who no one else was talking to, but who nonetheless had a lot to say about health care and other topics. This strategy helped the Oregon advocates to build a base that consisted of significant number of rural residents, rather than people exclusively from denser population centers.



PEOPLE WITH DISABILITIES

People with disabilities may need to interact with the health care and social supports system often. In addition, because people with disabilities constantly have to fight for their civil rights, many in the disability community are well-organized and passionate about speaking out. We recommend talking with your state's independent living centers and/or disability rights organizations, which can help to connect you with the disability community.



Best Practice Spotlight:

DISABILITY ADVOCATES ADVANCING OUR HEALTHCARE RIGHTS (DAAHR)

Keeping the Voices of People with Disabilities at the Center of the Discussion

[DAAHR](#), a joint project of the [Boston Center for Independent Living \(BCIL\)](#) and the [Disability Policy Consortium \(DPC\)](#), has been organizing people with disabilities in Massachusetts for many years. They have well-established email lists and social media accounts, and are continually able to add to their base, in part by talking to individuals seeking services at BCIL. When the state announced that it would be moving the majority of the MassHealth (Medicaid) population in Massachusetts into Accountable Care Organizations (ACOs), advocates had serious concerns about the transition process. They activated their existing base and also expanded that base by traveling to Centers for Independent Living in smaller urban areas of the state to collect stories and educate people about ACOs. In addition, advocates developed a relationship with a freelance journalist with a disability who has since published several stories that elevate the voices of DAAHR members.

In 2018, DAAHR organized a meeting for its members to discuss the new ACO program. MassHealth leaders, already familiar with DAAHR's work through their years of organizing and advocacy, heard about the meeting and asked if they could attend. Advocates were pleased to have MassHealth officials there, but concerned that the meeting would become an information session in which DAAHR members were listening to the state, rather than the other way around. Accordingly, advocates developed an agenda that focused on DAAHR members raising their concerns, and MassHealth officials only speaking when invited to do so. As of this writing, the ACO program in Massachusetts is still unfolding, but DAAHR advocates have been able to spread information about ways that enrollees will be able to keep their existing specialists, even if those specialists are outside of the ACO. The DAAHR forum very likely accelerated MassHealth's attention to this critical concern, and discussions with the state about ACO implementation are moving forward on that basis.

FAMILY CAREGIVERS

In addition to reaching out to consumers directly affected by chronic conditions, you should also reach out to their family caregivers. Be forewarned – these are incredibly busy people. They are often juggling jobs and parenting responsibilities along with their caregiving roles. However, caregivers can also be incredibly eager and effective advocates. Scour your existing base for people in their 40s and 50s who may be caring for aging parents. Reach out to the parents of children with special health needs. Reach out to caregiver organizations in your community. Caregivers will be as familiar with the health system's limitations as are the people they care for, and caregivers bring a compelling voice to your base.

PAID CAREGIVERS

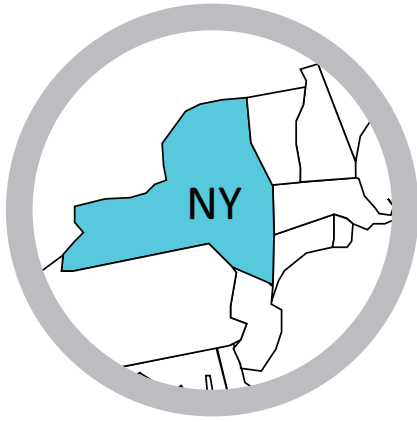
Paid caregivers, such as Personal Care Attendants (PCAs) and other home care workers, can be important allies in delivery reform organizing. In some states, these caregivers may already be organized through a labor union. The [Service Employees International Union \(SEIU\)](#) has been particularly successful at organizing PCAs in some states, and may be willing to let you talk to some of their members.

PROVIDERS

Depending on the issue, you may find that medical providers are strong allies and can help you to connect with the consumers you are seeking. For example, if you're organizing around transportation problems, community health centers and dialysis clinics whose patients may miss their scheduled appointments will be just as frustrated as consumers when inadequate transportation services are provided to low-income people. They may let you set up a table in their waiting room, or provide consumers with a flyer about your campaign.

YOUR EXISTING BASE

You might consider starting with your existing leadership/consumer activist base. The individuals in this base are already more knowledgeable about health care issues than the general population by virtue of the work they've done with you. In addition, these individuals have already moved up the [pyramid of engagement](#) to at least some degree. Similarly, if your organization does any kind of direct service provision, you can also start by focusing on that population. For example, does your organization (or an ally) help to enroll people in health insurance coverage during open enrollment periods? If so, you can include questions on your story-collection form that will surface delivery reform issues ([see Appendix B for samples](#)). You can then follow up with people one-on-one.



Best Practice Spotlight:

MAKE THE ROAD NEW YORK (MRNY)

Start with Who You Know

Make the Road New York faced a challenging task. They have a low-income, Spanish-speaking, immigrant constituency that is not always well-served by the health system in New York. The state's endlessly complex Delivery System Reform Incentive Payment (DSRIP) program provided a policy-change opportunity to improve care for that constituency, among others, but only if consumers could be organized and supported. The advocates decided to pilot their presentation on DSRIP with a group of Community Health Workers (CHWs) who are part of the organization's existing CHW training program and who work on a project that seeks to improve asthma-related health outcomes in key New York City neighborhoods. This "pilot" approach eventually became MRNY's primary recruitment strategy. After all, the CHWs were within the same demographic MRNY was trying to reach. However, these CHWs already had a history with MRNY, already had a history as advocates, and had also undergone MRNY's CHW training. In other words, these consumers were already relatively sophisticated about health care and health care advocacy. More importantly, because of the nature of their work, CHWs immediately understood the need to change the delivery system so it worked better for patients. The CHWs also proved to be a conduit to consumers with stories to share – both stories about problems with the delivery system and stories about how delivery reform innovations improved health outcomes. By starting with *who they knew* and *listening to what people told them*, MRNY advocates built a base of consumers well prepared for advocacy around delivery reform policy issues.



Photo courtesy of Maryland Citizens' Health Initiative

WHAT DO YOU SAY?

You're determined to listen and to surface consumer experiences, but how do you get the conversation started? While it might be relatively straightforward to ask a consumer about a coverage issue, determining how to ask people about delivery reform issues is far less intuitive. What, in fact, do you ask? "What do you think about the new value-based payment program at our hospital?" or, "How do you think our state's DSRIP program is working for patients?" These questions are not exactly conversation starters. Also, they miss the point, which isn't to create a new complicated delivery system full of jargon that stifles a vision of what patient-centered care could be like, but rather to listen to what consumers want out of their health care experience.

In this endeavor, consumer advocates have a lot to offer to policymakers and stakeholders. Indeed, our partners have identified a number of approaches to talking to consumers that can surface problems with our health care system and get people talking about their experiences in a comfortable way. These approaches have been most often used in group settings, but could also be used in one-on-one conversations.

1) Use the Center's *Shine the Light* Exercise (see Appendix C)

The *Shine the Light* exercise is a simple activity designed to make a group of people comfortable talking about problems they've experienced with the health care system. Give each participant a flashlight (or have them use their cell phones), and, one at a time, read off a list of common problems with the health care system. Ask participants who have experienced each problem to "shine their light." The exercise helps people to see that the individual problems they've experienced are, in fact, systemic problems that many consumers have experienced. You can follow up this exercise with an open-ended question (see below) to go deeper into people's experiences and to surface what people think would improve the health system.

2) Ask an open-ended question

Our partners have identified a variety of questions that can effectively get this conversation started. If you've been thoughtful in your outreach and put together an audience of people likely to be experiencing chronic health conditions, these questions can surface the kinds of problems consumers face in dealing with our health care system. If you are working with a large group, start by breaking people into smaller groups. This will make people more comfortable sharing with the full group. Examples of successful questions used by organizers include:

- Tell me about a recent experience you had with the health care system.
- What does it mean to you to age with dignity?
- What do you wish your doctor understood about your life?
- What do you need to be healthy?

3) Share information about yourself.

This is a common organizing tactic, and can work well in this context. Talk about the struggles members of your own family have faced with the delivery system. This will get your audience thinking along those same lines.

Now that you've gotten the conversation started, what should you listen for? How do you know when you've happened upon a good consumer story, or an experience that will make a consumer a strong advocate? We recommend listening for the following:

✓ *Care Coordination Problems*

Listen for stories of people having to have blood tests or x-rays a second time because one doctor is unable to access another doctor's test results. Listen for problems with people being prescribed medications that counteract one another or that shouldn't be taken at the same time. Listen for problems that consumers have accessing specialty care recommended by a primary care provider, such as long waits for appointments, or no specialists that are "in network."

✓ *Problems with Transitions*

Transitions – from the hospital to home, from the hospital to a skilled nursing facility, or even from one unit to another unit in the same hospital – are often trouble spots in our health care system. Records, doctor's orders and test results somehow don't follow the patient, and miscommunications are common. Too often, breakdowns in these transitions result in unnecessary readmissions to hospitals.

✓ *End-of-Life and Palliative Care*

Most Americans do not die in the way or the care environment they would prefer. Listen for stories that highlight this problem. Was the patient asked well ahead of time about her/his preferences? Were those preferences ignored? Was there overtreatment, relative to stated preferences, in someone's final months or weeks of life? Were requests for palliative care – whether at the end of life or not – met? Were patients even presented with any palliative care options?

✓ *Cultural Competency*

This can include anything from overt racism or other bias to more subtle implicit bias.

Consumers may report not being able to communicate with a provider in a language that is comfortable for them or that minor children were asked to function as translators. Ignorance of the kind of care needed by gay, lesbian or transgendered people is also common.

✓ *Social and Economic Barriers to Health*

Often, the medical interventions that providers offer are doomed to failure because of social and economic problems that get in the way. For example, it can be extraordinarily difficult for an individual with diabetes to safely store their insulin if they are homeless, without access to a refrigerator. Listen for ways in which the so-called “social and economic determinants of health” – unstable housing, transportation problems, violence, food insecurity, water or air pollution, employment instability, etc. – are impacting an individual’s health. This can be a good jumping off point for identifying consumers interested in advocacy in the delivery reform space.

“The challenge with this population is to stay in the advocacy world and not slip over into case work. You must do a little of both, of course, but you must be careful to stay in the advocacy realm.”



ORGANIZING TACTICS – WHAT WORKS AND WHAT DOESN'T

Delivery reform issues tend to be highly complex, and therefore do not lend themselves to quick explanations. For this reason, advocates have found that they are better off employing organizing tactics that provide time for more extensive conversations. Organizing tactics that allow for larger numbers of shorter, more cursory conversations – such as phone-banking or even door-knocking – do not tend to yield results as good as tactics that allow for longer conversations with smaller numbers of people. Specifically, advocates have had success with:

✓ *Community Meetings/House Parties*

Community meetings and/or house parties with groups of two to 20 people are a good way to start. This leaves space for a 45-60 minute program that both surfaces consumer experiences and allows for some more didactic information sharing. At the end of the meeting, distribute a form that will capture people's contact information and allow them to indicate their interest in delivery reform advocacy ([see Appendix B for samples](#)). For individuals who express an interest, organizers can follow up with one-on-one meetings.

✓ *One-On-One Conversations*

Conducting one-on-one conversations with people who have already indicated interest in delivery reform issues helps you to learn about a particular individual's situation and experience with the health care system, what they think is important to improving their own health and the health care system, and to gauge their current advocacy skills. If your organization (or an ally) provides direct services, such as signing people up for health care coverage, or helping people troubleshoot problems with their health care coverage or services, you can use that opportunity to both help

resolve the person's problem and learn about their experiences and interest in delivery reform issues. You can do this by asking questions and listening for the kinds of problems that are typical of our health care system. Capture this information and begin working with the individual so they can tell their story to policymakers or members of the media.

✓ *Leadership Trainings*

For advocates who begin by tapping into their existing consumer base to identify individuals interested in delivery reform issues, training sessions can be a good organizing strategy. This population of people is already interested in your organization and your work, and so would likely be open to attending a one-to-three-hour training session. Such a training gives you the time you need to surface consumer experiences and opinions, explore complex delivery reform issues, and build leadership among your consumer advocates on these issues. The Center has developed a portfolio of [consumer-oriented training programs](#) that can be customized to fit your needs. Be sure to provide assistance with child care and transportation for these trainings.

No matter what tactics you use, it is important to stay in touch with the individuals in your base. The life circumstances of low-income individuals with chronic health conditions change all the time. You need to talk with people frequently to keep up with what's happening in their lives.



WHAT DOES A DELIVERY REFORM BASE LOOK LIKE?

You'll notice that all of the organizing tactics identified above are labor intensive and time consuming. Don't panic! You are not trying to build a base of thousands of people. Instead, you are trying to build a smaller base of people whose experiences inform your policy agenda and whose knowledge and skill level you have built up over time. You might start out with just a small handful of people. *This is okay*, in large part because you're going to make a much larger investment in this smaller number of individuals. One organizer pointed out that it was not unusual to have a house party or community meeting with only two or three people. The small numbers allowed the organizer to fully connect with each person, and then build on each of these relationships over time.

Because the people most likely to have experiences with the shortcomings of our health care system are people with chronic conditions, your delivery reform base is likely to skew older, and perhaps more low-income. People with disabilities are likely to play a much larger role, and you are likely to have more caregivers in your base.

Over time, your delivery reform base will become very educated about the potential policy solutions to the existing shortcomings of our health care system. You will eventually develop individuals capable of serving effectively on statewide committees, delivery system governance bodies and highly technical work groups. Your leaders will start to specialize, developing expertise in specific issues. They will also develop very strong skills in speaking up and advocating in difficult environments, and working with challenging bureaucracies. They will need your ongoing support, training and encouragement to do this, but these investments can pay off in consumer leaders who are capable of being very powerful advocates – with policymakers, plans, health systems and the media.



Best Practice Spotlight:

ALABAMA ARISE CITIZENS' POLICY PROJECT

Building a Team

In preparing consumers and consumer advocates to serve on governing bodies, the advocates at [Alabama Arise](#) and the [Disabilities Leadership Coalition of Alabama](#) have worked to build a united team of advocates who meet periodically, both in person and via teleconference, to build their skills and knowledge, to support one another and to develop a unified agenda. This means that even as consumers and consumer advocates might seem isolated on their individual regional governing bodies, they have the support of a team behind them. In 2015, Arise arranged for a group of these advocates to go through the Center's two-day Consumer Advisory Council training ([see Appendix D](#)). In 2018, the group got a sneak preview of the state's proposed Medicaid reform project, straight from the Medicaid medical director. Even as Alabama's Medicaid transformation efforts have proceeded in fits and starts, and sometimes stalled out completely, the Alabama advocates have kept their group of consumers together and continued to build their knowledge and advocacy skills.



Photo courtesy of Maryland Citizens' Health Initiative

HOW TO ENGAGE YOUR BASE IN ADVOCACY ACTIVITIES

You've done it! You've successfully built a base – even a small one – of consumers interested in and with some knowledge about delivery reform issues. At this point, advocates sometimes find themselves wondering what to do next. The [pyramid of engagement](#) is one way to conceptualize different kinds of advocacy activities. Individuals will enter the pyramid of engagement at differing levels based on their earlier experiences and skillsets, and your work with them can support them in moving toward increasing levels of engagement. Your ongoing goal should be to continually reach out to new individuals who might become a part of your base, even as you work with the folks you've already organized to enhance their knowledge and skills ([see Appendix E for examples of delivery-reform-related activities at each level of the pyramid of engagement](#)).

The specific activities in which your base engages might be somewhat different than you are used to. For example, you might be accustomed to generating turnout for a rally or a big lobby day in your state legislature. Delivery reform campaigns often do not lend themselves to these kinds of tactics. For one thing, the decision makers are frequently not elected officials, but rather executive branch officials and staff, or health system and health plan leaders. Your relationships with these entities can sometimes be more productive if they are less confrontational than your relationships with elected officials. Even as you seek to persuade a hospital CEO or a state Medicaid director on a particular policy point, you must simultaneously be strengthening your working relationship with that individual. Staging a rally in front of their office, while sometimes necessary, will complicate that. Furthermore, as we've already noted, delivery reform issues sometimes do not lend themselves to sound bites or rally speeches. They can be complex and technical, and are often better discussed in a small group meeting than in a big public environment. While the fundamentals will be familiar to you, it can be helpful to identify some key tactics that will help you to work with your new delivery reform base most effectively.

COLLECT STORIES

No doubt you already use [story collection strategies](#) with your more traditional base, and you should definitely build a story bank with your delivery reform base as well. These stories will both shape your policy agenda and highlight problems with the existing delivery system. This helps you to build your case for change. You should also collect success stories – stories that demonstrate how a delivery reform intervention is improving people’s care. For example, perhaps you can talk with consumers who are benefiting from a new care coordination program. Or perhaps a hospital has incorporated Community Health Workers into their system and you can talk to consumers who have benefited from that intervention. Perhaps a plan is requiring providers to screen consumers for social or economic barriers to good health. You can gather stories about consumers who have benefited from that screening. In other words, collect stories that demonstrate the problem, but also stories that point to solutions. Once you have these stories, you can use them in the same variety of ways in which you normally use consumer stories. You can:

- Bring consumers to meetings with decision makers to tell their stories
- Connect consumers with reporters writing articles about delivery reform
- Package some of the stories with photos and brief write-ups for your website and social media, or create “story books” that package several stories you can provide to decision makers or members of the media
- Bring consumers to conferences that include delivery system decision makers to tell their stories

You should also collect stories about consumers who have become consumer advocates. As consumers begin shaping the delivery reform agenda in your state and you start to place consumers on governance bodies, consumer advisory councils and statewide working groups, be sure to document the journeys of these consumer leaders. You can use these “consumer-to-leader” stories to inspire and further build your base, and to market your work with consumers to funders and others to strengthen your organization.

PROVIDE REGULAR UPDATES

Schedule monthly conference calls or community meetings with your base to do some more listening and to update them on what’s happening with delivery reform initiatives in your state. This helps people to increase the breadth of their knowledge and to stay connected to you and to the issue.

CREATE PEER LEADERSHIP ROLES

As the size of your base grows, you may identify opportunities to “promote” people into peer leadership positions. These roles can be paid or unpaid, though if you are paying your volunteers, keep your eye on the income eligibility limits for your state’s Medicaid program. Advocates in Ohio, for example, created regional consumer leadership positions, which provided consumers with a local peer they could contact if they had problems or concerns about the state’s dual eligible demonstration project. Advocates in Alabama are creating “community liaisons” who will provide linkages between consumers sitting on regional governance boards and the local community. Roles like these serve multiple purposes. They expand your organizing capacity by allowing you to stay in touch with a larger number of people. They also allow you to continue to hear robust feedback from a diversity of consumers. Finally, these positions build the leadership skills of members of your base and help them to move up the pyramid of engagement.

INFLUENCE DECISION MAKERS

The decision makers you will be targeting with the new base might be different from the usual suspects. Decision makers in this space can include, but are not limited to:

- State Medicaid directors and their staff
- Other executive branch leaders and their staff
- Key legislative leaders who may help write delivery reform legislation
- Regional CMS administrators
- Hospital or health system CEOs and their staff
- Health plan CEOs and their staff

As you would if you were connecting your base to elected officials, be sure to connect the right consumer with a given decision maker. For example, if you are meeting with a health plan CEO, try to bring a consumer who is a member of that plan. If you are meeting with hospital staff, the consumer you bring should live in the hospital's service area and, if possible, have actually used the services of that particular hospital. If you can, do some research on your target to see if they have a personal experience that will help them relate to an individual in your base. Ground your conversation with the target in a consumer-centered approach by beginning the meeting with a consumer telling their story. It takes considerable effort to prepare consumers for meetings like this, but make sure you do that work so that the consumers can fully participate. Remember, you are putting more time and effort into a smaller number of people, but building their skills and knowledge will pay dividends in a variety of ways.



If you do find yourself in a situation where you need to bring larger numbers to the table, consider a letter-writing campaign among the members of your base. Even if your base is only 30 people, think about a Medicaid director or hospital CEO receiving 30 letters from consumers about the same issue. That will have an impact. Perhaps the state is seeking comments on an 1115 waiver. Organize consumers to submit comments, either orally or in writing. Comment submission processes are usually dominated by institutional players, so even a small number of consumers conveying powerful personal narratives in a coordinated way can have a significant impact.

PLACE CONSUMERS ON GOVERNANCE BODIES

An important goal of your leadership-building process should be focused on placing skilled and knowledgeable consumers on various decision-making bodies that focus on delivery reform policies. These kinds of bodies can include PFACs (Patient and Family Advisory Councils), CACs (Consumer Advisory Councils), governance bodies (such as boards of directors), and working groups of stakeholders. Some of these bodies are, at least theoretically, designed specifically to get consumer

input. Others, such as state working groups, are dominated by health plans and health system players and are notoriously inaccessible to ordinary consumers. With bodies designed specifically for consumers, your challenge will be to insure that the consumers you place are skilled and trained enough to prevent them from becoming marginalized. With bodies designed for industry stakeholders, the challenge is even greater. You must often fight a consumer's way onto the body in the first place. Once consumers are there, you have to provide them with the information and support they need to insure they have an impact ([see Appendix D for information about training that can help](#)). This takes considerable resources over time and the right kind of consumer, but once you develop an effective leader like this, s/he becomes an incredibly powerful asset.



Best Practice Spotlight:

MARYLAND CITIZENS' HEALTH INITIATIVE (MCHI)

Placing Consumers on Statewide Working Groups

There are a variety of opportunities in Maryland for consumer advocates to have input into the state's health care delivery system. The question for the advocates is, how accessible are these bodies to actual consumers? Typically, these bodies are dominated by industry players, who meet during the workday and have conversations which are highly technical, filled with acronyms, and often challenging to connect to the experiences of individuals. For years, the consumer advocates in Maryland served on some of these bodies themselves, and in 2016 they placed their first consumer on one of them: the [Maryland Health Care Commission's Health Information Exchange \(HIE\) Policy Board](#). Rev. Dr. Sandra Conner, who is involved in MCHI's [Faith Health Network](#), was placed on the workgroup and immediately began to make sure she had what was needed to be an effective consumer advocate. She advocated for simple things, like asking participants to explain acronyms and jargon. As such, an introductory webinar was presented to discuss HIE Regulations which not only proved to be beneficial to her, but to others participating on the workgroup. It is worth noting that Rev. Dr. Conner is a faith leader and has a Doctorate, and she still found it helpful to ask for basic explanations so that she could represent consumers effectively on this body.

Rev. Dr. Conner consistently paid attention to those policies and procedures that, based on her own experience, would have a direct impact on consumers' ability to have exceptional quality health care. She asked questions about how consumers would have an opportunity to comment on proposed policies and provide feedback. In January of 2018, she was able to identify a bill before the state legislature that impacted consumer privacy. Without her expertise, the advocates at MCHI would not have noticed that particular bill's significance. Thanks to her knowledge, MCHI was able to testify in support of the bill, which was passed by the Maryland legislature. The Maryland advocates continue to place consumers on various work groups in the state, and are slowly changing the culture, workgroup by workgroup.

SUSTAINING THIS WORK

Building a base of consumers to work on delivery reform is a long-run proposition that requires a sustained funding stream to support ongoing consumer recruitment and leadership development. State-based advocates must [grow the base of funders](#) who support their grassroots organizing work. This includes growing their individual donor bases, which provide more flexible funding for organizing. It also includes thinking about cultivating foundations' interest in their organizing work. Particularly in the delivery reform space, foundations may be interested in organizing work that results in consumer education, consumer engagement or patient activation.

Consumer engagement is fundamental to building a consumer-centered health care system, and as should be clear by now, it does not happen by magic. It takes significant infrastructure and resources to identify consumers with experiences to share, listen to and learn from those consumers, and build the skills and knowledge base of engaged consumers so that they can be effective in promoting policy change at any level. The organizing and consumer engagement work of the state-based advocates highlighted throughout this guide occurred because those advocates were given resources – including policy help, technical assistance and funding – to do the work. These advocates are establishing “proof of concept,” and their work can and should be used to enlist investment from the health system, much like the health system already invests in information technology or financial management systems.

Indeed, most of the advocacy organizations highlighted in this guide have sought, and some have successfully received, grants from health systems, health plans and the state to support their consumer engagement work:

- Advocates in Maryland have received funding from the state to enhance their work with faith communities on advance directive planning.
- Advocates in New York received funding from a health system to sit on a strategic advisory workgroup designed to enhance the health system's work with community-based organizations.
- Advocates in Ohio received funds from local health plans to train patients and family members on their consumer advisory councils.
- Advocates in Rhode Island received a grant from a health plan to do outreach to consumers around a delivery reform initiative.

These funding sources have thus far been small and short-term, but they are a beginning. Indeed, the Center itself has a growing [business development program](#) to sustain its delivery reform work over the long term. Advocacy organizations interested in helping to build a consumer-centered infrastructure must look to these institutional funders to sustain aspects of their work with consumers.

Publisher's Corner




We've had pleasant fall weather so far, but winter is right around the corner. Turn to page 15 for tips on how to winterize your home, save on your energy bills, and stay safe while going out.



Wishing everyone a Happy Thanksgiving!

Lynn Webster

WHY IS IT SO HARD TO FIND...

 **Doctors who take the time to listen**

Easy-to-understand information about how work

 & 

Help with services like:



HOW CAN WE BEGIN TO FIX IT?

Lift Up Your Voice!

Advocacy Training

Thursday, Nov. 9th
10am to 2pm
Kingsley Association
6435 Frankstown Ave.
Pittsburgh, PA 15206
Free Lunch! Please RSVP to Erin Ninehouser:
(412) 863-1047 PHAN

LOOKING TOWARD THE HORIZON, HOW DO YOU WANT TO BE REMEMBERED?



Is nature a part of your favorite memories? For more than 84 years, the Western Pennsylvania Conservancy has ensured that nature remains a vital part of our region by establishing natural areas and parks, community gardens and greenspaces, and stewarding Fallingwater. Explore how you can create a legacy for future generations to enjoy.

To learn more, visit **WaterLandLife.org**.



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*In Memory of
Carmella M. Hogan
John A. Hogan, Sr.
Michael J. Hogan, Sr.
Wayne Hogan*

LIVING WELL AT HOME:

What Do Seniors & Caregivers Need?



What we need to live well and stay healthy changes as we age.

It's important that people responsible for providing coverage and care to seniors have a clear picture of what you need to feel good, stay connected in your community, and live independently.

Thinking ahead to a time when your health may not be as good as it is today, what kinds of supports would you like to have available that would make it easier for you to remain independent at home? [Please circle all that apply, and add your own suggestions]:

- Free Transportation that's easy to arrange that I can use for medical appointments and everyday needs like groceries
- Help keeping my home clean and safe
- Healthy meals delivered each day
- Help paying bills and managing finances
- Regular social activities and connections in my community
- A go-to person or agency that can connect me with other supports as I start to need them
- Other:

We know that being healthy is just one part of living well. What other things are important to you? [In a few sentences, describe what "living well" means to you]:

What do you wish your health care providers knew about you? [Please circle all that apply]:

- That it's hard to manage all my medicines
- That I could use help at home preparing healthy meals
- That arranging transportation for appointments is difficult for me
- That it's hard to understand what they want me to do
- That I need more support when I'm not feeling well to stay on top of my medicines & DR visits
- Other:

Please complete on back —>

Has there ever been a time when you felt frustrated or alone in trying to get help for medical problem? [Please tell us a little bit about what happened, who you turned to for help, and if your problem was resolved. You don't need to reveal any personal details]:

Who do you call when you need help with a health care problem? [Please check all that apply]:

- My primary care doctor's office
- My specialist's office
- A close friend or family member
- My local Agency on Aging
- My local hospital
- Other:

If you'd like to stay in touch to get help or get involved in the advocacy work we're doing to protect and improve health care for seniors, you can share your information below. We will not share it with any other organizations.

Your Name:

Your Email:

Your Phone:

Your Zip Code:

What kind of health coverage do you have?

- Medicare (Red and Blue Card)
- Medicaid (ACCESS Card)
- Medicare Advantage Plan
- Medicare Supplement
- Medicare Part D Prescription Drug Plan
- PACE/PACENET for Prescription Drugs
- Other:

Had you heard anything about Community HealthChoices before today?

- No, I've never heard about it
- Yes, but I don't know anything about it
- Yes, one of my care providers told me about it
- Yes, I'm an advocate, caregiver, or health care provider


Please select your age group below:


[None of this information will be shared publicly]

- 60-64
- 65-69
- 70-74
- 75-79
- 80+



Erin Ninehouser, Consumer Engagement Manager
 Email: erin@pahealthaccess.org
 Cell: (412) 863-1047 Toll-Free: 844-474-2643

Southern Oregon Healthcare Access Survey	Date:	Location:
I oppose cuts to healthcare programs such as OHP and Medicare and I oppose discrimination against people with pre-existing medical conditions.		
Name	Email	
Phone	Zip Code	
Where do you get your health insurance? <input type="checkbox"/> OHP <input type="checkbox"/> Marketplace Plan <input type="checkbox"/> Parent's Plan <input type="checkbox"/> Employer Plan <input type="checkbox"/> Uninsured <input type="checkbox"/> Military insurance <input type="checkbox"/> Medicare <input type="checkbox"/> Private Insurance		
Do you have a pre-existing condition? <input type="checkbox"/> Yes <input type="checkbox"/> No		
Are you willing to share your healthcare story or volunteer with us? <input type="checkbox"/> Share your Story <input type="checkbox"/> Volunteer		
		
We will not sell or share your information without your permission.		

Southern Oregon Healthcare Access Survey	Date:	Location:
I oppose cuts to healthcare programs such as OHP and Medicare and I oppose discrimination against people with pre-existing medical conditions.		
Name	Email	
Phone	Zip Code	
Where do you get your health insurance? <input type="checkbox"/> OHP <input type="checkbox"/> Marketplace Plan <input type="checkbox"/> Parent's Plan <input type="checkbox"/> Employer Plan <input type="checkbox"/> Uninsured <input type="checkbox"/> Military insurance <input type="checkbox"/> Medicare <input type="checkbox"/> Private Insurance		
Do you have a pre-existing condition? <input type="checkbox"/> Yes <input type="checkbox"/> No		
Are you willing to share your healthcare story or volunteer with us? <input type="checkbox"/> Share your Story <input type="checkbox"/> Volunteer		
		
We will not sell or share your information without your permission.		

Page 1 of 2

My Story:

What race/ethnicity do you identify as?

- | | | | |
|---------------------------------|---|---|--|
| <input type="checkbox"/> Latinx | <input type="checkbox"/> African American | <input type="checkbox"/> Asian | <input type="checkbox"/> White/Caucasian |
| <input type="checkbox"/> Other | <input type="checkbox"/> Native American | <input type="checkbox"/> Pacific Islander | <input type="checkbox"/> Arab/Middle Eastern |

My Story:

What race/ethnicity do you identify as?

- | | | | |
|---------------------------------|---|---|--|
| <input type="checkbox"/> Latinx | <input type="checkbox"/> African American | <input type="checkbox"/> Asian | <input type="checkbox"/> White/Caucasian |
| <input type="checkbox"/> Other | <input type="checkbox"/> Native American | <input type="checkbox"/> Pacific Islander | <input type="checkbox"/> Arab/Middle Eastern |

Page 2 of 2



House Meeting Sign-in Sheet

Name/Nombre	Telephone Number/Numero de Telephono	Interest
1)		
2)		
3)		
4)		
5)		
6)		
7)		
8)		
9)		
10)		
11)		
12)		
13)		
14)		
15)		
16)		
17)		
18)		
19)		
20)		
21)		
22)		
23)		
24)		



SHINING THE LIGHT ON THE PROBLEMS IN HEALTH CARE SCRIPT

Note: Bulleted issues need to be written on flipchart paper and taped up on a wall.

We are so grateful that you are here to learn how you can help make the health care system work better. In other words, better care for lower costs. First, it's important to understand what we mean when we say "better care."

Throughout this training, we will talk about going on a journey to an improved health care system. The health care system is made up of people (us!), providers (doctors, nurses, and other medical specialists who provide medical care), and payors (everyone that pays for health care, including insurance companies, the government, employers, and you).

Each of us, to varying degrees, has already traveled a health care journey. It may have been our own health care journey or that of a loved one. Some days of the journey and some places we visit can be more difficult than others. Sometimes we might feel like it is really becoming difficult to reach our destination. But there are things along the way that people, providers, and payors can do to make the journey easier and better. That's why we're here today, and that is what we will talk about more.

So let's begin by talking about some of the difficult things that we've encountered along our journey. Let's first talk about what's wrong with our health care system so that we can understand what needs to be fixed to make it better. We are literally going to "shine a light" on some of the problems in the current health care system.

This is how we are going to do this activity. I am going to give each of you a flashlight. I will then read some statements that describe a real life barrier – or problem – in the health care system. If you or a loved one has experienced that problem along your journey, turn on your flashlight and aim it on the ceiling after I read the statement. I will use the words "I" or "we," but you should shine your flashlight if that statement pertains to you personally or to a loved one you have helped through their health care journey.

Before getting started, let's test those flashlights and make sure they work!

Are there any questions before we start?

Okay, let's get started. Be sure that your flashlights are turned off right now.

[Turn the lights off, or down, in the room. Co-facilitator records how many people flash their light for each problem on a flipchart.]

[READ OUT LOUD]

Along my health care journey...

- I have felt rushed through appointments.
- I have been confused about follow-up care such as how to take newly prescribed medication or when I need to see my doctor again.
- I have had doctors or nurses that don't listen to me.
- When I have needed to schedule a test or an appointment, I have had difficulty reaching the right person on the phone.
- I have had to repeat medical tests, such as x-rays or blood tests, simply because one doctor did not give the results to another doctor.
- I have been confused about how or when to take my medications.
- I have felt confused about how to navigate the health care system, including insurance.
- I have experienced cultural and gender bias when receiving health care.

Let's turn on the lights and see how we did.

[Review each statement and give the number of people who shined their lights indicating they had experienced that problem.]

It looks like many people in this room have experienced some very real problems along their health care journey. Are there other problems you think we should add to our list?

This training is about changing the health care system so that it provides quality, comprehensive and coordinated care. In other words, it is about making changes so that NOBODY experiences the problems we just discussed.





MEANINGFUL CONSUMER ENGAGEMENT: Preparing Consumers to Serve on Community Advisory Bodies

CONSUMER ENGAGEMENT: WHY IT MATTERS

Who understands consumer health needs better than consumers themselves? That's why it is critical to ensure that these voices—including those of older adults, persons with disabilities and family caregivers—are heard in the design, implementation, and oversight of new programs aimed at improving health quality and reducing costs.

TRAINING PROGRAM OVERVIEW

In consultation with consumers and healthcare organizations, the Center has developed an integrated, interactive and fun training program to improve the effectiveness of consumer advisory bodies. This program helps individuals serving on these bodies to improve their ability to provide meaningful consumer input and to ensure this input translates to improvements in care. The training package includes a 4-6 hour presenter training program (for advocates, consumer leaders and/or health organization staff), and a 6-8 hour training program for individual consumers.

TRAINING COMPONENTS

While we customize each training program to the needs of each partner, key components of the training curriculum may include:

- Understanding the most important elements of the health care initiative at issue
- Achieving clarity about the purpose of the consumer advisory body and its powerful role in transforming health systems
- Eliciting the concerns and hopes of consumer advisory body members
- Building members' skills in effectively preparing for and participating in advisory body meetings
- Creating systems that ensure a successful “feedback loop” with health care initiative decision makers

TO LEARN MORE

Contact Mark Rukavina, Business Development Manager,
Center for Consumer Engagement in Health Innovation at
mrुकavina@communitycatalyst.org.



APPENDIX E

PYRAMID OF ENGAGEMENT

While the table below is by no means exhaustive, it is meant to provide you with a sense of what kinds of activities fall into each of the five levels of engagement.

PYRAMID LEVEL	AT THIS LEVEL OF ENGAGEMENT, CONSUMERS MIGHT:
Awareness Consumer has knowledge of an issue or cause	Attend a community meeting or house party
Interest Is interested in learning more and perhaps participating	Follow your organization on social media; read your blog posts and/or newsletters; participate in regular conference call updates
Participation Contributes time, money or social capital to your organization or campaign	Contribute a personal story; participate in a letter writing campaign; submit written comments on an 1115 waiver; attend a planning meeting; make a one-time donation
Commitment Fully invests in the organization or campaign	Make oral comments at a hearing on a waiver proposal; participate in a meeting with a decision maker; share their story with a decision maker or the media; regularly make a financial contribution;
Leadership Becomes a decision maker or thought leader and engages or leads others	Serve on a consumer advisory council, state workgroup or other governing body; share their consumer-to-leader story; attend a conference on delivery reform issues





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