

# Community-Driven Strategies to Address Stigma and Build Healthier Communities in Maine

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# 1. Introduction

In 2013, the Maine Health Access Foundation began a multi-year initiative to support communities in finding homegrown solutions to complex health issues through community-informed system change. The Healthy Community program grants aim to transform communities into supportive environments that enable people to live healthier lives. Although grantees have broad discretion over specific strategies, they are required to develop cross-sector partnerships and to meaningfully engage community members that are often marginalized in their planning and implementation processes. The theory of change undergirding the initiative is that participatory processes are more likely to result in sustainable system change.

During their planning processes, grantees identified root causes of their communities' health issues and barriers to accessing and benefiting from services and supports that contribute to health and well-being.

This paper tells the story of three communities that are working to reduce stigma in order to create more equitable systems that enhance the health and well-being of all Mainers. Their efforts grew organically from community member stories about how they were treated in various systems, driving collaboratives to shift resources toward stigma reduction. These communities realized that if they didn't do some deep work around community mindset, their system change efforts would not produce the health outcomes they hoped for, and the benefits of their system change efforts would not be felt equally by all of the residents of their communities.

Information sources for this paper include grantee progress reports, staff and community member interviews, site visits, observations from grantee learning community meetings, and local evaluation materials. For each case study, the evaluators wrote an initial summary that grantees reviewed for accuracy; they then finalized the case study based on grantee feedback. The paper begins with a description of how stigma became a priority for many grantees, presents three community responses to reducing stigma, describes common themes emerging from the grantees, and concludes with a discussion of the implications for complex system change initiatives in health.

## 2. How Stigma Reduction Emerged as a Priority for Grantees

Early on in the planning phase, many grantees identified disconnection and social isolation as root causes of the health issues they intended to address as a community, but none specifically discussed stigma as a system barrier. By the first year of implementation, the most significant evaluation finding was that seven out of 11 Healthy Community grantees were directly addressing stigma. The decision on their part to respond to stigma came directly from community members who reported that the way they were treated by providers and systems was at times demeaning and kept them from seeking help or benefiting from services and supports that were provided. Even more striking was that people experienced stigmatizing behavior across health issues: aging, disability, food insecurity, poverty, substance use, and mental health. Along the way, grantees raised some important and challenging questions:

- » Why are so many organizations and providers unaware of how their bias affects their effectiveness?
- » How do we address the need for a common language (i.e. substance use disorder vs. addict)?
- » How do we address stigma in rural communities?
- » How can we get providers to “get it” when it comes to poverty?

Community members described stigma as both external (imposed by providers or systems) and internal (when people see themselves as undeserving or ashamed because of their conditions or circumstances). People shared stories around a variety of themes:

- » Provider lack of knowledge and misconceptions about health issues (e.g. addiction is a moral failing, not a brain disease);
- » Provider bias (negative stereotypes that affect how providers or volunteers treat their clients and patients, with implicitly or explicitly biased behavior);
- » Organizational policies and practices that are demeaning;
- » Punitive vs. supportive responses (e.g. to student behavior in school, to people with substance use disorder); and
- » Internalized stigma (e.g. not using services or supports for fear of being stigmatized).

Most initiatives to strengthen systems focus on increasing coordination and capacity of health care and social services to address health issues, and MeHAF’s community-based initiatives began that way as well. These grantees shifted resources to do something more—to address serious gaps in

knowledge, attitudes, and behaviors in service systems and in communities as a whole in order to improve health outcomes. The MeHAF grantees that are featured in case studies are Franklin County's HOPE, Healthy Community Coalition, Farmington; Healthy Youth-Healthy Lake Region, The Opportunity Alliance, Cumberland County; and Voices from Knox County, Knox County Community Health Coalition, Rockport.

### 3. Case Study: *Franklin County's HOPE*

#### **Franklin County's HOPE (Health Opportunities through Poverty Elimination) for the Future**

**F**ranklin County is a rural county that runs from Farmington, the main town in the south, to the Quebec border in the north. The Farmington area is relatively well-resourced in terms of services and health care, but the county is also characterized by vast rural areas with unincorporated communities and plantations<sup>1</sup>.

During its planning phase (2014–2016), grant staff and partners conducted a community health needs assessment that identified poverty and its association with obesity as the county's most pressing health issue.

Donna Beegle's poverty training<sup>2</sup> was influential in the community's decision to address stigma in the County. The project had an "aha" moment when they realized the focus area they initially selected (obesity) was in and of itself stigmatizing. Through the poverty training and feedback from school partners, community members and partners learned that food insecurity was a greater problem than obesity, especially among children.

Instead, they focused their efforts on reducing stigma associated with poverty, food insecurity, and system barriers associated with accessing healthy foods. The goals of the project became multi-pronged: a) address system barriers to access to healthy food; b) change people's perceptions about poverty in the county; and c) increase access to and awareness of resources to help people get out of poverty through a navigator<sup>3</sup> program. They based their intervention on Donna Beegle's Opportunity Community Model, a movement to create communities where all members thrive and are connected to one another.

Despite facing skepticism around such ambitious goals, staff and their partners wanted to dispel myths and change negative perceptions about people living in poverty. Assumptions

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1 In Maine, a plantation is a type of civil division falling between a township (or unorganized territory) and a town. Plantations were often organized around lumbering and cover large, sparsely populated geographic areas. (<https://maineencyclopedia.com/plantations>)

2 Donna Beegle conducts Poverty Institutes for professionals and community members who want to better understand poverty and to gain tools to help break down poverty barriers. (<https://www.combarriers.com/povertytraining>)

3 In Donna Beegle's Opportunity Community Model, a "navigator" is a community member who is trained on poverty and communication skills. The navigator agrees to use their networks to assist a neighbor to access resources and supports to help them move out of poverty. A "neighbor" is a person living in poverty who may be of any age, race, or family background. The navigator may work with individuals or whole families

like “people living off the state” needed to be challenged, as did admonitions to people to pull themselves up by their bootstraps. These attitudes ignore barriers, especially in rural communities where poor families are isolated from natural networks and are dependent on vehicles that are often in poor condition. Children and youth are also more socially isolated and may have few face-to-face conversations outside of school.

## **Strategies to Address Stigma and Results**

Stigma reduction became a significant emphasis and was viewed as foundational to successful implementation of grant activities. The goals are to change the perception of poverty in the county, bring awareness to the issues people are experiencing, and help people living in poverty feel more hopeful about moving out of poverty. Their anti-stigma work is multipronged: 1) Educating their own staff; 2) Educating people from other organizations and systems who work with people living in poverty and creating partnerships to respond to food insecurity in non-stigmatizing ways; 3) Contracting with Donna Beegle; and 4) Community member-driven efforts to develop relationships and trust with people living in poverty so people feel hopeful and know that someone is there to support them.

### **1. Overcoming health care provider bias through education**

The first step was for the staff at Franklin Community Health Network to address their own biases through poverty training. This was followed by addressing provider bias, especially around patients they described as “non-compliant.” A targeted intervention was to work with providers on scripting how to respond to people when they do not follow instructions (e.g. do not take medications, etc.). Poverty training helped providers learn about the barriers people experience, resources that are available to help their patients, and how to support them so that they feel respected. The ultimate goal is to ensure that every person who enters a health system is treated fairly and compassionately.

### **2. Educating and partnering with other sectors**

Educators have been another focus of the stigma reduction work, as they are first responders on food insecurity. The project conducted school-based training focused on increasing understanding of the root causes behind classroom behavior related to poverty, such as hunger. The message they tried to transmit was that good outcomes come from knowing someone cares about you. These efforts were successful in no small measure due to the support of the previous Mt. Blue Regional School District Superintendent. This success led to others getting involved. The local District Attorney attended a community event, prompting him to invite the team to educate his staff on how to refer people to the navigator program and other resources such as parenting classes.



### 3. Contracting with Donna Beegle for capacity building

An additional strategy was to contract with Donna Beegle to help the community build capacity and support for their Neighbors/Navigator program, in which community members were trained on poverty and communication skills in order to support people experiencing poverty. Ms. Beegle also headlined their kickoff and a "Prosperity Summit" attended by 120 people and told her story of getting out of poverty, which many found hopeful and inspiring. More recently, the project has increased its media efforts to raise community awareness and recruit navigators.

### 4. Community member engagement

Finally, community members living in poverty serve on a Bridging Communities Project Team alongside providers (social services, schools, health care) to guide organizational partners in ways to effectively communicate with the public and to co-design events. For example, it is hard for people struggling with basic human needs to plan or commit to events, or they lack transportation, so the program now brings events to places where neighbors gather. Another challenge to connecting with people living in poverty is that many experience frequent crises and are skeptical of trusting an outsider for fear of being exposed or losing control of some part of their lives based on past adverse experiences. This work focuses on creating relationships as a key component that will help reduce fear and shame and build trust.

*"Community members are really key in helping us communicate with the public, especially around the most appropriate language and in which ways people might want to get involved."*

—Andrea Richards, Program Coordinator

### Results

- » After nine trainings in schools, schools are responding with food, bathing facilities, and clothes. Teachers and staff appear to be more mindful that many of their students lack basic necessities and that poverty and food insecurity affect student learning and have started to reframe challenging situations in their classrooms. They started thinking together about how they might more effectively respond to a struggling child or upset parent.
- » Schools struggle with children in poverty and are overwhelmed. As a result, they are open to learning more and are now a major referral source for navigators. Several teachers have become navigators, demonstrating a commitment to make a difference in children and families' lives. One teacher who grew up in poverty became a navigator, and students formed a committee to figure out how they could better support their peers.

*"We have to do things differently...we can't expect to teach the same way we have over the years to these kids. Times are different and we need to change."*

—Teacher with 25 years of experience

- » Franklin Pediatrics, Good Shepherd Food Bank, and the grantee collaborated on implementing food insecurity screening, which has dramatically increased their access to food, referrals for services and supports, and referrals for navigators.
- » The local hospital, health network, and pediatric providers increasingly understand how poverty affects patients' health and well-being, and has affected how they interact with them. In the pediatric office, the Office Manager and medical assistants help families feel comfortable talking about their experiences. By asking if they have enough food or need resources, they have built trust; families now initiate asking for support.
- » Franklin Community Health Network conducts mandatory annual training for all staff on poverty and has incorporated ongoing anti-stigma education around poverty into its strategic plan.
- » Local businesses collected useful items for people living in poverty, such as new towels, sheets, and diapers.

Food insecurity is a growing concern in the county, and many who screen positive are unaware of local food resources. This community has learned that addressing stigma associated with poverty and food insecurity takes time and resources. Project leaders say that poverty education was key to the effectiveness of their food insecurity efforts. Most people thought the problem of poverty was too big to tackle and that they could not make a difference, but the community learned that poverty affects everyone who lives in Franklin County. Coupling education with concrete solutions around food insecurity and the navigator program gave people concrete ways to help alleviate the effects of poverty.

Making sure people have had a lot of community conversations and getting people to buy in to the process helped to increase understanding of biases and anticipate roadblocks.

### ***One Crisis Away***

Families are sometimes judged for missing appointments. HOPE learned that for families living in poverty, one crisis can have ripple effects throughout the family system. For example, one family had no money to fix a flat tire, so the mother could not get to work, the children could not get to their activities, and the family missed medical appointments. The family lost income and could not meet basic expenses, putting their home and health at risk.

Navigators found funding to pay for a new tire, thereby helping the family avert disaster.

Creating strong partnerships across organizations and systems helped garner their support and buy-in around the concept that people living in poverty deserve fair treatment and support.

Creating new connections helped the initiative gain traction and brought new areas of expertise to poverty solutions. Finally, it has been important for people to understand that they will not eliminate poverty, but that people can make strides toward self-sufficiency.

HOPE is sharing people's stories and successes, along with their struggles, during local and statewide speaking engagements, and they continue to collect stories from many who have participated in the work in order to continue to raise awareness of the effects of poverty in rural communities.

## 4. Case Study: *Healthy Youth—Healthy Lake Region*

### Healthy Youth—Healthy Lake Region

The Lake Region of Maine sits just 30 miles northwest of Portland in Cumberland County. It is known as a resort area and is primarily rural and comprised of small towns. The population of focus for this grant is youth and others with mental health challenges and substance use disorder in Bridgton and other parts of Cumberland County. Healthy Youth—Healthy Lake Region’s (HYHLR) lead organization is The Opportunity Alliance; its steering committee is comprised of youth and adults who meet separately every quarter. Main grant strategies include:

- » Restorative practices<sup>4</sup> in schools such as community circles for students to discuss topics of importance together and hear diverse perspectives;
- » Bring Change 2 Mind (BC2M), a multi-stakeholder collaborative concerned with mental health and substance use<sup>5</sup> campaign and planning committee comprised of 27 members from 7 sectors working on stigma reduction for mental health and substance use disorder (MH/SUD);
- » Lake Region Collective Action Network (LRCAN): monthly networking group comprised of 97 members (providers and community members) to share resources; and
- » Adult-youth mentoring activities.

The planning phase for HYHLR included an assessment of community needs, assets, and capacity. The implementation grant work plan added addressing stigma as an objective. Details of the campaign and activity originated from the work of two youth apprentices on root causes of mental health and substance use challenges among high school students. Stigma was one of the biggest barriers and root causes for their peers, so grant strategies in the school addressed stigma, bullying, and isolating peers. Initially these efforts were a “side project” rather than grant focus. However, stigma kept coming up during LRCAN meeting discussions, and the Substance Awareness Coalition<sup>6</sup> put addressing stigma into their

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4 Restorative justice is employed when harm has been caused, and it uses disciplinary practices that are not punitive but “restorative.” Restorative practices also encompass prevention. They create a culture or environment in which people feel welcome, useful, and connected so they are less likely to cause harm. (Jana Richards, HYHLR Project Director)

5 Based on a national model of the same name

6 A local coalition that often collaborates with HYHLR efforts and Opportunity Alliance staff.

strategic plan. Healthy Lake then convened a group to explore doing more about stigma which helped focus the grant activities and brought in a few new interested partners. Bring Change 2 Mind became the convener for anti-stigma strategy for the region.

## **Strategies to Address Stigma and Results**

The grant's overarching anti-stigma strategy was a campaign comprised of multiple events. Key partners for the BC2M anti-stigma campaign included high school staff, a young adult who graduated from Lake Region High School, Substance Awareness Coalition, Bridgton Hospital, two National Alliance of Mental Illness (NAMI) volunteers who are also involved with faith-based organizations, Tri-County Mental Health, and Head Start. The BC2M workgroup and campaign began and quickly gained momentum because once conversations about stigma began, stakeholders "latched on and wanted to be involved."

BC2M's approach to planning its anti-stigma campaign consisted of a combination of sharing personal stories and collecting national data on effective strategies. The BC2M workgroup members shared concerns about the negative effects of stigma including but not limited to low self-worth, poor physical health, disease progression, provider shortages and insurance barriers. They also did research on the published literature and SAMHSA resources to identify effective stigma reduction strategies, as well as what language to use from the [Frameworks Institute](#). Findings from this research indicated that merely bringing attention to the negative effects of stigma would not be effective and might actually reinforce stereotypes and stigma. Instead, activities should involve "contact strategies," convening those with first-hand experience as well as those not affected and then "facilitating storytelling and conversation...to build empathy, which reduces unconscious and overt biases towards people."<sup>7</sup>

The objective of the BC2M workgroup related to stigma was "providing platforms to encourage conversation to build understanding and acceptance of mental health challenges and substance use disorders" and "to assist those who have experienced negative impacts of stigma and don't typically have access to a platform to share their story."

The BC2M workgroup intentionally held at least one event each month for 12 months because they wanted the intensity—at each event they could refer participants to future events to continue their engagement. The campaign used a range of strategies targeting various audiences, ranging from hikes for mental health to a "Celebrating Recovery" float in the July 4th parade. Some events were led by Healthy Lake while others were led by partner organizations. BC2M ensured events were accessible by making them free of charge, and by providing food and assistance with childcare and transportation. BC2M also elicited

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7 June 2018 Progress Report

feedback from participants at each event about how the community can better support those with mental health and substance use challenges and used this information to help inform future events or partner organizations' efforts. The location of events was also intentionally diverse such as theaters and hiking trails.

## **Results**

Healthy Lake developed a ripple effects map<sup>8</sup> with the University of Maine evaluation consultant in early 2019 to document the BC2M activities, their impact on individuals and organizations as well as the larger community and system of care, and other activities that were generated. Using this method enabled the grant leads to gather numerous examples to illustrate the results. Key impacts included more critical thinking about stigma and improved public attitudes toward mental health/substance use disorder (MH/SUD). The following is a summary of the major themes and findings from the ripple effects map<sup>9</sup> as well as progress reports from Healthy Lake.

- » Providing structured events involving individuals with lived experience with MH/SUD facilitated more meaningful and natural dialogue and connections:
  - The film “Paper Tigers,” a documentary about trauma-informed education, was well attended and well-received by the public as well as staff from the schools. School staff came away with a better understanding of how student “misbehavior” is a misnomer because the behavior stems from adverse childhood experiences (ACES). This early success for BC2M helped engage partners to develop the campaign and plan numerous other events, including another film “Anonymous People;”
  - The hike allowed people to participate as hikers rather than self-label as someone with mental health or substance use challenges;
  - The Yellow Tulip<sup>10</sup> planting project provided a structured task during which participants could connect and share mental health stories in a more natural way;

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8 Ripple Effects Mapping (REM) is a qualitative data collection and visualization technique that illustrates impacts from system change or collaborative initiatives (David Wihry, University of Maine)

9 Bring Change 2 Mind Ripple Effects Map

10 The Yellow Tulip Project's goal is to smash stigma related to mental illness. (<https://theyellowtulipproject.org>)

- The “Community Conversations” event provided another way for people to share their first-hand experiences with MH/SUD with others and discuss stigmatization. Participants found that deeper dialogue was more effective than abstract conversation in shifting how the community views MH/SUD. The event also enabled participants to identify challenges they have had with getting coordinated service, which informed follow-up action on improving treatment and recovery services and supports; and
  - Events provided a comfortable and safe place to normalize talking about mental health and substance use. Moreover, they recognized their courage for speaking up and reduced their feelings of shame.
- » Language matters in addressing stigma (e.g., the term substance “abuse” contributes to the stigma). The BC2M campaign raised awareness of the importance of language, which:
- Provided the grant coalition and their partners tools to facilitate difficult conversations to make them more constructive and productive;
  - Provided language for community members to talk about mental health and substance use, which empowered individuals affected by MH/SU: “When you start naming it, you are addressing it;” and
  - Informed the shift in another community coalition’s language and focus, from the “Lake Region Substance Abuse Coalition” to the “Substance Awareness Coalition” which focused more on celebrating recovery than substance use as a problem.
- » Collaborative events among other coalitions and organizations expanded their reach and success:
- A collaboration between the Substance Awareness Coalition and The Opportunity Alliance expanded “Red Ribbon Week,” a substance use prevention awareness campaign for elementary to high school students who were so engaged that the length of the event was extended. In addition, the schools are developing a substance use policy;
  - Collaboration with BC2M helped ensure that Community Partnerships for Protecting Children’s trauma training be more responsive to community needs and helped staff understand how trauma affects them personally and professionally;

## *Case Study: Healthy Youth—Healthy Lake Region*

- Donations from businesses made possible a “Celebrating Recovery Float” during the 4th of July parade in 2018. Community members along the parade route were supportive;
  - The Tulip Project spurred interest among high school students and Head Start in participating in community change; and
  - Activities led by others such as law enforcement and a recovery center were well received in part because the messages to reduce stigma have been reinforced via other BC2M activities.
- » BC2M began to shift norms and beliefs (“the zeitgeist”):
- People can talk more openly about MH/SUD;
  - The community is now aware of how ingrained stigma is and its negative effects on the community such as preventing people from seeking help, eroding sense of community, and exacerbating other community problems; and
  - Community attitudes about MH/SUD improved.



## 5. Case Study: *Voices from Knox County*

### Voices from Knox County

From its early planning stage in 2015, grant partners knew that in order to conduct an effective community assessment with a focus on marginalized communities, they needed to engage people with lived experience. They recruited community members called “community consultants” to help inform the planning process. Ultimately, the community determined that substance use was something they could come together on, and that substance use prevention in youth was not being addressed in a systemic way by anyone else.

Voices from Knox County organized its system change efforts around a Substance Use Prevention Task Force/ Coalition comprised of community partners and community consultants that focused on building SUD capacity through community learning, community engagement, and action. The grant also supported a provider network that brought social service, law enforcement, and community members together to share information, resources, and services.

Data-informed learning and community engagement were critical factors in their decision to invest in anti-stigma activities. A recent project report<sup>11</sup> described the problem as follows:

*“Stigma and bias continue to create barriers (which are often invisible) to designing, funding, implementing, and accessing trauma-informed prevention, early intervention, treatment, and recovery programs and supports for people with SUD and their families in Knox County.”*

Using local data, collaborative partners mapped the treatment system. The map prompted questions from the network as to the extent to which providers understood what people struggling with addiction face, and the extent to which they understand child behaviors associated with exposure to parental drug use and trauma. Moreover, they asked themselves how welcoming they were as system providers. These concerns led to the creation of a Sense of Community Survey, which their local evaluator disseminated in August 2017 (and will be repeated in 2019). The survey asked questions such as “Do you feel that substance use disorder (SUD) is a health issue or a criminal issue?” Responses indicated that people saw SUD as a health issue that affected everybody. Another finding indicated that people feel disconnected:

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11 Knox County Community Health Coalition (2019). Reducing stigma and bias among decision-makers. Project Report: 2018 Overview

one in eight people reported that they did not feel a part of any community. People saw the importance of valuing all community members but did not know how to get there. Youth also felt disconnected, and the assessment revealed that drug use can result from youth feeling isolated and having nothing to do.

Community consultants recommended that grant activities include stigma reduction. Grant leads responded by sponsoring a presentation on substance use, but partners quickly recognized that reducing stigma was a complex process that would take time. To have impact, they would have to “move the needle from another community conversation to an action plan that would lead to community change.” (Connie Putnam, Project Director). The final plan for stigma reduction was much more comprehensive than the original plan.

## **Strategies to Address Stigma and Results**

The project implemented three key strategies to address stigma: 1) data gathering and expert training to dispel misperceptions about SUD; 2) a film version of the expert training to broaden dissemination; 3) learning about stigma from community and providers

### **1. Data gathering/expert training**

The grant staff and community consultants organized a community forum to increase understanding of SUD and to promote dialogue. Thirty community members heard a presentation on the brain science of addiction by Dr. Trip Gardner, Chief Psychiatric Officer at Penobscot Community Health Care<sup>12</sup>, who has been a leading voice in raising awareness about substance use disorder.

### **2. Create product for broad dissemination**

With additional support from a discretionary MeHAF grant, the project made a film of Dr. Gardner’s presentation *Addiction is a Brain Disease* (<http://bit.ly/addictionisabraindisease>) as part of an educational curriculum. The recently completed film was shown to law enforcement representatives from three Midcoast communities. Viewers reported that it was hard to argue with the science, and shared personal stories of the youth and adults they are seeing on the streets. Additional strategies to educate organizations and the wider community included an opioid conference in 2016.

### **3. Deepen learning about how stigma is expressed and experienced**

To learn more about stigma from different perspectives, the project facilitated focus groups with social service providers, health care providers, and women in recovery from addiction

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<sup>12</sup> Penobscot Community Health Care is the largest Federally Qualified Health Center in Maine and operates in multiple locations ([www.Pchc.com](http://www.Pchc.com)).

that included an educational component and storytelling. Participants viewed the Gardner film and discussed it. The discussions revealed that the brain science of addiction was not well understood among the social service and mental health professionals who participated. Health care providers shared many examples of stigma and bias in health care settings, including apprehension about serving patients needing drug treatment. Partners were shocked to learn from women in recovery that their children were being bullied by other students because of their parents' addiction. Women also spoke about ways in which people in recovery stigmatize those who choose Medication-Assisted Treatment over abstinence.

The team will follow up with participants after six months to ask them what they are doing or experiencing differently as a result of their participation in either the presentation or the focus groups. The network is also developing a storytelling panel, including video capture, of medical professionals, employers, and people in recovery and has developed a template and toolkit for replication of focus groups and stigma-reducing education events in other sectors and settings.

### **Results**

In December 2018, the grant reported that their work to build partnerships and reduce stigma was changing attitudes and was having an impact on systems serving people with SUD:

- » Community members report that they are more aware of the importance of stigma and believe that the topic is being discussed more often in community settings;
- » Conducting focus groups with educational and storytelling segments seemed to be very effective at initiating new ways of thinking about addiction, its root causes, and the potential for successful treatment and recovery;
- » Youth are becoming more connected to community via cross-partner interventions such as after school programs, youth mentoring, and increased youth volunteer opportunities;
- » In multiple venues, providers and people in the community are sharing stories and concerns that are catalyzing action and change. For example, Camden-Rockport High School approached the project with concerns that students are fragile and are having trouble learning because of trauma at home related to addiction. The project collaborated with the school to support district-wide ACES (Adverse Childhood Experiences) implementation and restorative practices to reduce stigma against children whose parents use substances;
- » Police now routinely refer people with substance use disorder to treatment and additional services, and all police now carry Narcan. The Rockland Police Chief now requires that every officer view Addiction is a Brain Disease and then meet with him to discuss how they will fulfill their duty to reduce stigma in the community;

- » In Rockland, the homeless shelter that houses women and families realized they needed additional services for youth and created an evening drop-in center; and
- » One community consultant who is in recovery gained the confidence to lead two 12-Step groups, and to hire additional consultants.

Voices from Knox County has learned community member engagement is the most significant outcome of the project. Community consultants identified stigma as a system barrier, helped design and promote anti-stigma strategies, and told their stories to raise awareness and prompt positive changes in the community. By demonstrating that working hand-in-hand with community members makes system change efforts more effective, other organizations in Knox County began to adopt community engagement as an organizational practice. Having a strong, committed group of organizational partners dedicated to substance use prevention contributed to action and system change. After two years, their Substance Use Prevention Coalition/Task Force and provider network continue to meet regularly. The project found that the key to good partnerships is threefold: there has to be give and take; collaboration helps achieve economy of scale; and the project is the superglue that keeps it all together.

***Law enforcement changes the way it responds to people with SUD***

After attending the project's opioid conference, the local Sheriff increased awareness of addiction as a disease and made a positive connection with the project and SUD providers. He realized that police cannot "arrest" their way out of the opiate crisis, prompting a new referral system to treatment.

Finally, creating the film was a significant effort that took more time and resources than anticipated, but it will live beyond the life of the grant and will be widely disseminated.

## 6. Discussion

When people are treated unfairly because of the conditions of their lives, they feel stigmatized, will not trust care providers, may feel uncomfortable in the organizations that are meant to help them, and may avoid health care and social supports altogether. A common theme among community member stories was that people seeking help from most systems are made to feel “less than” because of complicated forms, linguistic barriers, eligibility requirements, and providers who prejudge them for the very health issues for which they seek care and support. Thus, people experiencing poverty, substance use, mental health disorders, and food insecurity are stigmatized going through the process. Communities are learning that system change work is foundational, but in order to realize equitable health and social support systems, they need to add an entire layer of work devoted to anti-stigma activities. Below are some of the most common themes emerging from the grant communities about addressing stigma:

### **Preparation:**

- » Engage community members early in the process to learn about root causes of complex health issues;
- » Seek to understand the experiences and feelings of someone who enters a system;
- » Identify system inequities. Community member involvement is critical to understanding how stigma feels and which system functions and behaviors need to be changed in order for people to feel comfortable accessing services and supports;
- » Explore and learn about provider attitudes, bias, and effect on people’s experience of the system; and
- » Cultivate a learning mindset in organizations and communities.

### **Action:**

- » Training by experts can be an effective early intervention. MeHAF’s investments (direct or indirect) in training opportunities (e.g. Donna Beegle, the Reframing Aging Initiative, Dr. Trip Gardner film), jumpstarted conversations, raised awareness, debunked misconceptions about addiction, mental health, and poverty, and helped change the direction of these grant programs;

- » Recognize that implicit bias is common among providers across health and social conditions. Stigmatizing behavior can be addressed through training and education, along with personal stories;
- » Implement policies, practices, and structural changes that are welcoming;
- » Create structured activities in diverse venues to facilitate natural conversations between community members, service providers, and people with lived experience. Efforts must also be multi-pronged and targeted at staff, organizations, and communities;
- » Elevate and disseminate community member stories to build awareness and guide program design, language, and messaging;
- » Community-driven programs are more responsive to community needs, more acceptable, and more effective and sustainable than top-down programming;
- » Couple anti-stigma activities with direct interventions that demonstrate more welcoming, less stigmatizing practices. Hospitals, law, enforcement, school systems, and food cupboards are increasingly receptive to new ways of responding to the issues they see in communities. The common theme among them is that they replace punitive measures with supportive responses (for example, restorative practices and ACES training in response to difficult student behaviors; fast-track treatment referrals vs. jail for people with addiction, opportunities for social connection and fresh food, and food insecurity screening and food for people in need in hospitals); and
- » A coordinator or designated organization increases the coordination and effectiveness of anti-stigma activities.

### ***Reflection and learning:***

- » Collect and share data on the effects of interventions on attitudes, behavior, and systems. Test new solutions and be willing to make adaptations based on what was learned.

Finally, grant communities universally cautioned other community coalitions that reducing stigma takes time, is complex, and takes resource shifting.

## What these findings mean for system change efforts to improve the health of communities

Fran Mullin, the lead for MeHAF's Healthy Community grant in Waterville, says that improving health and wellness<sup>13</sup> for all Mainers goes beyond traditional system change work: "The goal is to change systems so they're more equitable." MeHAF gave grantees resources and guidance based on the latest research and experience to build the foundation for significant improvements in the way services and supports are organized and delivered. The original model, however, did not explicitly direct grantees to address inequities in the system caused by stigmatization. With time and experience, grantees learned that they had to address stigma to create sustainable change in their communities. This work has involved people examining their motives and how they perpetuate power over people who need help, and realizing that the old, punitive ways of working weren't working.

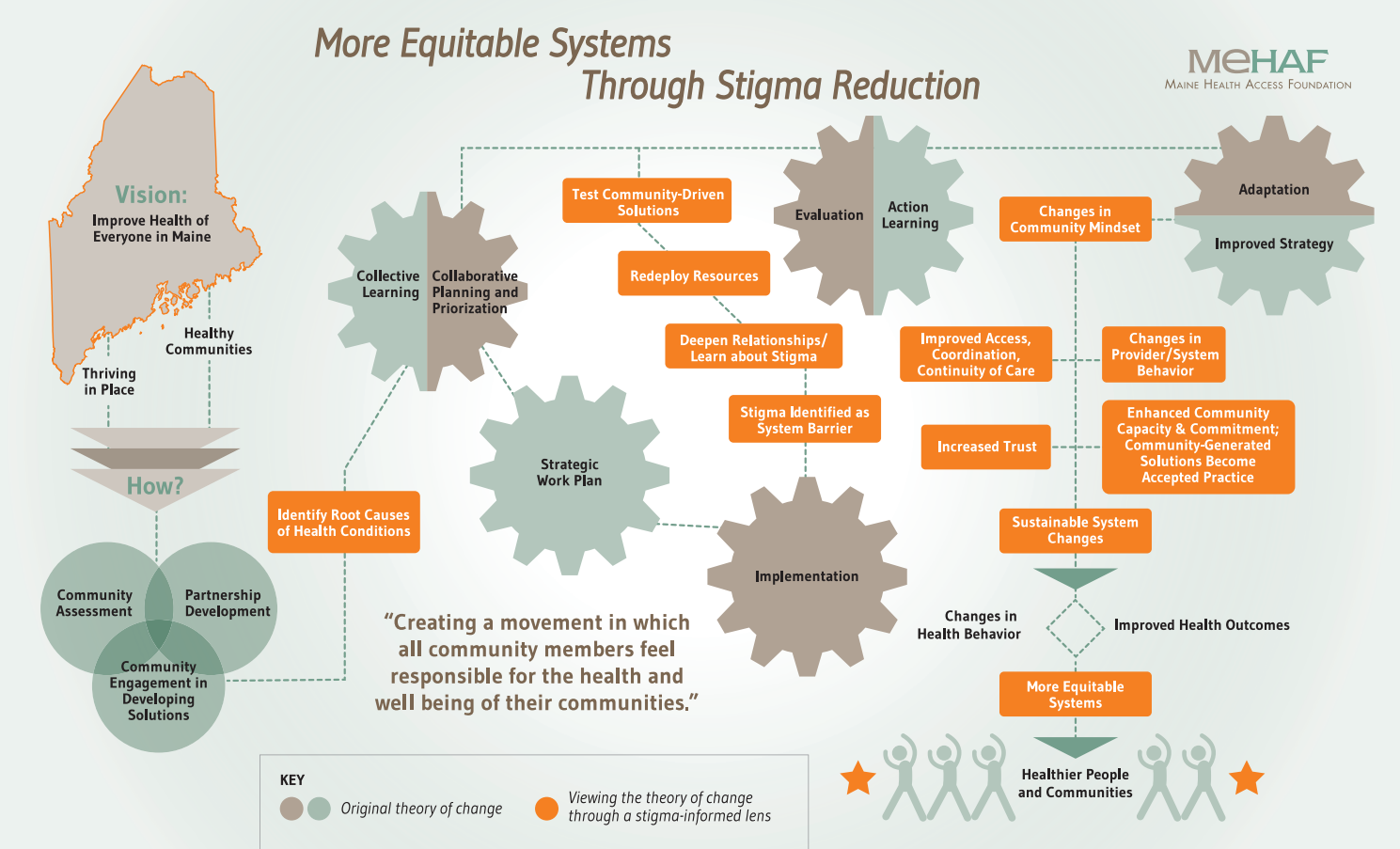
The data suggest that MeHAF's long-term investment enabled grantees to develop deep relationships in communities, build trust with people who are struggling, and do something transformative. Pope and colleagues (2007) write that interventions aimed at reducing inequities are more effective when communities reallocate resources to enable systemic investment in community-based programs and take the time to redress unfair rules and change attitudes<sup>14</sup>. MeHAF knew that community engagement was a good and necessary component in the system change process, but what we have observed is what happens once organizational leaders cede power to community members who truly guide initiatives. We therefore propose a revised theory of change that describes how adding anti-stigma activities to other system change activities can advance and accelerate progress toward a more equitable system of care.

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13 Community well-being is characterized by a sense of cohesion, sense of belonging, equality, and freedom from discrimination, access to health care, and democratic institutions (Prilleltensky, Issac and Ora, Promoting well-being: Linking personal, organizational, and community change. Hoboken, NJ: John Wiley and Sons, 2006.)

14 Pope, C., Mays, N., and Popay, J. (2007). Synthesizing qualitative and quantitative health evidence: A guide to methods. Maidenhead, Berkshire, England: Open University Press.

## Exhibit 2: Community-based System Change with a Stigma-Informed Lens



The theory of change for MeHAF’s Community-based initiatives assumed that its building blocks, community assessment, partnerships, and community engagement, would lead to new and sustainable system changes such as increased access to care and supports, increased coordination, collaboration, better continuity of care, changed policies, and reaching the most isolated individuals. Although it has been adapted somewhat, the basic theory of change holds up over time. By applying a stigma-informed lens, communities are finding that changing mindsets and provider behavior is resulting in better short-term outcomes for children and families across settings, and that engaging community members in designing and implementing programs makes them more responsive, acceptable, and effective. Communities also report examples of teachers, police officers, and health care providers becoming more compassionate and community-engaged, and that people who are served in those systems feel less shame and are more able to ask for help.



The Institute for Healthcare Improvement writes that “equity is realized when each individual has a fair opportunity to achieve their full health potential.<sup>15</sup>” Gita Gulati-Pardee of Open Source Leadership<sup>16</sup> goes further, suggesting that achieving equity is an intentional process. Equity is achieved when people, organizations, and systems operate based on a goal of fairness and justice, but one is always striving to get there. In practice, this work means recognizing that providing the same strategies for everyone privileges some over others. The work of equity requires listening and responding to people in new ways across differences; most importantly, it means that people must give themselves permission to make mistakes.

Most grantees were not familiar with the language of health equity when they started, but with the help of their community partners, they saw that the system changes they made would not benefit community members equally if they did not address stigma directly. Their efforts are beginning to bear fruit, and it is our hope that what they have learned along the way will help others seeking to create more healthy communities.

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15 The Institute for Healthcare Improvement ([www.ihi.org/Topics/Health-Equity/Pages/default.aspx](http://www.ihi.org/Topics/Health-Equity/Pages/default.aspx))

16 Personal communication. Open Source Leadership ([www.opensourceleadership.com](http://www.opensourceleadership.com))