Bringing Purpose to Community Engagement

A Framework for Reconceiving Health Care’s Relationship with Communities

March 2018
Summary

In March 2017, we presented 12 Principles gleaned from the work of the many innovators within the Creating Health Collaborative. We founded the Collaborative in the belief that at the heart of our struggle to meet the growing demand for care is our inability to define health as more than just ‘the absence of disease’. The innovators within the Collaborative were trying to understand how communities define ‘health’, and to create those versions of it.

The innovators found that communities’ definitions of health included things like financial security, safety, nourishing relationships, and being able to do what matters to them. The health sector conceptualizes these things as the ‘social determinants of health’. Yet research has made clear that risk factors alone – whether personal, environmental or social – cannot fully explain why people are healthy or sick. The missing link is whether people have a sense of control over their lives.

This insight helped us to make sense of the 12 Principles. They describe an inclusive, participatory and responsive process that has the potential to foster something core to having a sense of control: agency – the ability to make purposeful choices.

This year’s report brings together what we have done and learned since our 2017 report, specifically:

- Hosting our first national symposium, Community Agency & Health
- Creating a tool to help put the 12 Principles into practice
- Recruiting pilot sites to apply the principles to their community health practice
- Delivering our message, principally to the health sector
- And engaging health philanthropy

We have learned that the importance of agency to health is well-appreciated within the community sector and public health, but health care lags far behind. There’s something unsurprising about this. As an industry, it has been successful in deploying technical solutions for acute illnesses and trauma – in effect, removing disease from people’s lives. But as illnesses have become chronic, disease has become something to be managed as part of living. And by becoming something to be managed, it becomes just one of the many priorities in people’s lives. This shift, from removing to managing, from absolute priority to relative priority, is something that health care is struggling with.

Health care needs to look beyond what has made it successful and reconceive its role as supporting people and communities to define and shape their own health. We have come to realize that the 12 Principles provide health care with a framework for that change.
In trying to catalyze that change, we have come up against two of the core challenges that we identified at the end of our March 2017 report. Firstly, while the need for change is arguably greatest in under-served communities, those communities are also most in need of the current approach to health. And secondly, if health care can be convinced to change, how can it redirect some of today’s resources to exploring a new way of working, especially in the absence of the kind of proof that the sector usually looks for?

The answer to the first is brave leaders who see those two things as complementary rather than in competition. We have seen examples of it this past 12 months that give us hope.

The answer to the second has three parts. One, apply the 12 Principles to where the health sector is already required to invest in community engagement to help make that engagement more meaningful and effective. Two, find third party money, likely local philanthropy. And three, describe the value we can bring in terms of building capacity within health care to reconceive its role, with improved bio-medical health outcomes or reduced health care expenditures as only part of the rationale.

In light of what we have learned, we see our mission as enhancing the health sector’s ability to work with communities in an inclusive, participatory, and responsive manner. We’ll be looking for those in the sector who are bravely willing to adopt the 12 Principles as a framework to reconceive their role in the lives of the communities they serve.

What we’ve not learned is how to sustain ourselves financially. Over the next few months, we’ll be exploring our options. The survival of our organization, however, is unimportant compared to changing health care’s approach to health. If you’re in the sector and have not yet started, start. If you’ve started, keep going.

And if we can help, get in touch.
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With Contributions From

Introduction

In March 2017, we presented 12 Principles key to the future of health. Those principles were gleaned from the work of the many innovators within the Creating Health Collaborative. We founded the Collaborative in the belief that at the heart of our struggle to meet the growing demand for health care is our inability to define health as more than just ‘the absence of disease’.

This definition comes from the ‘bio-medical model’. Although this model has served us well, in a world increasingly blessed with longer lives and greater understanding of the human body, the presence of disease is becoming a norm – something to be managed as part of living. If health care is solely based on the bio-medical model, demand can only grow.

Our approach to health has to change.

The innovators who became part of the Creating Health Collaborative were identified on the basis that they were trying to understand how communities define ‘health’, and to create those versions of it. They often worked with communities in difficult social circumstances, including poverty and exclusion. Through the Collaborative, they shared their work and, more importantly, their struggles.

The innovators found that communities’ definitions of health go beyond the ‘bio-medical model’. They included things like financial security, safety, nourishing relationships, and being able to do what matters to them.

The health sector conceptualizes these things as the ‘social determinants of health’ – the social circumstances that pose a risk to health. Yet research has made clear that risk factors alone – whether personal, environmental or social – cannot fully explain why people are healthy or sick. The missing link is whether people have a sense of control over their lives.

This insight helped us to make sense of the 12 Principles. They describe an inclusive, participatory and responsive process that has the potential to foster something core to having a sense of control: agency – the ability to make purposeful choices. That’s why our last report was called Fostering Agency to Improve Health, and why we believe the principles are key to the future of health.
The 12 Principles

Although presented as a list, the principles are really a web of inter-related ideas, each needing to be considered in constant context of the others.

1. Include in a community’s collective effort those who live there, those who work there, and those who deliver or support services provided there
2. Spend time understanding differences in context, goals and power
3. Appreciate the arc of local history as part of the story of a place
4. Elicit, value and respond to what matters to community residents
5. Facilitate and support the sharing of power, including building the capacity to use it and acknowledging existing imbalances
6. Operate at four levels at the same time: individual, community, institutional and policy
7. Accept that this is long-term, iterative work
8. Embrace uncertainty, tension and missteps as sources of success
9. Measure what matters, including the process and experience of the work
10. Build a vehicle buffered from the constraints of existing systems and able to respond to what happens, as it happens
11. Build a team capable of working in a collaborative, iterative way, including being able to navigate the tensions inherent in this work
12. Pursue sustainability creatively; it’s as much about narrative, process and relationships as it is about resources

It is important to note that no innovator within the Creating Health Collaborative applies all of these principles in their work. The 12 were gleaned from across their work. Last year’s report, which is available online, elaborated on each principle, including examples of how they’ve been applied in practice, as well as how they have evolved through our work (Appendix 7 of that report).
Since Our Last Report

This year’s report brings together what we have done and learned since our 2017 report, specifically:

- Hosting our first national symposium, Community Agency & Health
- Creating a tool to help put the 12 Principles into practice
- Recruiting pilot sites to apply the principles to their community health practice
- Delivering our message, principally to the health sector
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Through our work, we have been mindful of the fact that fostering agency to improve health is not a new field of practice – indeed, many existing practices have been shared through the Creating Health Collaborative. We’ve also been mindful of the four core challenges that we identified at the end of our last report, paraphrased below:

1. Arguably, the need to rethink our approach to health is most acute in under-served communities. And yet, at the same time, such communities require more of the current approach to health. How do we create the space needed to make the future when the demand for the present is all-consuming?

2. If we are able to create the space, how can we talk about health as a social construct when the power over it is based on a bio-medical one? Those who already work in ways that foster agency (whether as part of a health initiative or otherwise) have language for social constructs, but we need their insights to resonate with those in the health sector.

3. If the conversation does resonate with those in the health sector, how can we redirect some of today’s health resources to fostering the agency of communities? Remembering that such agency would be used by communities to focus on what matters to them, is it possible to foster agency as an intended bi-product of research or the delivery of care?

4. And, if there is the willingness to share power over the definition of health, how will that be resourced? The innovators within the Creating Health Collaborative believe that for change to happen there needs to be readiness and capacity, as well as certain pre-conditions; who funds this type of work, who are the recipients of those funds, and what does oversight look like?
Context From Our Last Report

Before we share and reflect on our activities over the last year, we want to remind readers of some of the key, context-setting insights from our 2017 report.

Agency is More Than a Mechanism

While it’s true that some people with agency may make choices to purposefully improve their bio-medically-defined health, reducing its value to a mechanism is to miss its core importance as part of health. This extends to collective agency. Fostering community agency can improve health because interventions are more feasible and effective when planned and carried out in ways that directly involve community members. But beyond that, a sense of being able to come together to create change is, in and of itself, as core to the health of a community as a sense of control is to an individual’s health.

The Problem with ‘Creating Health’

When we first started using the term ‘creating health’, it was a contraction of: “Broader definitions of health may enable us to create it and so offset the growing demand for care”. Since then, we’ve seen it used as a synonym for the prevention of sickness. In our work, ‘creating health’ and ‘preventing sickness’ are fundamentally different. The former is defined by how people and communities describe ‘health’, the latter is defined solely by biological measures. We have stopped using ‘creating health’, although we’ve maintained the original name of the Collaborative.

The Problem with ‘Well-Being’

‘Well-being’ suffers from the strange paradox of meaning too little and too much. In terms of ‘too little’, there are so many definitions of ‘well-being’ that it is hard, if not impossible, to make sense of results across different efforts intended to improve it. In terms of ‘too much’, the ubiquity of the term creates a false sense of meaningfulness, especially within the health system where professionals are given to grouping anything not measured by biological measures as ‘well-being’. All in all, we have found the term unhelpful for our work.
Our First National Symposium

In May 2017, we held our first national symposium. Called Community Agency & Health, it was in Oakland, CA, and had 150 participants.

We decided to hold a symposium in light of the growing interest in our work. Not only were people asking to participate in the Creating Health Collaborative’s annual meeting, but over a thousand attended our November 2015 webinar, Organizing Communities to Create Health, held in collaboration with Stanford Social Innovation Review. Our decision to organize a symposium was very much in the spirit of an ‘alpha’, to borrow a term from product development – formulating something to see how it fared in the market.

The need, as we understood it, was that many people in the health sector know that the way they’re engaging with communities is not working. At the same time, they’re unclear about how to operate differently and are hampered by obstacles in the current system, both of which are creating discomfort. They were hungry for examples of approaches being tried, tools being used, and connections to others trying to address similar challenges.

Meeting the Need

To meet this need, we recruited a dedicated and thoughtful planning committee, innovative editorial partners, generous sponsors and supporters, and amazing presenters. We aimed to build knowledge, capacity, networks, and readiness amongst the participants:

- **Knowledge**: broaden how participants understand health so as to establish purposeful empathy and mutual respect for people across sectors and in communities
- **Capacity**: share methods, tools, and techniques used across sectors to support the design, implementation, evaluation, and financing of initiatives
- **Networks**: create new relationships among people who understand the plurality of health and the importance of nurturing community agency
- **Readiness**: through the knowledge, capacity, and networks attained, as well as through the examples and experiences shared, embolden participants to try new approaches in their communities that embrace the potential of community agency

We sought to convene a broad cross-section of participants, from the health sector (health care, public health, health finance), those in other sectors exploring their relationship with health (such as community development, housing, education, social services), leaders of community-based organizations, and resident leaders in local communities.

We designed the symposium so that participants had significant time to get to know each other by sharing their perspectives in small groups and informal interactions. To aid this, we had a plain language policy, everyone was addressed by their names not their titles, and facilitators ensured there was space and respect for different perspectives. The full program is available online.

Appendix 1 is the agenda of the symposium. Appendix 2 lists the 15-part series that foreshadowed the symposium containing articles by, or interviews with, the planning committee, supporters, and presenters. Appendix 3 is the write-ups of two case examples presented at the symposium (3.1 and 3.2). Appendix 4 is a summary of the feedback from participants at the symposium. And Appendix 5 is an 11-part series of commentaries by presenters and participants written a few months after the symposium in which they reflect on their enduring memories and the impact on their work.

Participants

The participants self-identified as coming from the following sectors (they were able to choose more than one):
Reflections

Considering the feedback from participants (Appendix 4), the reflections shared in the 11-part series (Appendix 5), and our experience of putting on the symposium, the following reflections come to mind:

1. **The importance of agency is not new to public health or the community sector.** As we say on page 7, we already knew this but, given the sectors the participants came from, we may have been preaching to the choir while not doing enough to reach out to other sectors, especially health finance and health system administration.

2. **Ticket sales are not enough to fund this kind of convening.** While we had significant interest in the symposium, our initial price of $1000 was too high for many, especially those in the community sector. Although we changed the pricing to be sector-specific, revenue from sales covered only about 8.5% of the overall costs, the rest being covered by grants, with additional support from in-kind contributions.

3. **Scaling up would likely diminish the intimacy that was so valued.** It's clear that many participants enjoyed the space we created to enable them to build relationships with each other. Increasing the number of participants to generate more revenue through ticket sales would potentially diminish that value.

4. **Each 'side' of the bridge wants time together as much as time with those from across the bridge.** Building on the idea of ‘bridging health and community’, participants appreciated the symposium as a space for building understanding across different perspectives but they also wanted time with colleagues in similar roles and experiencing comparable challenges. A future convening might tailor spaces for groups of participants coming from similar daily realities, before or after bringing together those with diverse backgrounds.

5. **Many of those who need to be at the table do not have support for participation.** We did not succeed in including many community-based organizations or residents beyond those that we supported as part of the agenda. Such people either do not have access to funds for professional learning or are not doing this work in a professional capacity – meaning that their participation would require taking time away from their own paid work.

6. **Health care systems need to shift the most.** While this reflection may be influenced by the relative lack of those in health finance and health system administration at the symposium, it does resonate with our wider experiences. Leaders in health care systems seem the least aware of the importance of agency to health, and least ready to change their way of working to foster it.

7. **We cannot talk about health without talking about race.** It became clear that an abstract dialog about relationships between the health sector and communities fails to appreciate the specific realities of different communities. People form communities through shared experiences and a sense of shared history. The dialog can only be meaningful if those experiences and history are brought in. And they include sources of inequality in voice and power - race, and also gender, class and other sources. Embracing this takes the dialog from the abstract to the personal, from the comfortable to the uncomfortable. But doing it well requires making space for it, valuing experiences as a key form of knowledge, and facilitating what happens as a result. We did not do this with enough intent.

8. **In the end, it comes down to ‘how’.** Participants valued that we went beyond conceptual content to get to some of the pragmatics of implementation, with examples that included challenges and failures. But many wanted even more on the ‘nitty-gritty’ of the work. Future convenings could achieve this through sessions focused on operational problem-solving so that participants can learn tactics to apply in their day-to-day environment.

Our ‘alpha’ taught us a lot. We have a strong sense of what a ‘beta’ version of the symposium might be, although do not have any plans for it in 2018.
In May 2017, we launched a tool to help organizations in health apply the principles to their work (see announcement). Much like the symposium, we saw the tool as an ‘alpha’, a first version to be tested in the market. We wanted to help organizations take stock of their way of working, explore how they might change to make fostering agency an intentional by-product of their efforts, and, in due course, implement those changes and evaluate their impact.

Implicit to this was the idea that many organizations do not have to change what they’re doing, but how. For instance, if your community health strategy includes considering people’s housing or food security, how you go about that can either foster or dampen individual and collective agency.

We wanted as many people as possible to use the tool so we made it free to download from our website. Unfortunately, we did not make it prominent enough, nor did we track its downloads, so our ability to learn from those who accessed it that way has been limited.

We were, however, able to get more feedback through other avenues we used to share the tool. We workshopped it at conferences with audiences in health philanthropy, public health, and care coordination (see ‘Delivering Our Message’ below). In addition, through our efforts to recruit pilot sites (see ‘Recruiting Pilot Sites’ below), we have heard from several senior leadership teams, largely in health care delivery, using the tool to reflect on their ‘population health’ or ‘community health’ practice.

The response to the tool has been encouraging. For instance, one health system used it to assess their population health initiatives. They found that using the tool helped them take time to reflect, test assumptions, and embrace a staged design process. They concluded that they were not sufficiently considering the importance of agency. This encouraged them to change the way they planned to engage the community as they developed a project on social isolation, a growing phenomenon linked to increased morbidity and mortality.

While we welcomed the encouraging feedback about the tool, we also wanted to learn from these initial users about how we might improve it. The feedback we have received consistently is:

1. **Users were overwhelmed by the idea of working on all 12 Principles.** Although we did say in the instructions to the tool that “you do not have to engage with every principle, nor do you have to approach them in order” this message failed to connect with many users. The guidance for how to use the tool needed to be more prominent and accessible.
Participants in the community health effort acknowledge there are differences in context, goals, and power among them. Effort has been made to cultivate relationships and trust among those participating to help you assess and deepen understanding differences in power and understanding differences in context, goals and power.

Consider these prompts to help you assess and deepen understanding differences in context, goals, and power:

1. Participants in the community health effort intentionally dedicate time to observing, inquiring and listening to identify differences in context, goals and power among them.

2. The prompt questions were useful but not prominent enough. The design of the tool emphasized the principles and a continuum describing what it would look like to be aligned with each principle. Under the continuum were a series of prompts that were the most powerful part of the tool as they were key to instigating the kind of discussions needed to bring about change.

3. Users were ready for more on next steps. Although getting users to think about changes to their way of working was valuable, many were left wanting more. How far could the tool produce benefits that matter to internal stakeholders? The other is what capacities are needed to envision next steps. Users needed to think through what differences in power exist? What differences in power exist? What are the implications of those differences? Participants in the community health effort in the new way. The tool's prompt questions could focus more on potential benefit and capacities.

4. The design of the tool emphasized the principles and a continuum describing what it would look like to be aligned with each principle. Under the continuum were a series of prompt questions that were the most powerful part of the tool as they were key to instigating the kind of discussions needed to bring about change.

In response to feedback on how the content of the tool was organized, we have created a revised version, which is available online.
Recruiting Pilot Sites

In August 2017, we partnered with Collaborative Consulting and announced that we were looking for up to five organizations to apply the Principles into practice. We wanted to help these organizations become more intentional in fostering agency as part of their community health practice, while learning what it really takes to make the shift to the ways of working described in the principles.

We were open as to which sectors these ‘organizations’ might come from (payer, provider, public health, employer, foundation, or a community-based organization) and, once recruited, wanted to establish some form of cross-site learning. Our engagement needed to be on a consultancy basis, given that we’re boot-strapping our organization (operating without external investment).

As of February 2018, we are yet to recruit the pilot sites but have learned the following from scoping discussions with 10 organizations.

1. The community sector is already working this way.
   Building on the reflections on the symposium (see ‘Our First National Symposium’ above), although we had some interest from community-based organizations, many felt they were already working in alignment with the principles. Their interest, therefore, was in whether we might help them explain the importance of their work, through the lens of agency, to the health sector. Although we considered trying to meet this need, the organizations did not have the funds to engage us.

2. For the health sector, this work is ‘unproven’. Despite the community sector’s understanding of the importance of agency, it is yet to meet the health sector’s criteria for value – essentially that a prospective intervention to foster agency can reliably improve bio-medical health outcomes or reduce health care expenditures. Our response to this was that we have decades of proof that many of the current interventions for lifestyle-related, chronic conditions have, by those same standards, been proven to have minimal impact. While there is much agreement with that, there is little opportunity within the current system to try something new.

3. The uncertainty surrounding the Affordable Care Act made people pause. Given the ongoing uncertainty about the future of the Affordable Care Act, many organizations were dedicating time and effort to prepare for contingencies and holding on to their financial reserves, making them even less willing and able to try anything new.

4. Organizations already had their hands full with new strategies. The health sector seems to be experiencing a tipping point, in which so-called ‘social determinants’ or ‘upstream’ influences on health are receiving more
5. **Looking in the mirror isn’t always easy.** Ultimately, the Principles and the questions within the tool are encouraging organizations to look in the mirror and ask themselves if their way of working is part of the problem. This isn’t easy, and some leaders talked about the “anxiety” that would be generated through the work. So, although there was acknowledgement of the decades of failure and the possibility of fostering agency as part of new strategies, there was also good old-fashioned fear – that ever-present emotion in systems change work.

6. **The work needs to be co-designed with organizations.** As we scope potential work with organizations, we’re effectively co-designing products to enable the implementation of (some of) the principles into practice. This process is ongoing but what’s beginning to surface is the need for an initial small-scale engagement, such as a site visit, both to share our work and understand the organization’s context, and then to collaboratively create a deeper engagement that will enable the organization to be intentional about fostering agency through their work.

7. **It’s unclear which budget should be accessed for this work.** At first, we made the clinical argument that risk factors, whether personal, social or environmental, cannot fully explain why people are healthy or sick. However, such framing pushed our conversation towards clinical budgets, which are hard to access in the absence of the ‘proof’ that the health sector looks for (see point 2 above). Community health budgets seem like a natural fit but tend to be small and often aren’t seen as core to health systems operations, where internal advocates for our work felt it needed to be embedded. Of late, we’ve found that framing our work as creating new capabilities within the health sector not only leads to a more exploratory dialog but also towards budgets for organizational development.

Commercially-minded readers will, of course, understand the above list as market insights from which to derive the value proposition of our work. As we’ll share in the conclusion of this report, we increasingly see our role as helping the health sector evolve to a new way of working, one that goes beyond deploying technical expertise to treat illness.
Delivering Our Message

After developing a speaker profile reflecting the work of BH&C, we started getting requests to deliver talks. We delivered eight keynotes at corporate gatherings: four for state hospital associations, three for a health insurer, and one for a nonprofit hospital system.

We also presented at conferences that enabled us to reach different audiences in the health sector, including Grantmakers In Health, the American Public Health Association, and the National Center for Complex Health and Social Needs.

Corporate Gatherings

In general, these gatherings are forums for new ideas and building relationships across and within sectors. They tend to be organized around a theme. The themes that we spoke within were:

- Value-Based Health Care
- Thriving Communities
- Preserving the Safety Net
- Leadership, Collaboration, Innovation & Commitment as Keys to Success
- Workplace Wellness
- Creating a Culture of Sustainable Innovation

Individually, the gatherings’ themes read like buzz words but, bringing them together, you get a sense of what the industry is thinking about.

Changes to the policy environment were clearly on organizers’ minds, some of which have been a long time coming, such as value-based health care, others more sudden, such as the possible loss of the safety net. In response, leaders in health care were asking themselves what skills they needed to respond to the changing environment. In recent years, the quick but not always meaningful answer has been ‘innovation’, but there appeared to be a growing understanding that ‘doing new things’, a loose definition of innovation, requires new skills and an underlying culture to sustain those skills.

Reassuringly, some gatherings looked beyond the clinic walls. Much of that was to understand what strategies might be deployed by other systems to improve people’s health, such as workplace wellness. Some, however, went further to ask what, fundamentally, health care is for. If, as one gathering framed it, it was to enable communities to ‘thrive’, what is health care’s role beyond deploying technical expertise to treat illness? The people of that gathering have proven to be some of the most engaged in our work.

One of the rules of keynote speaking is that in any audience there is only ever one person, perhaps two, who will want to
do something off the back of what you share. Some of those that followed up are now part of our work to design pilots. Others remain in a ‘holding pattern’ while they try to find fertile ground within their organization to take things further.

Finally, in delivering the keynotes, two ‘hooks’ seemed to catch people’s attention. The first was that most of what we’ve tried to curb the growth of lifestyle-related diseases has failed. We sensed that people in health care are yearning for someone to say that out loud. It was almost as though they needed permission to push back on yet another year of ‘community engagement’ that they know is not getting to the heart of the challenge.

The second was the opioid epidemic, a hook that resonated particularly in rural communities. We sensed that people in health care felt trapped in the knowledge that they have some responsibility for the epidemic but are now powerless to change its course. The epidemic seems to be shining a light on the loss of hope in some communities, something that is intrinsically linked to having a sense of control over one’s life.

Conferences

We had three opportunities to share our work at national conferences. These allowed us to reach health philanthropy through the Grantmakers In Health (GIH) annual conference, public health professionals through the American Public Health Association (APHA) annual meeting, and practitioners within the growing field of integrated care at the National Center for Complex Health and Social Needs’ annual conference.

At GIH, we were joined by a team from a participatory action research partnership as part of the Healthy Neighborhoods Equity Fund in the Boston area. They illustrated how they foster community agency through their work. At APHA, a small group size and longer session allowed for a particularly deep dive using our tool.

At the National Center conference, we were part of a ‘beehive’ session in which participants had the chance to come to us for individual or small-group overviews. They also had the chance to work with our tool and discuss the experience with us and with each other.

In each case, we found that we primarily attracted those who already value the concepts we describe. They shared with us an appreciation for two things: one was finding other like-minded individuals within their spheres; and the other was having what they know to be important captured in a way specifically intended to convey it to the health sector.

For many, the motivation to attend our workshops was to get better at recruiting or motivating others to improve their approach to community engagement. But what surprised them was the discovery that even in their own work – which they thought was deeply engaging communities – they were not doing as much as they could. They were, for example, underestimating constraints in their systems or avoiding identifying and addressing differences in power.

A message that resonated with each of these audiences was that building the ‘capacity’ of communities with the least voice and power to help them engage with the health sector – something that more and more people are trying – is important but can only take us so far. If a bridge between health and community is going to transform anything, there is as much of a need to change the capacity of those on the health side. However, the health side is less aware of, or ready for, such work.
In 2017, we made concerted efforts to engage philanthropy in our work, partly to share our perspective and partly to explore whether we might be funded to develop the field of practice that fosters community agency. Our reading of the sector was that, although many foundations value community engagement in some form, very few have fully embraced the importance of agency to health, not in what they fund, the ways of working they require of their grantees, nor in how they themselves operate.

The key thing we learned was that place-based foundations, or foundations that fund place-based work, often appreciate the importance of community agency. This was especially true in foundations with long-serving staff members who’d seen only limited results from their years of grant-making. There was something about the fact that the foundation could not walk away from the ‘place’ that made its staff more likely to look beyond providing programs and think of the capacity of the community itself.

By contrast, some national foundations seemed to acknowledge the importance of agency to health, but their national scope and geographical spread made it hard for them to directly experience the work they supported – and assess whether their own ways of operating were helpful or a hindrance.

We found ourselves in a catch-22. Some place-based foundations wanted to support us but had strict rules on whether they could fund outside of their ‘place’. They suggested finding a national foundation to fund us, the presence of which would act as a form of endorsement enabling them to fund out of place. But we had limited bandwidth to work on making in-roads with national foundations.

In the conversations we had with a few national foundations, a key barrier was that most already have established strategies with defined priorities, pre-determined program portfolios, and fixed requirements for how to demonstrate progress toward specified outcomes. This is inconsistent with funding work that explicitly calls for a highly local and open-ended approach, as ours does. If we engage with more national funders, we’ll be on the lookout for those whose approach leans more to the open-ended than the pre-determined.

Although frustrating, these experiences have helped us to see the current role of philanthropy as local and project-specific. Combined with our experience of establishing pilot sites – specifically the challenge of finding a budget to access – we’re starting to explore whether and how local philanthropy can supplement work with the health sector.
Grantmakers In Health

Throughout the year, Grantmakers In Health was supportive. Their interest was in helping philanthropy to understand and explore community agency as a strategy within population health.

We were invited to present a workshop at their annual meeting in June 2017. As described earlier (see 'Delivering Our Message' above), those who attended came with an understanding of why community engagement has to be more than a box that gets checked. What emerged was that to advance that practice will require not just focusing on what grantees do, but on their own way of working – who has a voice in setting the priorities of the foundation, deciding what to fund, and determining whether it was worth the investment. The takeaway seemed to be that this internal work could be the steeper climb.

We were also invited to write a viewpoint for their newsletter in November 2017, which is available online and has been included in this report as Appendix 6.

The California Endowment

Another supportive organization has been The California Endowment. In addition to part-funding our symposium, we have been helping them to understand how the ‘story’ of their Building Healthy Communities initiative can be told in ways that shift dialog, policy, and practice in health and public health.

Building Healthy Communities focuses on building the voice and power of communities as a pathway to improve health. The initiative was one of the examples that informed the 12 Principles for fostering community agency. A case example of their work was presented at our symposium (see Appendix 3.1).

To date, we have looked at how three comparable initiatives ‘went national’: the Camden Coalition of Healthcare Providers and National Center for Complex Health and Social Needs; the Nurse-Family Partnership and the Maternal, Infant, and Early Childhood Home Visiting Program; and the Harlem Children’s Zone and Promise Neighborhoods Initiative. We’ve also mapped out the landscape of key influences on policy decisions and interviewed journalists to glean their insights into how different forms of media and journalism influence public narratives related to health.

Currently, we’re looking at how building the power of communities can be taken up more broadly in public health practice by:

- Reviewing seminal documents about organizational change and social movements as they relate to public health,
- Gathering insights from public health leaders and practitioners about what gets in the way of adopting power-building practices and what opportunities there are to create buy-in and capacity,
- Crafting a narrative that makes the case for power-building as a strategy to improve health and advance health equity, and
- Identifying key audiences and vehicles to spread practices and messages related to power-building for health.

We hope to share the outcomes of this work in late 2018.
Responding to What We’ve Learned

The importance of agency to health is well-appreciated within the community sector and public health, but health care lags far behind. That is not to say that individuals within health care – especially those that have worked with the same communities for many years – do not appreciate its importance, more that health care’s leadership seems least aware and least ready to change their way of working. Even when readiness is there, there is an uphill climb within systems whose operational norms run counter to the kind of change needed.

There’s something unsurprising about this. As an industry, health care has been impressively successful in developing and deploying technical solutions for acute illnesses and trauma – in effect, removing disease from people’s lives. This approach is consistent with the bio-medical model, the idea that health is the ‘absence of disease’. But as illnesses have become chronic, disease has become something to be managed as part of living. And by becoming something to be managed, it becomes just one of the many priorities in people’s lives. This shift, from removing to managing, from absolute priority to relative priority, is clearly something that health care is struggling with.

Health care needs to look beyond what has made it successful. Deploying yesterday’s solutions to today’s problems has not worked and is not going to work. Approaching health through the frame of the bio-medical model is no longer enough – and has not been for some time.

To embrace a new way of working, health care needs to fundamentally reconceive what it is for. What we have learned, and what the community sector and public health have known for some time, is that health care needs to support people and communities to define and shape their own health.

A Framework for Change

By sharing our work over the last 12 months – through the symposium, our tool, in trying to find pilot sites, through keynotes and workshops, and in engaging health philanthropy – we have to come to realize that the 12 Principles provide health care with a framework for change.

But in trying to catalyze that change, we have come up against two of the core challenges that we identified at the end of our last report. Firstly, while the need for change is arguably greatest in under-served communities, those communities are also most in need of the current approach to health. And secondly, if health care leaders can be convinced to change, how can they redirect some of today’s health resources to exploring a new way of working, especially in the absence of the kind of proof that the health care sector usually looks for?
Responding to What We’ve Learned (cont)

The answer to the first is brave leaders who see those two things as complementary rather than in competition. We have seen examples of it this past 12 months that give us hope. Sadly, we have no doubt that institutional norms will dampen their efforts, but some will make it through and we hope to work with them to start to generate the kind of experiential knowledge needed to create followership.

The answer to the second has three parts. One, apply the 12 Principles to where the health sector is already required to invest in community engagement, to help make that engagement more meaningful and effective. Two, find third party money, likely local philanthropy. And three, describe the value we can bring in terms of building capacity within health care to reconceive its role, with improved bio-medical health outcomes or reduced health care expenditures as only part of the rationale.

The Fear of Change

Change is always hard but the change health care has to go through is perhaps the hardest – to share power.

We’ve learned that those health care systems willing to reconceive their role can only do so in small, careful steps. Brave leaders need buy-in from administrators, managers, and care providers. Motivated management need to find ways to influence leadership. The process is slow, perilous, and at the mercy of the day-to-day fire-fighting that typifies the frontlines of health care. As is well-documented elsewhere, existing systems only change incrementally, if at all. We’ve seen examples of this over the last 12 months.

If health care is to share power with the communities it seeks to serve, it needs to confront its own power and the effects of how that power is used. This means being willing to examine its own historical and current role in perpetuating the daily realities of a community’s pervasive sources of inequity. We have no doubt that the change health care needs to go through will be an uncomfortable one.

Looking Ahead

In light of what we have learned, we see our mission as enhancing the health sector’s ability to work with communities in an inclusive, participatory, and responsive manner.

We’ll be looking for the sector’s brave leaders and motivated staff willing to adopt the 12 Principles as a framework to reconceive their role in the lives of the communities they serve.

What we’ve not learned is how to sustain ourselves financially. We’ve boot-strapped the organization since October 2016 but in reality, that has meant the Co-Founders (the authors of this report) putting personal resources towards keeping things going. That is not sustainable. And, while some health care organizations might become pilot sites on a consultancy basis, we’re not clear that will be enough to sustain us. Over the next few months, we’ll be exploring our options.

The survival of our organization, however, is unimportant compared to changing health care’s approach to health. If you’re in the sector and have not yet started, start. If you’ve started, keep going.

And if we can help, get in touch.
Appendices

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Appendix 1 | The Agenda of Our Symposium

Community Agency & Health

Marriott City Center, Oakland, CA
May 15-16, 2017

PLANNING COMMITTEE

MAJOR SPONSORS

EDITORIAL PARTNERS

ADDITIONAL SUPPORT
# Agenda | Day 1

As published in the symposium program

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<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker(s)</th>
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<tbody>
<tr>
<td>9:30am</td>
<td>Arrival and Registration (Light Breakfast Available)</td>
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<tr>
<td>10:00am</td>
<td>Welcome</td>
<td>Anne E Price, Insight Center for Community Economic Development</td>
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<tr>
<td>10:10am</td>
<td>Meeting Overview</td>
<td>Bridget B Kelly, Bridging Health &amp; Community</td>
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<tr>
<td>10:30am</td>
<td><strong>Breaking the Ice, Establishing The Tone, and Sharing Perspectives</strong></td>
<td>Facilitators from MIT CoLab: Alyssa Bryson, Katherine Mella, Lawrence Barriner, II Yorman Nuñez</td>
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<tr>
<td>11:45am</td>
<td>Break and Pick Up Box Lunch</td>
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<tr>
<td>12:15pm</td>
<td><strong>Table Top Lunch Conversations</strong></td>
<td>Tabletop Facilitators</td>
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<tr>
<td>1:00pm</td>
<td><strong>Setting The Stage</strong></td>
<td>Facilitated by Bridget B Kelly, Bridging Health &amp; Community</td>
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<td></td>
<td>The evidence for agency, how it can potentiate health care and public health, and why it matters of its own accord.</td>
<td>Pritpal S Tamber, Bridging Health &amp; Community</td>
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<tr>
<td></td>
<td><strong>Overview Presentation</strong></td>
<td>Risa Wilkerson, Active Living By Design</td>
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<td></td>
<td>Introducing sustainable thinking.</td>
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Appendix 1 | The Agenda Of Our Symposium (cont)

Agenda | Day 1 (cont)  

As published in the symposium program

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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| | The need to create mutually accountable partnerships between institutions and communities.  
Phil Thompson, MIT and NextShift Collaborative |
| | The need for new ways of thinking about how to understand, assess, and communicate value, including what communities value and the value of ‘health’ beyond biological measures.  
David Chavis, Community Science |
| | The need for capital – financial, political, and social – to be invested in ways designed to explore and nurture new ways of working.  
Sue Grinnell, Public Health Institute |
| | Pathways to Solutions  
A facilitated conversation to surface the intersections among these perspectives and how new ideas for solutions might emerge from thinking about them together instead of each in their own “lane”. |
| 2:30pm | Break |
| 3:00pm | Table Top Workshopping  
Participants will be facilitated in small groups to reflect on the ‘Setting the Stage’ session, share whether and how it affects their view of barriers to progress, and use the framing of a hypothetical case example to surface ways to approach things differently in the three areas of need.  
Tabletop Facilitators |
| 4:15pm | Break |
| 4:30pm | A Candid Conversation About Failure  
A candid conversation about flaws in reasoning and failures in health and public health, including ideas that have been tried, why they have failed, and how we can learn from their failing. Followed by a facilitated, open Q&A/discussion.  
Facilitated by Pritpal S Tamber, Bridging Health & Community  
Carl Baty, Rounding the Bases  
Len Syme, UC Berkeley |
| 5:30pm | Table Top Reflections  
Table-mates will be facilitated to share what stood out to them about the day.  
Tabletop Facilitators |
| 5:50pm | Wrap-up  
Pritpal S Tamber, Bridging Health & Community |
<p>| 6:15pm | Reception, Skyline Room |</p>
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<th>Time</th>
<th>Session</th>
<th>Location</th>
<th>Facilitators/Participants</th>
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<tr>
<td>8:00am</td>
<td>Arrival and Breakfast</td>
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<tr>
<td>8:30am</td>
<td>Welcome and Day 2 Meeting Overview</td>
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<td>Bridget B Kelly, Bridging Health &amp; Community</td>
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<td>8:40am</td>
<td><strong>Table Top Conversations</strong></td>
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<td>Tabletop Facilitators</td>
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<td>9:00am</td>
<td><strong>Case Examples</strong></td>
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<td>Facilitated by Leigh Carroll, MIT and Ollie Smith, Telefónica Innovation Alpha</td>
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<td></td>
<td>Building Healthy Communities, South Kern</td>
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<td>Gema Perez, Greenfield Walking Group</td>
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<td>Javier Arreola, Interpreter Phoebe Seaton, Leadership Counsel for Justice and Accountability</td>
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<td>Yolanda Alcantar, County of Kern Public Works Department</td>
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<td>Bronx Healthy Buildings Program, Northwest Bronx Community and Clergy Coalition</td>
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<td>Evy Viruet, Northwest Bronx Community and Clergy Coalition</td>
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<td>Maggie Tishman, Emerald Cities Collaborative</td>
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<td>Sandra Lobo, Northwest Bronx Community and Clergy Coalition</td>
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<td>10:45am</td>
<td><strong>Break</strong></td>
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<td>11:15am</td>
<td><strong>Small Group Breakout Sessions</strong></td>
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<td>Partner Organization</td>
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<td></td>
<td><strong>Creating Leadership Capacity for Long-term Change</strong></td>
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<td>Active Living by Design</td>
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<td></td>
<td>Room 201, Second Floor</td>
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<td>Dina Newman, Center for Neighborhoods, University of Missouri - Kansas City</td>
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<td>Genoveva Islas, Cultiva la Salud</td>
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<td>Risa Wilkerson, Active Living By Design</td>
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<td>Sarah Strunk, Active Living By Design</td>
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<td><strong>Designing and Testing New Business Models</strong></td>
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<td>Business Innovation Factory</td>
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<td>Grand Ballroom</td>
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<td>Eli MacLaren, Business Innovation Factory</td>
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<td>Jodie Lesh, Kaiser Permanente</td>
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<td>Peter Roberts, Children’s Health</td>
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# Agenda | Day 2 (cont)

**Shifting the Conversation: Using Strategic Communications to Change How Health is Understood, Practiced, and Experienced**  
Room 208, Second Floor  
Jacki Schechner, Independent Consultant  
Nishith Bhatt, Hershey Cause Communications  
Rhonda M. Smith, Live Healthy DC  

**Navigating Power in Health and Community Partnerships**  
Room 202, Second Floor  
Doran Schrantz, ISAIAH  
Jeanne Ayers, Minnesota Department of Health  

**Using Participatory Research and Evaluation**  
California Room, Third Floor  
Andrew Binet, NextShift Collaborative  
Jomella Watson-Thompson, University of Kansas  
Mark Wieland, Mayo Clinic  
Miriam Lopez Daumas Goodson, Alliance of Chicanos, Hispanics, and Latin Americans of Rochester, MN  
Shannon Simpson, Dudley Street Neighborhood Initiative and Brandeis University  

**Leveraging Opportunities and Collaboration to Bolster Community Agency**  
Oakland Room, Third Floor  
Emmanuel Kintu, Kalihi-Palama Health Center  
Kate Paris, UnitedHealthcare Community & State  
Katherine Keir, Goodwill Hawaii  
Nicole Dickelson, UnitedHealthcare Community & State  
Andy McMahon, Corporation for Supportive Housing  

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<th>Time</th>
<th>Activity</th>
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<th>Facilitator/Co-host/Contact Person</th>
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<tr>
<td>12:30pm</td>
<td>Break and Pick Up Lunch Box</td>
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| 1:00pm     | **Lunchtime Conversation Clusters**          |                           | Themed discussions and networking  
Led by symposium participants                                           |
| 1:40pm     | **Table Top Commitments**                    |                           | Table-mates will be facilitated in developing at least one short-term commitment and one long-term commitment to action as a result of the experience of the symposium. They will also be asked what output from the meeting would help them and what supports they suggest to build a field of practice.  
Tabletop Facilitators                                                                 |
| 3:00pm     | **Sharing Surprises**                        |                           | Participants will share something unanticipated from the meeting.  
Facilitated by Oscar Espinosa, Community Science                       |
| 3:25pm     | Closing Remarks                              |                           | Pritpal S Tamber, Bridging Health & Community                         |
| 3:30pm     | Adjourn                                      |                           |                                                                       |

As published in the *symposium program*
Breakout Session

Creating Leadership Capacity for Long-term Change

Editorial Partner: Active Living By Design

Presenters:
Dina Newman, Center for Neighborhoods, University of Missouri - Kansas City
Genoveva Islas, Cultiva la Salud
Risa Wilkerson, Active Living By Design
Sarah Strunk, Active Living By Design

Session Description

Working toward the achievement of sustainable, healthy community change can be a heavy lift for any community. Given the complexity and rigorous requirements of systems change, a community’s capacity to meet this challenge is a strong predictor of success. Community capacity includes the collective ability of residents, leaders and organizations to define, pursue and achieve their goals. How can this capacity be strengthened to help more communities, especially those with the greatest health challenges and disparities, succeed long term? Participants will identify why facilitative leadership is important in community transformation and discuss lessons for leaders in community capacity building that should be considered in every collective effort focused on creating health.

Some Quotes from the Session

"We have intentionally tried to create avenues where there are micro business opportunities for [residents]. With interpretation and translation, can one of our residents be the interpreter translator and then can we reimburse them for that? And for food, is there one of our residents that has food handling experience? Thinking along those lines is really important." – Genoveva Islas, Cultiva La Salud

"We ended up taking a third-acre vacant lot and...grow 7,000 pounds of locally-grown, pesticide-free produce right there in the neighborhood. And our champions were able to go throughout the neighborhood and tell the story. That was very, very important for us." – Dina Newman, UMKC Center for Neighborhoods

"One of the ways that we have found really productive in particular with Latino immigrants is to connect them to other existing communities. Ninety percent of these rural communities are largely Latino. So, we definitely have the numbers but it does take building those alliances for people to feel like they're not alone in trying to make change." – Genoveva Islas, Cultiva La Salud

"You want to expand your partnerships, not necessarily grant money. You go talk to the Walmart, you go talk to different people in the community to find out if there's a little pocket of money to do something that will benefit the community that's not necessarily tied to huge outcomes and data. And those small impacts...you can take...to a bigger funder and say I've got a proven record right here." – Dina Newman, UMKC Center for Neighborhoods

"We have plenty of examples where we've really benefitted [from] anchor institutions. Having that anchor organization really did help us in terms of bringing in capacity building, speaking. We made a lot of contacts with groups who had other resources. I think where it's been harmful has been when those anchor institutions then vie for the same funding that we do." – Genoveva Islas, Cultiva La Salud

"This was a leadership training program to give people the voice they want to advocate for changes in their community. And what happened was people then went out and took even more formal leadership positions on school boards and on city council. And you think to yourself well we needed allies in those places, we just supported that to happen in very organic ways." – Risa Wilkerson, Active Living By Design
Breakout Session
Designing and Testing New Business Models

Editorial Partner: Business Innovation Factory

Presenters:
Eli MacLaren, Business Innovation Factory
Jodie Lesh, Kaiser Permanente
Peter Roberts, Children’s Health

Session Description

Business models - the story about how institutions create, capture, and deliver value to consumers - don’t last as long as they use to. Whether it is disruption from more nimble upstarts or internal pressure from increasing costs or archaic delivery systems, all leaders need to be more adept at exploring and testing new business models. In this session, we’ll explore a proven methodology for making business model innovation safer and easier to manage in the complex world of health care.

Some Quotes from the Session

“We don’t necessarily know how to do...transformational change. We can easily talk about how do we make incremental improvements, but if we want to be really transformational, how do we do that? The risks of doing that are really high. That said, we also know that we can’t get there from here. We need new models and new ways in which those models can scale and network.” – Eli MacLaren, Business Innovation Factory

“As our friend, Angela Blanchard, from Neighborhood Centers, who is on the BIF board told us, there’s no such thing as sustainable funding. You have to milk every cow as often as you can and that becomes your life’s work and it will never change.” – Eli MacLaren, Business Innovation Factory

“I believe very much that the healthcare institutions and the insurance organizations need to be a part of these social change initiatives but I think we have to guard against letting them become the focus.” – Peter Roberts, Children’s Health

“A huge amount of work went into what did the community want? The whole project is woven into the community. It’s not a thing in and of itself.” – Jodie Lesh, Kaiser Permanente

“There were a lot of people who felt that it wasn’t right to say that we were doing things that were good for us too. I kept on saying to people if it’s not good for us, if it’s all philanthropy, it is going to go away and we have to find sustainability in what we do.” – Jodie Lesh, Kaiser Permanente

“Improving the health of children requires improving the health of the whole family. That sounds logical, but...my insurance company didn’t care about my family unless my family was insured by that insurance company. My doctor didn’t care about my spouse unless my spouse was going to be a caregiver for a very serious illness. (So now,) our health and wellness and prevention programs focus on families and engage families, not as we define families but how they define their particular family unit.” – Peter Roberts, Children’s Health
Breakout Session

**Shifting the Conversation: Using Strategic Communications to Change How Health is Understood, Practiced and Experienced**

*Editorial Partner: Hershey Cause Communications*

**Presenters**
Jacki Schechner, Independent Consultant,  
Nishith Bhatt, Hershey Cause Communications,  
Rhonda M. Smith, Live Healthy OC

**Session Description**

Efforts that involve changing people’s behavior stand to benefit greatly by taking a strategic approach to their communications and outreach activities. Yet, as simple as it sounds, this does not always happen – often communications is tactical, relegated to being an afterthought. Building on the premise put forward by the conveners of the symposium – that we need to rethink entrenched conceptions of health as the absence of disease – this panel will use the example of a community-centered health organization in Orange County, California, to explore the role strategic communications can play in helping to change the practice, and the experience, of health.

**Some Quotes from the Session**

“It is often the case in health that there’s an attitude towards communications that it’s the work that’s done after the work is done. So there’s doing the work and then there’s talking about the work, and that’s not approaching communications as an integral part of the process from the get-go.” – Nishith Bhatt, Hershey Cause Communications

“First is finding the stories, and that’s why bringing me in early is helpful because I can go [find the] good stories. I look and I say here’s a story that can bring this initiative to life. Because just telling people about the initiative isn’t going to do that.” – Jacki Schechner, Independent Consultant

“Reaching out to lawmakers and giving them stories that they can use on the house floor. If you can find a way to put it into the conversation that’s already happening the next thing you know you’ve taken your small initiative and made it something much larger.” – Jacki Schechner, Independent Consultant

“Communicating with the funders is also extremely important. I [try to] communicate with them even when they don’t ask for information. I think they really like to hear about what’s happening all along the way not just when it comes time for the report. I’ve seen it be successful.” – Rhonda M. Smith, Live Healthy OC
Breakout Session
Navigating Power in Health and Community Partnerships

Editorial Partner: ISAIAH

Presenters
Doran Schrantz, ISAIAH
Jeanne Ayers, Minnesota Department of Health

Session Description

This session will explore how health institutions and health systems leaders can transform themselves to move toward supporting the capacity for communities to create their own health rather than approaching health as though it is created in and by institutions. Key to this transformation is a willingness to acknowledge and grapple with issues that arise from existing power dynamics in relationships between health institutions and communities, and to allow room for the productive tension that can occur when those dynamics are addressed directly. The session will explore how to do this, using the context of community organizing’s approach to power and agency. This session will provide conceptual framing and examples of practices, which will prompt discussion and engagement around participant’s own experiences.

Some Quotes from the Session

“We’ve socially designed communities of opportunity that lead to good health and communities of low opportunity that lead to poor health, and when you see that pattern, and it becomes normalized, it’s structural racism...We have to practice and build the muscle of saying this in every space that we have influence in. This is part of this practice called organizing the narrative or expanding the understanding.” – Jeanne Ayers, Minnesota Department of Health

“We had to get our heads around the fact that we actually, in our program design, in what we’re funding, are part of perpetuating structural racism - and create the expectation in our agency that we will change our strategies and our assumptions.” – Jeanne Ayers, Minnesota Department of Health

“Our health is almost completely connected to our living conditions, and our living conditions are connected completely really to our capacity to act. We have to build our ability, our skills around capacity to act. Power properly understood is the ability to achieve purpose.” – Jeanne Ayers, Minnesota Department of Health

“I worked for 30 years in public health and healthcare and thought I was doing good work only to realize that I was part of a system that was picking health winners and health losers and that I was responsible. And so [being discontent] is how I show up in every space. I am really unhappy about the role that I am playing. I believe you start with your discontent.” – Jeanne Ayers, Minnesota Department of Health

“One of the biggest stumbling blocks for...the field of public health is there’s a sense that if there’s tension, something went wrong in a meeting, and that is a negative, like if you can run a meeting with no tension that was a good meeting. From my experience with organizing, if you run a meeting with no tension that is not worth your time; it wasn’t a good meeting. If there’s no tension there’s really nothing being negotiated and there’s no evenness in power, there’s no power negotiation going on.” – Jeanne Ayers, Minnesota Department of Health

“Most political philosophers would say that human dignity, my ability to be a full human being means I can fully live my life as a political being. And political isn’t a word like republicans and democrats. Political is self-determination. Political is I am heard.” – Doran Schrantz, ISAIAH
Breakout Session

Using Participatory Research and Evaluation

Editorial Partner: Rochester Healthy Community Partnership

Presenters
Andrew Binet, NextShift Collaborative
Jomella Watson-Thompson, University of Kansas
Mark Wieland, Mayo Clinic
Miriam Lopez Daumas Goodson, Alliance of Chicanos, Hispanics, and Latin Americans of Rochester, MN
Shannon Simpson, Dudley Street Neighborhood Initiative and Brandeis University

Session Description

A shift in how we view knowledge is fundamental to fostering community agency. This session will explore two approaches to participatory and inclusive research and evaluation. An emphasis on the elements that they have in common will provide a framing for how to incorporate a more participatory approach across all phases of information-gathering and measurement. Doing so enables a mutual understanding of key influences on health, including how the community sees its own health, what results matter, and potential ways to intervene. It pushes the work to be cognizant of the inherent complexity of improving a community’s health and the reality that to address many seemingly intractable health issues we need to trust in the power of process above any specific intervention or outcome.

Some Quotes from the Session

“Rather than just having a purely external evaluation, being part of the process really helped generate a new level of understanding about ourselves. The take-home was that partnership processes do in fact inform outcomes. And that wasn’t just from the qualitative work. Even from the quantitative work, from the survey work, those partnership dynamics that were high were statistically significantly correlated with those outcomes that are most meaningful to the partnership. And so that was a powerful affirmation of process over product. We concluded that process is our most important product.” – Mark Wieland, Mayo Clinic

“Believe me there’s barriers everywhere. I mean I’m educated but not to the level of research and intervention that the politics and the policies are making you have a different kind of language...They use all these terminologies, and whenever I’m doing anything on the ground I have to use the language that I believe is okay to use.” – Miriam Lopez Daumas Goodson, Alliance of Chicanos, Hispanics, and Latin Americans of Rochester, MN

“If [the process] moves too slow, people sometimes don’t stay as engaged. Make sure it’s 100 percent about the process but that you can also push out the information in ways that are meaningful so people can say, and see, we’re moving along.” – Jomella Watson-Thompson, University of Kansas

“I think one of the most difficult things is balancing the tensions that come with these different visions of success. It’s a never-ending process. I don’t think we’ve reached any sort of resolution, and I don’t intend to, but it’s just a matter of trying to continuously engage in the tensions that come up when we have, at the end of the day, very different goals.” – Andrew Binet, NextShift Collaborative

“The process of creating the questions and being in the field to ask other residents about the survey was very eye-opening [as to the] value in my own neighborhood. It gave me appreciation for my city in terms of the individual people that I was meeting and hearing their stories. They are wanting to be part of the change.” – Shannon Simpson, Dudley Street Neighborhood Initiative and Brandeis University
Appendix 1 | The Agenda Of Our Symposium (cont)

Breakout Session
Leveraging Opportunities and Collaboration to Bolster Community Agency

Editorial Partner: United Healthcare Community & State

Presenters
Emmanuel Kintu, Kalihi-Palama Health Center
Kate Paris, UnitedHealthcare Community & State
Katherine Keir, Goodwill Hawaii
Nicole Dickelson, UnitedHealthcare Community & State
Andy McMahon, Corporation for Supportive Housing

Session Description

The importance of addressing social and economic factors has become increasingly apparent to the health care sector. This increased focus presents an opportunity to introduce new collaborations and new ways of working at the local level. Join us as we explore how partnerships in Honolulu, Hawaii between the Kalihi-Palama Health Center, UnitedHealthcare Community & State and other community-based organizations are developing to address some critical issues in the community. This example will be the basis for a discussion on how local, state and federal players can shape the environment to bolster meaningful collaboration and foster community agency.

Some Quotes from the Session

“Two for-profit companies [came] into our territory to take away what is ours. This is how the community looked at it. There was a lot of rejection in some of the area... but we said we’ll work with you. We asked these [companies] how many languages do they speak? How long have they been in these communities? How have they navigated and how will they? Of course, they couldn’t.” – Emmanuel Kintu, Kalihi-Palama Health Center

“In our organization we are really trying to figure out... how do you come into a new community? We want to be in places that we aren’t right now. That’s the objective [of] our business. We often use a variety of methods to be part of the community that we’re in. We hire a lot of people from the communities that we’re serving. Our health plans live, work, are housed in the communities that they’re serving. But they are also part of a bigger national organization. So we try and balance and sometimes do not succeed appropriately at that balance.” – Kate Paris, UnitedHealthcare Community & State

“One of the things that we appreciated is that we’ve been involved from the very beginning. So, as [UnitedHealthcare] started to wrap their head around the grant and the outcomes, it was another conversation. Are these the numbers we need to hit? Is this even feasible? If we put these outcomes in the grant how do you think they’re going to be received by the community, not just by the potential funder? That was really great as well to be able to give that feedback in terms of what was realistic so that they can set us all up for success with the grant.” – Katherine Keir, Goodwill Hawaii

“I can see tremendous change in our thinking and our strategy around what are the communities that we plan to continue entering into and what is the work that is before us to really try to get this very messy integration of health and social services work right, because to date no other large payer, at least in the Medicaid space, has ventured to do it in this way and has gotten it right. So we’ve got a lot before us.” – Nicole Dickelson, UnitedHealthcare Community & State