Appendix 4 | A Summary of The Feedback
From Symposium Participants
A Summary of the Feedback
From Symposium Participants

We collected feedback in four ways:

1. A ‘rapid feedback survey’ provided at the close of the symposium (42 completed)
2. Notes captured by tabletop facilitators during symposium (notes from 9 tables)
3. A post-symposium survey emailed to participants (14 completed)
4. And individual feedback via personal communication with the BH&C team (phone and email)

Rapid Feedback

In the rapid feedback survey, we asked participants to share their immediate impressions on the level of ‘knowledge gained,’ ‘practical application,’ ‘connections made or deepened,’ and ‘overall value’.

- Almost 90% of respondents felt the symposium provided ‘quite a bit’ (45%) or ‘a lot’ (43%) of overall value
- More than half of respondents (62%) stated the symposium led to connections made or deepened; however more than 1/3 of respondents (38%) stated the symposium led to only ‘a little’ connections made or deepened
- More than half of respondents (62%) stated the symposium had practical application; however more than 1/3 of respondents (38%) stated the symposium had only ‘a little’ practical application
- Almost 75% of respondents felt they gained ‘quite a bit’ (50%) or ‘a lot’ (24%) of knowledge from the symposium

What Was Liked

Looking across all of the feedback, when participants were asked what they liked about the symposium and what they found most useful three areas emerged:

1. The environment that was created
2. The people and connections made
3. The content

When highlighting the environment created participants noted that they liked the:

- Environment in general (positive, warm, welcoming, high energy)
- Variety of sessions
- Intentionality of the structure
- Creation of spaces conducive to meaningful engagement, learning and processing
- The small table dialogs
When highlighting the people and connections made participants noted that they liked:

- The people (other participants)
- The diversity of perspectives and experience of participants
- The ‘wisdom in the room’ (of participants)
- Connecting and networking with others in the field
- Deepening their understanding of the various players in the field
- Learning from others in the field

When highlighting the content, a few participants highlighted specific aspects:

- ‘Great presentations’
- The candor in talking about the failures of health and public health
- The diversity of the speakers
- The breakout sessions
- That the examples were ‘real-life’
- The accountability exercise (at the close of the symposium, we asked the participants to write down their goals for the next three weeks, three months, and three years)

What Could Have Been Better

Again, looking across all of the feedback, when participants were asked what could have been better a preponderance of respondents highlighted a desire for:

- More framing or ‘level setting’ at the beginning of the symposium
- An organizing frame for the symposium (some attendees suggested using the 12 principles as that frame)
- A stronger closing call-to-action or commitment to tie it together
- More networking time, both during and before the symposium (in contrast, one respondent requested fewer breaks and less networking)
- More breakout sessions and workshops, including increasing the number and variety
- More case studies and tangible examples highlighting practical steps, successes, and failures
- More practical tools of how to apply learning from the symposium

Some participants highlighted the need to:

- Incorporate the local community and community providers into the symposium, whether in setting the context, planning or facilitating (some suggested a tour of the area, talking more about where the symposium is being held, and highlighting case studies from the area)
- Have more elicit and direct discussions on the role of racism and systems of oppression
- Have more concrete conversations on community engagement and community, noting that some of the conversations felt ‘heady’ and tended to talk about ‘community as if it was a homogenous group’
- Reduce the amount of table work and/or mix up the small table groups for more networking (in contrast, other participants appreciated the depth of time with one consistent small group)

In addition to the reflections shared in the main body of this report, we previously reflected on the feedback in a post published in June 2017.
Appendix 5 | An 11-Part Series
Reflecting on Our Symposium

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The Cost of Learning

Part one of the 11-Part Series Reflecting on The Symposium

By Leigh Carroll

"Who was doing the learning?" asked Lawrence, one of the facilitators from MIT CoLab.

We were reflecting on our first symposium, Community Agency & Health, which CoLab helped to plan and deliver. It was immediately after the event and it quickly became clear that people felt very differently about the experience. For some, it exploited the trials and raw emotions of people of color, while for others it was eye-opening and heart-changing. Indeed, for some, it was one of the most racially diverse events they’d ever been to, while others didn’t consider it very diverse at all, feeling that the same old racial and gendered hierarchies were reproduced in the speakers.

In that reflection circle, as well as at the event, there were people with very different world views: there were people within and outside of public health; people with lots of economic and political power; people with little economic and political power; people with different perspectives built from navigating the world with different skin colors, sexualities, or genders. In many ways, the group in reflection, those of us that planned and delivered the symposium, mirrored the worlds that we at Bridging Health & Community know need to come together if our health system is to change for the better.

The problem is that it’s hard to work together when we all experience the world so differently, and hence need to learn vastly different things to do our work better.

Opening Ourselves to Learning

So, who is doing the learning at events like ours? In a session about how our failing health system has a disproportionate impact on people of color, those who have never felt the pain of these impacts were benefitting while those who understood the pain all too well were made to live through it again. Or, a session about health care financing might be old news to someone who works in the system but might be immensely helpful to a community organizer looking to fund social justice work.
The Cost of Learning

Often, we don’t even know what it is we need to learn. At one point during the symposium, an audience member asked someone from the public health field (and excuse my paraphrasing), “What is it about people in your profession that makes them feel that they always need to be right? Or in charge of finding the answers?” I don’t think the question was understood at that moment. We weren’t ready to be so introspective. And it was bold – perhaps unprecedented – to ask for introspection from an expert on a stage. I sensed that that many of us didn’t really hear what the question was asking.

I want to ask it again. What is the gap within many of us that we try to fill by being right? What is it about people (like me) who have gone through prestigious education, who have entered career systems with relative ease, who receive much mainstream social affirmation? We know that our approach to health is not working so what is that thing, deep in our souls, that stops us learning from the different people around us, perhaps those without the esteemed accolades or those whose marginality inspires views that many find too radical? What do we need to do to start thawing our hearts to their view of the world?

The Cost of Teaching

Chipping away at the inequities of the US health care system will require everyone to learn. For instance, public health professionals and community organizers alike have incredibly valuable knowledge, all important and necessary pieces of the puzzle. But we need to be aware of how much each group is learning at the expense of the other’s time, emotional energy, and resources. We probably didn’t get this balance right at the symposium.

Focusing on what Bridging Health & Community might do next, perhaps this means hosting smaller gatherings where people from different backgrounds and professions can spend time together, get to know each other, and, in time, teach each other about how they see the world. Perhaps this way, we can help each other connect the dots, the hope being that through this (likely messy) process we can grapple towards opportunities previously unnoticed.

One thing I do know is that the path before us will require a lot of personal learning and introspection, which is a frightening endeavor for many of us until we’re no longer afraid of being wrong. Or unaffirmed. Or unimportant. Then, with an eye on the people around us – rather than on our egos – we can open up to a truly collective journey.

Leigh Carroll is an organizer with SEIU Healthcare Pennsylvania and a member of Bridging Health & Community’s Board. Previously, as a graduate student, she worked on a participatory study of the relationship between neighborhood change and health, to inform an evaluation of the Healthy Neighborhoods Equity Fund. Her past work also includes research and project management at the Institute of Medicine, and teaching science to high school students in Tanzania through the Peace Corps. She received a Masters in City Planning at MIT and a BS in neuroscience from the University of Rochester.
The Healing of Exploitation

Part two of the 11-Part Series Reflecting on The Symposium

By Carl Baty

Changing any long-established system will be difficult at best.

First, everyone must decide what is working and what isn’t before there can be a decision as to what needs changing. This ‘everyone’ must include: the most marginalized, those who are living in situations where survival overrules compliance; the professionals providing the services; the intellectuals with the ideals of a best-case scenario; a translator able to speak the language of these very different worlds; and the facilitator to bring all the parts together.

Second, and most importantly, these parts, and all in attendance, must maintain an open mind to the equality of, and the necessity of, each part, as well as the single mindedness of the unit created to effect change.

One of the biggest obstacles to overcome is the inability to view speakers from the most marginalized segment of society as equals. There is always talk of these people being exploited, but exploitation can only be imposed on those of lesser stature. This inability to view all participants as equals prevents the observer from grasping the value derived from an invitation to participate.

Perhaps my experience can best demonstrate what I mean.

When I was asked to share the stage with Professor Syme at the May 2017 symposium, Community Agency & Health, I could not envision what I could possibly bring to the conversation. Of course, I knew I had an individual story, and I was more than willing to share it, but I had no idea how my story could impact anyone. I had shared my story several times in Twelve Step Program meetings, but this setting was so different and intimidating.

What I had no way of knowing was that the sharing of my experiences would have the greatest impact on how I would view myself. During the session, I shared my story of how, at the age of 65, I was told for the first time that I had reason to be angry. While I was speaking, I became overwhelmed with emotion. Several times in my life I had been called
Appendix 5.2 | An 11-Part Series Reflecting on Our Symposium (cont)
The Healing of Exploitation

angry, and it caused me to constantly look for what was wrong within me. But for the first time in my life, someone was telling me that I had reason to be angry. There was nothing wrong with me. There I sat, telling a room full of people that there is nothing wrong with me. The sharing of this information reinforced that belief within me. It was an emotional experience for sure.

To anyone looking on, without the experience of, or empathy for, my background all that could be derived from what was taking place is some form of exploitation or aggrandizement. But, in my view, you can only exploit that which is not equal. If I am considered as equal, then I am not being exploited - I am acting within the purpose of my experiences. What could never be known by the organizers, anyone in attendance, or myself for that matter, was that I would grow to realize that all of what were previously viewed as liabilities had immediately become my greatest assets.

One lesson to be taken away from the symposium is that regardless of who the presenter is, what the educational background is, or how negative the experiences sound, each participant must be viewed as equal and necessary. Everyone stands to gain from this approach, and none more so than the one most would deem ‘exploited’.

If there was one thing I would change about the symposium, it would have been the panel discussion. The panel was diverse by definition, but there was no one on the panel that looked like me. There is a new term being used today, ‘people of color’, and this is now the standard to judge inclusion. My question is this: does this new term perpetuate the racism that has for too long been present in society?

My experience at the symposium can be summed up in three easy to understand parts:

1. All my liabilities became my greatest assets overnight; I went from not even understanding what I had to offer, to understanding that I can give voice to those like me that go on unheard.

2. Healing became real; we talk about healing, but it is not until you start to talk about it in front of a group like we had there that it takes hold. I walked away a new person, and one that I am still getting to know.

3. It takes all of us working together to effect any lasting change, and to make everyone understand

Carl Baty is Executive Director of Rounding the Bases.
I’m reflecting on the ‘Community Agency and Health’ symposium having just completed a training course in non-violent communication, a technique developed by psychologist Marshall Rosenberg in the 1960s that enables people to connect more meaningfully by listening compassionately to each other’s feelings and the underlying needs that they are expressing.

This power of listening was a striking theme for me during the symposium.

Travelling to the meeting, I read Carl Baty’s foreword to Bridging Health & Community’s 2017 report, Fostering Agency to Improve Health. Baty talks about his experience of being an addict for 47 years, of being ‘sent home to die’ from hospital after being attacked, and of being listened to for the first time. His expression that “healing is about being able to express yourself, about people listening to you” rang true with a sort of radical obviousness. And it made me consider how rare this listening is within the care provided by much of our health systems. Just as in our culture more broadly, health care often focuses on the latest, shiniest technology, and doesn’t leave much space for the basic human needs of being listened to, of our stories being acknowledged and accepted.

Types of Listening

The importance of listening was placed very firmly at the heart of the symposium. The whole of the first morning’s programme was focused on helping participants be aware of how they take part in the meeting. The facilitators from MIT CoLab set the scene by sharing ideas from Theory U about the different types of listening that we might use during the
Listening as a Radically Obvious Act

It’s often said that the best conversations at conferences happen in the corridors and coffee breaks because that’s where the real human interactions occur. In leading the team of volunteers who helped keep the symposium running smoothly, I noticed that there was very little ushering needed after the coffee breaks. Participants wanted to get back in to the hall to where the juicy conversations were happening. The structure of the symposium enabled this conscious engagement with fellow participants to continue over the two days. Instead of being sat in anonymous rows, we were placed in groups, just like the seating plan at a wedding, and remained with the same group of carefully mixed backgrounds throughout. We genuinely got to know and learn from each other.

After each speaker from the stage, table facilitators helped each group explore what we had heard, and enabled us to learn from each other’s perspectives, creating a much deeper level of understanding and insight than we would have got had we been sat in rows just receiving a broadcast from the stage. My table had a mixture of people from various roles and levels of seniority in healthcare, community organising, and political science. And the framing around how to listen seemed to pay off. The conversation around the table was collaborative, we found our way through areas of discomfort, and there was mercifully little of the adversarial intellectual one-upmanship that can so easily come out when there are a bunch of experts around a table.

Meaningful Connection

After spending my weekend learning non-violent communication, I reflected on how strange it was in these hi-tech times that these fundamental human skills of listening and empathy can seem a rare commodity. And after the symposium I was reminded how rare the structures are in professional settings that enable meaningful connection between colleagues.

I also see listening as being a vital part of engaging with the symposium’s central concept of agency. By understanding each other human to human, artificial power imbalances can start to be dissolved. We become people, not just representatives of whatever professional, social, or ethnic group we might be identified as, and can begin to work together in much more meaningful ways.

Elizabeth Slade is an independent consultant exploring how our culture and society can enable more of us to live happy, healthy, fulfilling lives. She is particularly interested in how the technologies developed in religious contexts (from communities of purpose to pilgrimage) can be implemented in a secular way. She was COO of Sunday Assembly (a global network of secular congregations), has collaborated with Bridging Health & Community to explore the role of agency in health, and has a background in health care information and improvement.
In May 2017, Bridging Health & Community hired me to cover the Community Agency & Health Symposium in Oakland, California. I was to wear several hats: as a qualitative researcher, I would serve as rapporteur for the symposium; as a transcriptionist, I would produce transcripts of the audio files recorded throughout the two-day event; and as a writer, I would produce a synthesized report of the transcripts using my rapporteur experience as a backdrop. I’d worked a good deal in the field of community development, but my experience with healthcare, per se, was limited. While I’d done some preliminary research, I didn’t have a clear picture of what I was getting into when I entered the grand ballroom of the Marriott Hotel.

The room was abuzz with conversation and energy. Clearly, some people had met before, while many others had not. Table seating was assigned to cross-pollinate various sectors of participants, and from my table, and my observations within the room, this proved fruitful. There was a keen interest in knowing who else was working in the field of community agency and health, what they were doing, how they were doing it. It was as if a tribe had found itself. As one participant told me, it was a “relief” to be able to talk about the complexity of the work and to have valuable conversations.

Throughout the day, panel presentations and discussions pertaining to the field – its successes and failures, challenges and ways to tackle them, stories of hope and heartbreak – illuminated the complexity of the situation, and I began to connect the dots. Poor housing conditions and expressways running through communities will, of course, lead to high rates of asthma. A region that produces and exports 25 percent of America’s table food yet leaves its neighbors in a food desert with polluted water will, of
course, lead those residents to high rates of diabetes and hypertension. When self-determination is undermined, particularly in poor communities, the road to good health is fraught with stumbling blocks, with or without a dose of prescription medication.

With a clearer understanding of the situation, I simultaneously felt overwhelmed and hopeful (if not secretly relieved my job that day was limited to rapporteur). The challenges of building healthy communities that foster collective and individual agency, thereby promoting health and wellbeing, seemed monumental. Yet examples of success were clear, tools and principles key to health were developed, and those involved in the movement to create the change seemed ready to take action. There appeared an ardent interest in moving this field forward, a desire to change entrenched models, and determination to find ways to go about it.

Participants were diverse and knowledgeable. A warm fellowship, the opposite of sterile, and an appreciation for the combined wisdom and experiences in the space remained evident. As well, a sense of adventure existed, of being on the ground floor of something that might actually take off. At times the energy and concentration was palpable, both in the ballroom and, later the following day, in the breakout session I attended. This interest played out in other breakout sessions I eventually transcribed.

Ultimately, synthesis of 215 pages of transcripts lead me to envision the human body as metaphor for this field, all the workings within it connected and circulating back to the whole. The transcripts revealed overriding themes, like process and power and funding (always funding). Just as importantly, however, were themes of the heart (opening hearts, listening with your heart, giving from your heart), personal transformation, reflection, healing, humility, and courage.

Among the list of challenges, funding was ever present: funding for infrastructure, funding outside of corporate or foundation mechanisms, funding to provide innovative space, to go beyond pilot programs and bring initiatives to scale, funding for knowledge share-back. Other challenges included issues of race and racism, how to institutionalize civic infrastructure, how to change mindsets, shift power structures, address issues collectively as a community and a nation, and how to spread the word about this field.

In the wake of completing my job, I see things with a sharper focus. I examine my own agency; if it feels demeaned in any way I consider the threat it holds over my wellbeing, and, by extension, that of my community. I try to listen to others with a deeper understanding. I contacted my local hospital, encouraged them to take part in Bridging Health & Community’s efforts to recruit organizations that will put the principles into practice. These are small things, but, as I learned at the symposium, seeking partnerships and fostering agency to improve health is a process, and we must start where we are and from there move forward.

Diane Wellman is an independent writer, researcher, and interview transcriptionist. She holds an MA in English from Marshall University and has worked in her field for two decades. Visit her at dianewellman.com
Reflections on Othering, Oppression and Why Inclusion Matters

Part five of the 11-Part Series Reflecting on The Symposium

By Katherine Mella & Lawrence Barriner II

As co-facilitators of the 2017 Bridging Health & Community (BH&C) symposium, Community Agency & Health, we had the pleasure of supporting and designing the convening with the BH&C team. And, like any well-facilitated process, the conveners had a debrief session immediately following the symposium to capture initial reflections. In the first post in this series, Leigh Carroll, a BH&C board member, began the process of elaborating on those initial reflections. Below we continue that work by sharing three of our own reflections, each with a proposal for how to make improvements on this first symposium, and the work of BH&C, in general.

‘Community’ discussed homogeneously inadvertently lumps people into a faceless, nameless, powerless stakeholder

Some participants spoke about their desire to cultivate deeper relationships with particular grassroots community groups. They wrestled with the best ways to establish authentic connections and develop trust as a collaborator. They understood the work of building relationships as a necessary precursor to collaboration and wanted to learn about tools that supported that critical phase of the process.

Others, typically those who identified as outsiders, who worked (or hoped to work) in partnership with groups in their local contexts shared reflections of “community” homogeneously, or in a way that some felt ‘othered’ those stakeholders. Those ‘outsider participants’ often generalized experiences, initiatives, and groups into the broad term. Sharing comments like, “I want to do X with ‘the community’” or “We need to build stronger relationships ‘the community’” inadvertently lumps people into a faceless, nameless, powerless single stakeholder that isn’t given the respect, dignity, or authority they deserve.

To combat this potential ‘othering’ of stakeholders (particularly diverse, vibrant, and dynamic communities) we propose BH&C makes space for more context-setting,
including storytelling activities, such as Story Circles. This would allow for a more nuanced understanding of people’s circumstances and experiences, and could support more authentic conversations. Ensuring an even higher number of participants reflect grassroots stakeholders would also allow for those voices to be more present across different conversations.

**Spaces are needed to explicitly address systems of oppression as they intersect with health care**

One of the most contentious moments of the symposium occurred during the session titled, ‘A Candid Conversation on Failure.’ During that session, participants heard from Carl Baty of Rounding the Bases. Carl shared his experience as a black man, and the ways that systems, including healthcare, had failed him and impacted his life.

The session had varying impacts on participants. Most appreciated Carl’s candor in sharing his story with a room of strangers, but some felt uncomfortable hearing the hard realities of his life. Others shared that the session felt exploitative and, in particular, some folks of color were hurt and traumatized by the experiences that Carl shared, which were personally triggering for them.

A crucial take-away from that session is that it’s impossible to discuss health system transformation and the role of community agency without acknowledging systems of oppression, including racism. This means understanding how oppression impacts who has access to care, how those people are treated, and the compounding social, economic, and environmental factors that disproportionately affect people’s health outcomes.

The session also illustrated why spaces are needed to explicitly discuss these systems of oppression as they intersect with health care. It’s important that people listening to a story of this intimacy understand that, while intensely personal, this story is also indicative of many systems designed to exclude. Having such discussions requires intentionality and planning.

It is critical that these kinds of personal, uncomfortable, and potentially triggering experiences are centered as valuable knowledge. And it is just as important that, in the centering, the experiences are handled with care and structured so that they honor the lived experience while not harming the sharer(s) or audience members by reliving the trauma(s). This can be accomplished through intentional agenda setting and skilled facilitation; ensuring that people who have lived experience with system failures are lifted up as experts in conversations and involved in determining what gets shared from the front of the room; and providing breaks and physical space for participants who need to step out of emotionally loaded conversations.

**“Nothing about us without us”**

The conference attendance was more diverse than most. There was clearly attention paid to involving participants across many dimensions of identity. And yet, the BH&C team (staff and board) is almost entirely white and some key members of it are not from the US.

Of course, being white and/or not being from the US shouldn’t stop anyone from working to solve the complex problems of the US health care system (quite the opposite, actually). And it certainly doesn’t mean that the US health care system doesn’t fail white people and people who weren’t born here (again, quite the opposite). But given the disproportionate negative impacts on marginalized communities – folks who are poor, of color, queer, disabled, and more – what the BH&C team unintentionally communicated to the conference attendees was: ‘We believe that we are the people who should lead this work.’ Although the BH&C leadership team is great at verbally positioning itself as ‘not experts’, the professional identities of people on the team still position them as experts. And, words aside, the identity of the team – mostly people whom the healthcare system does not historically and systematically fail – still had impacts on the conference – such as the two reflections above.

We believe that you cannot effectively organize interventions for people that systems fail without the people that the systems fail. It is important – we might even argue necessary – that in order to move on its mission, BH&C support the deep, meaningful inclusion (by way of representation) of all people who are the intended recipients of a health care system where communities have agency over their own health. For
example, if the group intends to support work in a specific city, the BH&C team (board members, staff, consultants, partners, etc.) should reflect that city. If the scope of ‘the communities’ includes poor people of color, the team should reflect that, etc.

In closing we would like to share an encouragement based on principle 8 of BH&C’s [12 principles to fostering community agency](#):

> “Embrace uncertainty, tension and missteps as sources of success.”

This blog series is a direct embodiment of BH&C living out that principle.

We hope that these reflections and proposals support BH&C moving on its mission to overcome the disconnect between the health sector and communities. Thank you to the BH&C team for the opportunity to share our reflections. We’re looking forward to reading what others will share in this series!

**Katherine Mella** is a Program Associate at the MIT Community Innovators Lab, where she supports the Bronx Cooperative Development Initiative (BCDI). BCDI is a network of grassroots leaders, anchor institutions, elected officials, and finance partners who are working together to achieve a sustainable, equitable and democratic economy in the Bronx. Katherine leads BCDI’s community health agenda alongside grassroots partners, leveraging opportunities tied to local and national healthcare system transformation, and using the social determinants of health as a key framework. Katherine earned her Bachelor’s degree from Brown University in Urban Studies and completed her Master’s in City Planning at MIT.

**Lawrence Barriner II** is Program Director for Community Media at CoLab and Executive Editor of CoLab Radio. His work at CoLab includes communications, narrative strategy, storytelling, and using media and media platforms to advance economic democracy and self-determination. His experience in these areas includes facilitation, implementation, and teaching. He is working towards a world that supports all people to imagine and achieve better, more whole futures for themselves and their loved ones. In his non-CoLab time he runs a life coaching practice, teaches strategic storytelling workshops, writes, and devours books and podcasts. Lawrence earned his Bachelor’s and Master’s in City Planning at MIT.
I was eager to attend Bridging Health and Community’s symposium, *Community Agency & Health*. At the time, I was five months into a new position with *Buncombe County*’s just-formed Community Engagement Team. I arrived ready to learn.

The people at our tables were curated and mine was a dazzling mix of professions, backgrounds, locales and perspectives. Our facilitated and impromptu conversations encouraged me to think deeply about the issues of improving community health. Impressed with the work being done by others and enthralled by their talent, I was most of all transfixed by the common thread that something was missing. I returned home with a sense of camaraderie based on the knowledge that we all knew that we were losing in one way or the other, but were intrigued and inspired to figure out what to do next.

**Fear?**

In my assessment, the single most important step we must take is to address the health care industry’s obstruction of authentically partnering with community. I asked at the symposium, “What is the fear of this new way of working?” *Linda Gonzalez*, the racial justice facilitator articulated the idea to ‘tend to the emotion’ of a contentious issue. So, what emotion is behind health care’s reluctance to bring community to the table? Tradition? Uncertainty? Job security? Loss of power?

I am not a long-standing member of the health care industry. There are no two- or three-letter acronyms after my name. I have never been published. And I’m not sure I aspire to these accolades. Then who am I to ask these questions? I am a piece of the puzzle. My role...
Appendix 5.6 | An 11-Part Series Reflecting on Our Symposium (cont)

We Are Losing, So What Are We Protecting?

is to be a bridge and translator between institutions and community. My charge is to intimately understand institutions’ and community’s independent motivations, capabilities and limitations, and to then weave that knowledge into a path forwards.

Parity?

I am often in a room of white professionals calculating how to aide those who, more times than not, are not of the same race. The myriad of emotions, decisions, and missteps that happen in these rooms are nearly impossible to decipher, but I absolutely know race plays a factor. At the symposium, race, discrimination and bias were missing from the conversation. We all know the destructive force these things can be, so, again, what and who are we protecting by not addressing them directly? During the symposium, Carl Baty, a black man, shared his experiences of being let down by multiple systems. I found his presence and contribution to be on par with the rest of the presenters but my sense is that others may not have felt the same. Again, what are we protecting?

My hope is in some distant future we will no longer need a ‘buffer class’ of occupations like mine to bring together institutions and communities. They should already be at the table and should know how to be in a relationship with each other. Until then, we must include race in further discussions, especially as we consider how systemic and invisible structures continue to undermine individual and community agency.

From one puzzle piece to the other.

Rebecca Brothers works in Community Engagement at Buncombe County Government, NC.
I did not know there was healing in research until I heard Carl Baty share his story.

At the symposium, Community Agency & Health, Carl described how negative portrayals of black people, displayed as truth, not only harm black families today but also rob them of their futures. These portrayals have a long history that is part of the oppression of black communities; it has created a stigma that black people have to navigate to survive.

I believe that healing from oppression takes finding inner peace. It's about self and social reflection, about acknowledging that oppressed people are set up to fail. This reflecting seldom takes place, perhaps because poor black people often have multiple jobs and no time to question the systems around them. Nor do they have time to heal from the anger and pain of exploitation. As James Baldwin said, "To be black and conscious in America, is to be in a constant state rage".

While true, what matters is how we employ that rage. Rage employed to dismantle the hateful systems we live with can be positive. Rage employed as violence only hurts more people – and potentially perpetuates the systems of oppression we hope to reform. Without healing, the cycle of hurt can only continue.

Communities that have been oppressed need to be encouraged to share their stories; their struggles should be at the forefront of the dialog, the foundation of solution building. No one but us can make decisions about us. There is healing in telling one's story, in learning that many hardships are not our own fault. As Carl shared, he did not know he had a right to be angry until he shared his story aloud.
Within that sharing there is also expertise. Oppressed communities can create solutions. In fact, it is impossible to have sustainable solutions if those within the struggle are not a part of creating them.

There is more and more ‘social justice’ work using the methods of participatory action research (PAR). For oppressed communities, this work can be very eye-opening. Facilitators need to be prepared to handle the personal traumas that may be triggered when people talk about their lives. There needs to be willingness on both sides for learning and healing through transparent communication and empathy. Genuine relationship building is crucial to all social justice work. If we cannot learn and build together there is no healing. The healing process needs to be deeply ingrained in PAR and all research methods.

It takes agency to find inner peace, to heal. Exploring one’s past and questioning how it affects one’s present is a purposeful activity. However, agency is also needed to build the relationships necessary to sustain people in this work.

It takes agency to create changes for the future which also diminish the power difference between the oppressors and the oppressed.

In my work, we use PAR. But it was only when I heard Carl share his story did I realize that we needed to be intentional about healing as a process. And that I, too, was healing through research.

Shannon Simpson deeply values infusing youth and resident voice into institutional decision making. She is a Resident Researcher in Roxbury, MA, with the Dudley Street Neighborhood Initiative. She specializes in youth development, participatory action research, community organizing, and building capacity for community and resident leadership. As a Resident Researcher, she works on finding and creating best practices for residents, youth and the community that center on housing and development. She enjoys traveling and is proud of her Jamaican-Irish culture. She hopes to inspire one person to inspire another person to inspire another person.
I attended the conference as a co-presenter for a workshop titled: ‘Creating Leadership Capacity for Long-term Change’. The session explored how community capacity includes the collective ability of residents, leaders and organizations to define, pursue and achieve their goals. My co-presenter, Genoveva Islas, and I planned a fun and engaging session during which we shared brief vignettes about our community engagement work and how community transformation happens at the grassroots level. It was fabulous.

But only a few – very few – attended. I was curious about this. Our session was in parallel to five others that sounded a whole lot more related to the ‘health care industry’. So, if the majority of the symposium participants were, in fact, from the health care sector, which certainly seemed to be the case, it made sense to me that they would attend sessions like, ‘Using Participatory Research and Evaluation’ or ‘Using Strategic Communications to Change How Health is Understood, Practiced, and Experienced’. In retrospect, then, I am not sure that we – the non ‘health care’ participants – were necessary to the goals of the meeting.

Nevertheless, our presence made for interesting conversation. “Nooooo… I am not a community health worker. I work with neighborhood leaders who are organizing their community around a culture of health.” The difference was not clear to many.

The symposium’s title was, ‘Community Agency & Health’ and I arrived not knowing what ‘agency’ meant in this context. It wasn’t until early during the second day that it finally clicked. To quote the webpage through which the tickets were sold:
“To foster community agency, the health sector must adopt, and adapt to, a more inclusive and participatory approach that requires participation in a sustained process for deriving and implementing solutions together with other sectors and community stakeholders, including residents.”

We non ‘health care’ folks have been doing this in our communities for years. “Nothing about us, without us!” has been the rally cry of our residents. We have listened and we have learned from the wisdom in the room, and often times the real ‘expert’ is the one we are trying to help. So, for me, what was most encouraging and enlightening at the symposium were the stories of the communities rising to meet their challenges – the case examples of the Bronx Healthy Buildings Program and the Building Healthy Communities, South Kern. With those, I raised my hand in solidarity and nodded my head in agreement, as they told their how-we-got-over stories of success.

When I reflect back on the symposium, I also remember Carl Baty. I remember the vulnerability of this man, who, with the rawest of emotions, shared his testimony of survival and resilience through addiction. I remember the stuttered silence amongst the crowd who, at first, giggled nervously, and then quickly realized that this moment was not scripted, but, indeed, was a purging of the soul for the sake of transparency and knowledge – and we had better learn something. I will forever remember Carl.

By the time the symposium came to a close I had an abundance of great handouts, a renewed sense to keep on doing what we were doing, and contact information from a few people who wanted to learn more about my work and I wanted to know more about their work.

We agreed we would stay in touch. But, we haven’t.

I’m not sure why.

Dina Newman is the Director of Leadership at the University of Missouri-Kansas City’s (UMKC) Center for Neighborhoods in Kansas City, Missouri. Housed in the Architecture, Urban Planning and Design Department, the Center for Neighborhoods opened in April 2016, and has contributed to the leadership development and capacity building of 40 neighborhoods and 89 neighborhood leaders. Prior to this position, Ms. Newman served as the Health Initiatives Manager/Advocate for Change, in Kansas City’s Ivanhoe Neighborhood, where she created successful and award winning-place-based strategies and campaigns to address childhood and family obesity, health/wellness inequities and social determinants of health.
When public health departments support all aspects of the public’s well-being – beginning with striking at the roots of health inequity – it can create transformational change. Part of this process is encouraging people in communities to determine their own futures – to express agency – something that is rooted in action and power. So, how does local public health get there?

We already have examples of success. For instance, local public health departments have been at the forefront of health equity work by building internal capacity and infrastructure, fostering strategic community partnerships to build power and engage in social justice work, and working across government agencies to develop shared ownership for health equity.

However, although these examples exist, all too often public health’s efforts fail to improve population health – and often because of the fear of failure. There is fear of trying new initiatives that might not work out. There is fear of running out of time, will, allies, and money. There is fear of not meeting funders’ expectations, even when their expectations do not align with the community’s needs. There is fear of going against the governing bodies, such as mayors and other officials, even when their agendas may conflict with the community’s needs. And, underlying all of this, is the fear of losing ever-dwinding vital resources.

Addressing the roots of health inequity requires operating out of a social justice – and not just a medical – framework. In their role as scientists, public health practitioners can no longer shy away from addressing issues of unequal power and structural bias, such as racism.

While Bridging Health and Community’s (BH&C) 12 Principles are not new to public health practitioners, how they are framed within the context of building community agency is powerful. They describe an inclusive, participatory, and
responsive processes to create a holistic shift in how healthy communities might be developed. Too often, we in local public health inadvertently perpetuate the problems we are looking to address – especially when we exclude the community's voice in our efforts. It renders our work fragmented and narrowly focused on specific health conditions, rather than being a holistic approach that appreciates and responds to how good or bad health is the result of the many systems that serve a community, and the intersections between them.

As a framework for overcoming this narrowness, the 12 Principles resonate strongly with how NACCHO and local public health departments should – and often do – engage the communities we serve. For example, the 12 Principles directly correspond with our Mobilizing for Action through Planning and Partnerships (MAPP) approach for guiding health departments and their cross-sectoral partners to work collaboratively to improve community health through health assessment and planning.

What does addressing the roots of health inequity look like in practice? At BH&C’s May 2017 Symposium, Community Agency & Health, the session Designing and Testing New Business Models, facilitated by Jodie Lesh of Kaiser Permanente described one such effort. I was inspired by her presentation describing how staff realized Kaiser was underserving key South Los Angeles communities. Despite having more members than wealthier communities, South Los Angeles did not have the equivalent number of doctors and facilities. Kaiser found it was unintentionally reinforcing the structures and beliefs that often prevent services and economic opportunities from being located in communities, particularly communities of color, which have been historically disadvantaged. This prompted Kaiser to go against the forces that traditionally drive their work, and to do things differently to correct the problem.

Echoing the 12 Principles, one of NACCHO’s partners, Human Impact Partners, has developed a full range of strategic practices rooted in the theory that to systematically dismantle the patterns of othering and exclusion in government practice, we must pursue wall-to-wall transformation of how local health departments work, internally, with communities, and alongside other government agencies. This inside/outside approach requires health departments to build internal capacity and a will to act on the social determinants of health and health equity.

These practices clearly align with the 12 Principles and are articulated in HIP’s HealthEquityGuide.org website, a remarkable resource with inspiring examples of how health departments have advanced health equity, both internally (within their departments) and externally (with communities and other government agencies). Of particular note are more than 25 detailed case studies from departments that describe how they advanced their practice, as well as more than 150 resources from allied organizations and others to advance the strategic practices. The Health Equity Guide clearly documents how the 12 Principles are made real in communities.

A local health official once commented that the role of local public health is to be the mirror and conscience of the communities they serve, bringing the health and health disparities data to the community to raise awareness of what needs to be addressed and the consequences of inaction.

For local public health to truly support community agency, this consciousness raising needs to be done in coalition with the communities they serve, respecting not just professional knowledge, but also community knowledge. By acknowledging that communities have agency, rather than conceiving of residents as victims who need our help, we can contribute to some of the key elements that cultivate community agency: transparency, full participation and accountability for decision-making.

Chris Aldridge serves as the Senior Advisor over the Public Health Infrastructure and Systems portfolio at the National Association of County & City Health Officials (NACCHO). He oversees the programmatic areas of Public Health Transformation, Performance Improvement, Leadership & Workforce, Health Equity & Social Justice, and Research & Evaluation. Chris’ work includes supporting NACCHO’s response to Public Health 3.0 and building the capacity of local health officials to become community health strategists. In addition, he oversees work related to public health financing and is engaged in behavioral health issues. Chris previously served as the Senior Director for Infectious Disease and Informatics at NACCHO.
Appendix 5.9 | An 11-Part Series Reflecting on Our Symposium (cont)
Fostering Agency Through Local Public Health

Peter L. Holtgrave is the Senior Director of Performance Improvement at NACCHO, where he oversees performance improvement programs and services for local health departments and their cross-sectorial partners. Mr. Holtgrave brings over 15 years of public health expertise, including serving as the National Health Manager at the OASIS Institute, a national nonprofit focused on healthy and productive aging, managing the evaluation of the Healthy Kids, Healthy Communities national initiative, funded by the Robert Wood Johnson Foundation, and directing programs for the Boston Public Health Commission.

Andrea Grenadier joined NACCHO in October 2015, and is a communications specialist supporting Public Health Transformation and the Public Health Infrastructure and Systems team. Previously, she was freelance editor and writer, with clients ranging from ad agencies and academia to nonprofit organizations and authors. From 2007-2013, Grenadier served as a development specialist for international and domestic programs at American Councils for International Education. She worked for over 25 years in communications, promotion, media, and public relations for the public television and radio industry for the Public Broadcasting Service, public radio’s Development Exchange, and public television’s lobbying group, Association of Public Television Stations.
Fostering Agency to Improve Health and Social Participation in Mexico

Part ten of the 11-Part Series Reflecting on The Symposium

By Catalina A Denman, Elsa Cornejo and Rodrigo Cornejo

While some headlines paint Mexico as an emerging, middle-income country with sound government institutions, the real picture is more complex. During the last decade, Mexico has endured an armed conflict, considered to be among the most violent in the world, and a stubborn poverty rate of around 50% of the population – both of which make participation in common and public affairs very difficult or outright impossible.

Mexico’s struggles stem from a 70-year legacy of one-party rule, a complex relationship with the United States (i.e. trade dependency combined with the drug war), general distrust of all institutions, and a populace understandably disappointed by poor public services, national politics, and common affairs in general. The challenge, as in many Latin American and middle-income countries, is to spur citizen participation – to purposefully work to define and build equity and justice for all social sectors in all development areas.

At the Community Agency and Health symposium we were encouraged by examples from projects in South Kern, in California, and the Northwest Bronx, in New York, describing the collective efforts of communities to improve health. This article draws on two examples of how we have also used the 12 principles for fostering agency – as described by Bridging Health & Community – to improve health and social participation in Mexico.

Meta Salud Diabetes

The first example is Meta Salud Diabetes (MSD), a community-based educational program for people with diabetes that provides basic information on how to manage their condition and encourage them to leverage personal and community resources. It was developed as part of a community-based participatory research project that brought together academia, communities and government institutions.
Fostering Agency to Improve Health and Social Participation in Mexico

– a significant achievement considering that health research, community mobilization and government programs in Mexico rarely intersect. The researchers started from previous evidence-based programs, consulted with local communities of practice, and ensured the program met with government guidelines. It was then implemented by the health system’s existing chronic disease self-help groups.

MSD operates on several socioecological levels. At the individual level, the program teaches skills necessary for adopting and maintaining healthy habits, and addresses the way in which context – including the availability of healthy foods and the ability to engage successfully with the health system – affects an individual’s ability to make healthy choices.

At the community level, the program includes mapping neighborhood resources, including identifying members of the community as a resource. In neighborhoods where residents do not live close to their extended families – their traditional source of support – this work helps to create a sense of community and encourage participants to organize collectively. It also encourages them to interact with health workers beyond the consulting room.

At the institutional level, MSD was designed to enable community health workers and other front-line health personnel to move beyond individual, disease-based health education to a more holistic focus on community health promotion. This includes the facilitators within the chronic disease self-help groups who, traditionally, do not receive training. In addition to training, the facilitators receive a Handbook (and the participants, a Workbook) that not only includes information on self-care but also promotes patient participation and encourages the community to organize.

Two Challenges

Our experience in implementing MSD in the state of Sonora has taught us that it is very difficult to make individual changes in the face of vast power imbalances – specifically the influence of the food industry, the unwieldy bureaucracy of the health system, and the inequality and lack of access to resources that is inherent to poverty.

Another challenge is engaging people with diabetes in a discussion on how health is a human right and that they should demand quality health care services and systemic change. This was what the population affected by HIV did in the 1980s; they recognized that eradicating HIV required community organization, not only to guarantee access to free prevention and treatment services, but also to reduce stigma and homophobia. For the population affected by, or at risk of, diabetes in Mexico, this sense of urgency and organization for systemic change is yet to emerge.

Wikipolítica

The second example is Wikipolítica from the state of Jalisco. In 2015, a group of about 12 young adults, mainly college students, decided to organize an all-volunteer grassroots campaign to run for the State congress. They championed basic principles meant to restore trust in politics as a tool, such as respect for human rights, radical horizontal democracy (see PDF), gender equality and, perhaps most importantly, localism – the belief that the local population has a share and say in solutions for its community.

Coached by several prominent academics who broke a taboo in academia by getting into politics, Wikipolítica went from being a group of young adults with little political experience to a group of devoted volunteers who taught other groups how to politically impact their surroundings. A victory over old political parties, using a few thousand dollars from clearly identified donors, was a victory for transparency and radical grassroots democracy.

Pedro Kumamoto, the Wikipolítica candidate, is now a national example of how people want their politicians to be. Some clear examples of his impact in public health include successfully rallying people to vote in a referendum on whether a bike lane should be removed from the city and sponsoring a bill to foster transparency, quality assurance and the use of non-polluting buses in the city’s public transport system (traffic-related pollution significantly impacts the health of millions of people in Jalisco).

Guarded Optimism

Based on these, and similar experiences, our attitude is one of guarded optimism. On the one hand, the political history of Mexico, and the institutions it led
to, have not been conducive to fostering agency among individuals and communities. On the other hand, MSD and Wikipolítica provide examples of how the landscape is beginning to change.

Last year, when a 7.1 earthquake shook central Mexico killing hundreds of people the citizenry organized within hours of the quake, quickly overtaking the official response. On reflection, we see it as a nod to BH&C’s third and fourth principles – ‘appreciate the arc of local history’ and ‘elicit, value and respond to what matters to community residents’.

The earthquake struck on the exact same day as a destructive 8.1 earthquake 32 years earlier. The government’s response was inept, contributing to the deaths of 20,000 people. Aware of their history, the residents rose to the challenge, not only by helping one another but also by showing the government that they would not stand for the kind of failings their communities had endured in the past – a glimmer of hope made possible by increased agency.

Catalina A. Denman is a professor-researcher at the Center for Health and Society Studies at El Colegio de Sonora, in Hermosillo, Sonora, Mexico. She is currently the Co-Principal Investigator on the NIH-funded project, ‘Tools and practices to reduce cardiovascular disease and complications in the diabetic population of Mexico’, and has written articles, chapters and books on health issues including non-communicable disease prevention and health promotion, gender, reproductive health and working women, border health collaboration, primary care, self-care practices and qualitative research methodology.

Elsa Cornejo is a Research Associate at the Center for Health and Society Studies at El Colegio de Sonora, where she has collaborated on research-action projects on issues such as chronic disease prevention, community health promotion, sexual and reproductive health, and gender and health. She currently coordinates field activities for the Center for Health Promotion in Northern Mexico, a collaborative project between El Colegio de Sonora and the University of Arizona’s Zuckerman College of Public Health. In addition to her research, she is an activist and community promoter on health and human rights issues.

Rodrigo Cornejo has a degree in International Business from the Universidad de Guadalajara. He is a member of Wikipolítica Jalisco, an all-volunteer organization that fosters participation in political affairs. He has championed transparency and the fight against corruption in Mexico for over 5 years. He’s currently running for office as an independent to win a seat in the federal Chamber of Deputies in the upcoming general election.
The Inside Game

Part eleven of the 11-Part Series Reflecting on The Symposium

By Erin Hagan

‘Bridging Health & Community’, the name poses a dichotomous worldview. On one side, there are the institutions; on the other, the community.

I spent the first half of my career working on the community side of the dichotomy. At one point, my primary job was to train government institutions about how to meaningfully engage with community members. I even helped create a tool to facilitate this process – the Community Engagement & Participation Checklist – based on the principles of participatory community change.

Then, about eight years in, I made a career shift that landed me on the institution side. Happily, I found myself in an institution that prioritized and practiced community partnership. One of the first things I learned, however, was that the principles I had been promoting for years were just that - principles. They didn't play out so well in practice - especially in government (and government-funded) agencies; there are all sorts of rules and regulations about how resources may be allocated, which, ironically, often pose barriers to practicing the principles of community engagement.

Serendipitously, being able to see things from inside institutions makes it possible to understand what tactics to employ in order to elicit change. This is the unique opportunity the Bridging Health & Community (BH&C) team – as members of the health system – can capitalize on.

There is no shortage of non-profits advocating on behalf of community engagement, empowerment, and self-determination. Indeed, many of these organizations were represented at BH&C’s May 2017 symposium, Community Agency & Health. What there is a dearth of is participation from the health care sector in these dialogues. And I’m not referring to the community benefits or the social responsibility departments, but the business operations, care delivery, and coverage providers. This is where Bridging Health & Community is best poised to add value.
Appendix 5.11 | An 11-Part Series Reflecting on Our Symposium (cont)

The Inside Game

The mix of participants and programming at the symposium didn’t quite hit this mark. Despite a comment from one of my tablemates that every face in the room was new to him, they were mostly familiar to me, and mostly representing the community perspective. The programming seemed geared toward making the case for building community agency, yet most participants were already convinced of this. This isn’t to discount the value of the convening altogether. It was clearly carefully planned and well-executed, offering interesting and engaging content. But I’m not sure it achieved its full potential.

Fortunately, Bridging Health and Community is still in its nascent stages; and the need and opportunity are still ripe to capitalize on their connections in the health care sector. The team has the experience, perspective, and relationships required to create that bridge between the sector and the community. It just might require a slight shift in approach – to leverage their understanding of how to navigate and influence the health care system in order to move beyond the principles and achieve the goals of fostering agency and improving health.

Erin Hagan is the Deputy Director for Evidence for Action - a national program of the Robert Wood Johnson Foundation. Over the course of her career she has worked across a variety of sectors including non-profit, academic, and public. Prior to joining E4A, Erin was the Policy and Government Affairs Manager for the San Francisco Public Utilities Commission. She also previously worked with PolicyLink – a national social and economic equity advocacy organization. Erin started her career working with youth in the North End neighborhood of Hartford, CT. She earned her PhD in Kinesiology from the University of Connecticut, her MBA from Seton Hall University, and her B.S. in Nutrition and Fitness from the University of Missouri.
Appendix 6 | Our View to Grantmakers In Health
It is Time to Place an Explicit Focus on Agency
It is Time to Place an Explicit Focus on Agency

Our View to Grantmakers In Health

By Pritpal S Tamber

There is a risk that initiatives resulting from the health sector’s growing enthusiasm for influencing social determinants will be too limited to meet the mark because they leave out the knowledge and power of those most affected by the very challenges they intend to address. To truly embrace meaningful and effective solutions, there are key ways in which philanthropy could play a pioneering role.

The Limitations

An example of how this risk might play out can be seen in how population health has fallen short of its potential. In its origins, population health asked us to think not only about health outcomes within a group but also the reasons for differences in those outcomes. This opened up the possibility to examine the influence of people’s day-to-day choices, environments, and social circumstances—the social determinants of health. However, many population health initiatives are about delivering medical care to more people, leaving little space to address other factors except as context for people’s ability to consume care.

The concept of value-based health care provides a similar lesson. In its origins was the possibility to have a conversation about what matters to people. This would have revealed that retaining health, which increasingly means living with chronic illness, is only one of many priorities people juggle, along with things like economic security, family support or spiritual nourishment. We would have seen health for what it really is—a means to the ends that people value, not the end itself.

What is limiting in these examples is that both continue to view health as primarily the concern of the health sector—despite increasing awareness that the vast majority of our health comes down to our day-to-day choices, environments, and social circumstances. As long as the health sector is the main driver of the conversation, the resulting work drifts towards sickness, too narrowly defining what we measure and remunerate.

What People Value

Work on the social determinants of health needs to involve other sectors, but also needs to be framed by what people value. It is a basic tenet of influence and change that you start from what people care about. This has been my focus since being the Physician Editor of TEDMED 2013 convinced me that little of the innovation in health was likely to affect those suffering the worst health outcomes—those in the most difficult social circumstances.
For the past four years I have spent time with almost 100 innovative practitioners, looking for patterns across their work. Along the way, I cofounded a nonprofit and we have gleaned 12 guiding principles for what it means to genuinely and effectively work with communities. The principles describe a way of working—new to many in health—that is inclusive, participatory, and responsive.

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 is as much about narrative, process, and relationships as it is about resources.

Beyond Risk Factors

As these principles surfaced, I asked myself what they were for. Sure, they describe a process but what is the product of that process? The many practitioners I have spent time with have taught me that what matters is whether people are engaged, able to think beyond the present, and confident they can affect the world around them. I learned that this can be summed up as having agency – the ability to make purposeful choices.

The concept of agency has sat squarely in the research that is now packaged as the social determinants of health. Risk factors—whether personal, environmental, or social—explain less than half of why people are healthy or sick. The rest seems to come down to whether they have a sense of control over their lives, which requires agency. And yet we rarely see fostering agency embedded in work trying to influence health.

It is time to embrace the importance of agency. You can see it from the perspective of the research or you can listen to courageous practitioners working deeply with communities. Agency matters.

Philanthropy’s Role

The field of practice capable of fostering agency needs to be supported. What does it take to apply the principles we have described into practice? What are the challenges and what can we create to overcome them? How do we get more people trying? And how do we evaluate this kind of work, without limiting its success to sickness-defined health outcomes?

If philanthropy is to support this work it must also look in the mirror. How well do its processes align with the 12 principles, and hence the importance of fostering agency? In our experience, governance structures are very much at odds with the principles, as are accountability frameworks—most of which lean heavily towards sickness-defined outcomes. Both diminish agency.

Without an explicit focus on agency, most current work on social determinants of health is likely to fail. It will become yet another strategy subverted by seeing it only through the lens of the health sector. Philanthropy can help avoid this. Not only by providing the patient, long-range capital needed to grow the field of practice, but also by changing how it operates.

Pritpal S Tamber is the CEO & Co-Founder of Bridging Health & Community. This article was first published as a ‘View from The Field’ in Grantmakers In Health’s monthly newsletter and then republished on Bridging Health & Community’s website.
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