

# Engaging People with Lived Experience of Inequity: Relationship Building



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## Engaging People with Lived Experience of Inequities: Relationship Building

This Relationship Building guide is part of a series of papers that includes the following:

### **Engaging Community Members with Lived Experience: SCALE 1.0 Synthesis Report**

Coleman S, Byrd K, Scaccia J, Saha S, Schall M, Callender S, Anderson J, Behrman N, Budnik A, Smith D, Brown L, Douglas W, Bussey R, McDermott E, Munene E, Mullin F, Hatchett L, Pohorelsky J, VanLanen T, Pairolero B, Mann Z. *Engaging Community Members with Lived Experience: SCALE 1.0 Synthesis Report*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2017. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

### **Engaging People with Lived Experience of Inequity: Assessment Tool and Resource Guide**

Rumala BB, Coleman SE, Roary Y, Canedy C, Turk A, Knuckles D, Glaze E, FallCreek S. *Engaging People with Lived Experience of Inequity: Assessment Tool and Resource Guide*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

## About the SCALE Series

This Relationship Building Guide grew out of a collaboration between organizational leaders and leaders with lived experience from multiple communities nationwide. The People with Lived Experience Co-Leadership Team committed to digging deeper into how best to engage people with lived experience in community improvement as partners in 100 Million Healthier Lives. This work began in 2017 when a group shared their experiences of best practices for engaging people with lived experience during the Spreading Community Accelerators through Learning and Evaluation (SCALE) initiative of 100 Million Healthier Lives. The results of this discussion were shared through an [Engaging People with Lived Experience Toolkit](#) and SCALE 1.0 Synthesis Report<sup>1</sup>. After applying that learning in a network of communities, we found ourselves motivated to dive even deeper into the practice of engaging people with lived experiences in all communities.

To make the community-based work possible, 100 Million Healthier Lives has collaborated with many partners, each of whom brings unique expertise and knowledge. These partners include, but are not limited to:

- SCALE Communities
- SCALE-Up Communities
- SCALE Coaches
- SCALE Implementation Team
- SCALE Evaluation Team
- Institute for Healthcare Improvement
- Georgia Health Policy Center
- Heluna Health

In this guide, you will find stories that demonstrate real-life experiences, a collection of definitions to ground you, and “bright spots” that will give you and your participants the confidence you need to implement effective change in your community.



<sup>1</sup> Coleman S, Byrd K, Scaccia J, Saha S, Schall M, Callender S, Anderson J, Behrman N, Budnik A, Smith D, Brown L, Douglas W, Bussey R, McDermott E, Munene E, Mullin F, Hatchett L, Pohorelsky J, VanLanen T, Pairolo B, Mann Z. *Engaging Community Members with Lived Experience: SCALE 1.0 Synthesis Report*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2017. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

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## Executive Summary

To build lasting change — whether in an organization or in a community — requires intentionality. Bringing intentionality into improvement takes practice and work. Building relationships that advance equity takes time and commitment from everyone who is engaged, including those who experience inequities every day and those who benefit from privilege and relative power. This implementation guide explores relationship building and offers resources, reflections, and tools for action. Each of these components will guide you on your journey to strengthen existing partnerships and build new relationships in your work.

Community of Solutions<sup>2</sup> (CoS) is a framework, anchored in co-design, that supports communities to nurture behaviors, processes, and systems that, over time, result in a Culture of Health. A Culture of Health sustains improvements in health, well-being, and equity. Understanding the CoS framework will support efforts to achieve more meaningful relationships with your community and your team. Concepts that may seem unfamiliar, such as teachable moments, lessons learned, and “bright spots,” will be explained and illustrated. Leadership skills for engagement, such as Leading from Within, Leading Together, Leading for Outcomes, Leading for Sustainability, and Leading for Equity, are pillars of the CoS framework.

Each of these pillars entails best practices for engagement and illustrates how to prioritize and build on the lived experience of community members. This guide features the shared experiences of the entire team to show how centering the expertise of individuals who are systematically marginalized improves relationship building, creates community engagement, and drives improvements that are valued by the community.

Through a collaborative process of co-leadership and co-design, the team that created this document was able to form deeper relationships. We, the team members, conducted listening sessions and shared our lived experiences with community members. Together, we encouraged each other through periods of hardship, and shared innovative new ideas and tools to bridge the equity gap.

The team members who created this resource understand the inequities that illustrate the need for it. From experiencing housing insecurity (homelessness), food insecurity, job insecurity, financial insecurity, racism, discrimination, and myriad personal, family, and health obstacles, this group is deeply familiar with the many dynamics that should be considered when working with people. Our own lived experience, and the experiences we carry from our communities, constitute our expertise. These challenges helped the People with Lived Experience (PLE) Co-Leadership Team to pour our hearts into change.

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<sup>2</sup> Saha S, Howard P, Lewis N, McPherson M, Schall M. *Foundations of a Community of Solutions: SCALE 1.0 Synthesis Reports*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement, 2017. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

“For in all of us there is a destiny tied to someone else. Let us love, share, and give, that we may grow in greatness together.” - Yolanda Roary

“Sharing our lived experiences brings the faceless issues to the heart to promote change.” - Bernice B. Rumala

“Be a mirror alongside others, when they cannot see the brilliance within themselves.” - Shemekka Ebony Coleman

**Yolanda Roary, MA**



**Bernice B. Rumala, PhD**



**Shemekka Ebony Coleman, MS**



## A Letter to Community Champions

### DeAngelo Knuckles, Community Champion

Hello, I can't help but notice the positive energy that you have. It seems that you're genuinely passionate about your neighborhood. A Community Champion is who YOU are! Standing up to be seen, making a difference, or just having great ideas in the background for a neighborhood of unity. Just like most of the communities around the country, it's safe to say so many familiar things have changed. Change can be good or bad, so what keeps you going, Community Champion? What makes you stay? Community Champion, what do you think we can do to make this community a little better? We want ideas, no matter how big, but we also want to know the small things because they get overlooked. What resources is this community full of so we can stand on them right now? And what resources do we need to continue improving and attracting more Community Champions like yourself? There is so much diversity of people in the neighborhood, but the neighborhood is sustained by people like you. Community is built by people like you and it's the reason communities grow. The neighborhood needs you, Community Champion, we need you and thank you!

Community Champions carry an inward passion and drive for equity and wellness in their community. The vitality of a Champion's presence is immeasurable. Community Champions are a voice for the voiceless. With an intention to educate government officials and organizations that exhibit discrimination or lack of awareness of need, Community Champions are on the front lines, advocating and encouraging. Going against the grain is a common practice for Champions as they reveal hidden policies and practices. Champions fight for what's right, offer shoulders to cry on, and listen to the unheard with compassion. Every community needs a Champion!



## Pre-relationship and Relationship Building Overview

### Engaging People with Lived Experience in Pre-relationship and Relationship Building

People with lived experience have a unique, critical role in the relationship building process. They understand inequity because they have lived with it. They bring distinctive perspectives to the work of identifying and delivering equitable solutions. These equitable solutions emerge in both the early and later stages of relationship building when PLE are involved in co-leadership and co-design. Co-leadership and co-design in the relationship building stage help to strengthen the partnership through equitable shared decision making and expansion into new ways of thinking about solutions. The practice gives both credibility and authenticity to the solutions that are developed.

### Lived Experience as Expertise: People with Lived Experience are the Experts

Lived experience is defined as expertise that comes not from training or formal education but rather from personal experience with an issue or challenge. People with lived experience are the experts. They know a system, process, or issue from the perspective of those affected by it or trying to engage with it. PLE know what is likely to work in the real world of day-to-day community life. They also know what is not likely to work and what might be modified to give improvement a better chance. They are often knowledgeable, especially collectively, about what resources (formal or informal) may be available to advance desired changes. PLE know what's needed to make things better.

When we refer to PLE throughout this document, we are identifying a way of understanding people that you may be seeking to engage in improving health, well-being, and equity in your community. These individuals also may choose to identify themselves in a different way, and you may learn a new term to describe their role.

### The Joys of Relationship Building

Relationship building, including the pre-relationship stage, is a rewarding process. Pre-relationship building refers to the preparation process and early-stage connections, such as encounters leading up to the first collaboration meeting. For example, a community organization or community leader may wish to form a team to address improvement in their community together. Early-stage connections create space to build familiarity, commitment, and trust, and to introduce activities that lead to stronger relationship building. Relationship building is the nurturing of ongoing relationships from the initial collaboration meeting and beyond.

Increased attention to pre-relationship and relationship building pays off in the long term, with benefits such as less attrition in participation, greater success in meeting shared goals, establishing buy-in, and promoting advocacy when it comes time to implement change. When this is prioritized, the gains far outweigh the challenges.

Relationship building creates opportunities for insight into fresh perspectives, and for strengths and gifts to emerge that will make the work more meaningful and effective. This is especially true for people with

lived experiences of inequity. Prioritizing this process deepens people's commitment to the work, and creates a climate for honest communication. Engaging people in these early stages of design and planning expands everyone's thinking and helps make sure the group doesn't miss key opportunities or solutions. Early engagement also promotes mutuality and fosters an environment where ongoing co-learning, co-leadership, and co-design can be nurtured in all stages of the change efforts.

The relationship building process yields both personal and professional benefits to individual participants. These benefits include identifying opportunities to improve your health and well-being as well as your team's. If an atmosphere of safety is established in the relationship building stages, then the group will find ways to challenge each other when needed — for example, to decrease implicit biases and deepen commitment to the work. These Leading from Within skills also enhance our own sense of connection to individuals and communities, which strengthens our own commitment to the work.

Strong relationships with people with lived experience create champions who will ensure that co-designed change ideas are well-received in the community. The team puts a great deal of time and effort into generating ideas, and if people with lived experience co-design and co-lead the improvement initiatives, they can help make sure that these ideas are not rejected by the community. Focusing on relationship building further expands social networks, ultimately increasing the community's ability to reach more people in the health improvement work. Investing time in these stages is key to ensuring that health improvement plans don't just sit in a professional-looking report on a desk, but that they are actually implemented and truly of benefit to those most in need.

## Key Steps for Implementation

From listening sessions with the PLE co-leadership team and external facilitators, partners have determined that meeting navigational guidance needs will be key to moving the work forward. Therefore, both existing and proposed resources are included as part of the pre-relationship assessment tool based on types of need. Areas of potential navigational guidance are highlighted in the assessment tool and resource guide.

## What tools and resources are available to help me?

The People with Lived Experience Co-Leadership Team conducted listening sessions to explore community needs in terms of relationship building. Several themes arose from this session, including the need for a pre-relationship building assessment. As a result, the team created an assessment tool and resource guide to enable communities, organizations and individuals to assess where they are in the following areas: engaging people with lived experience, ensuring everyone's voice is heard and their value recognized, resources, co-design, and process. Existing tools/resources, new tools/resources, and navigational guidance resources are provided as part of this assessment to enable implementation towards action (Rumala, Coleman, Roary, Canedy et al., 2020).

## Community of Solutions Framework and Relationship Building

Over the last few years, SCALE Communities have implemented the CoS framework and built the skills to operationalize it. These skills enable communities to develop a set of behaviors, processes, and systems that, over time, lead to sustainable improvements in health, well-being, and equity (Saha, 2017). The skills focus first on individuals and how they work together with communities. The foundations of the framework are described in the Overview of SCALE and Community of Solutions<sup>3</sup>.

In this implementation guide, we contextualize the CoS framework specifically for relationship building in local and global communities. This intentional relationship building creates capacity to focus on equity, outcomes, and sustainability. Without the pre-work on relationships, we have found that communities struggle to achieve sustainable results. Utilizing the CoS framework leads to a Culture of Health. The CoS framework includes five categories: Leading from Within, Leading Together, Leading for Outcomes, Leading for Equity, and Leading for Sustainability. The CoS skills highlighted in this guide illustrate how to embed relationship building into every level of the work.

### Leading from Within for Relationship Building

This concept involves the inner journey of a leader in health equity work. Self-awareness of individual strengths and areas for growth allows for people to demonstrate vulnerability and can unlock the leadership potential of others.

SCALE Communities learned over time to approach the work from a place of abundance, even in the midst of scarcity. An abundance mindset helps illuminate the value in our collective diversity. Knowing oneself and what inspires people to leadership (including biases and areas for potential growth, or “growing edges”) is essential. This process opens groups up to humility. At times, this means using instances of perceived “failure” as an opportunity to grow. When individuals learn from what could have gone better, they are able to embrace change (Leading Together).

### Leading Together for Relationship Building

We are all in this together, and the work is more rewarding as relationships deepen and as we understand that mutuality. Leading Together skills are grounded in a perception of the community as a dynamic network of people, organizations, structures, and systems that are linked to a place. It is necessary to lead together with all individuals who affect or are affected by a community to create equitable change.

#### Elements of leading together

- Developing trust
- Building relationships and interconnectedness
- Effective teamwork
- Inclusive collaboration (including creating a “brave space” for collaboration)
- Asking open and honest questions

<sup>3</sup> Saha S. *Overview of SCALE and a Community of Solutions*. SCALE 1.0 Synthesis Reports. Cambridge, Massachusetts: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement, 2017. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

Each of these elements influences the relationship building journey and will be utilized often as your collaboration efforts progress.

Part of Leading Together is honing facilitation skills to cultivate the leadership of others. As relationships grow, communities develop greater ability to have difficult conversations when needed and to appreciate the value of differences. Through this piece of the framework, communities may gain an ability to be at peace with potential conflict, which ultimately leads to growth. This ability is called holding tension in life-giving ways. Community members who are part of this process each have a sense of personal voice and agency from the Leading from Within skills, and they build capacity to create community and accomplish sustainable outcomes together.

### **Leading for Outcomes for Relationship Building**

This supports communities in applying design thinking skills to co-create a theory of change. This work includes identifying measures, testing theories, and planning for implementation and scale-up in a way that makes these tasks easier. While Leading for Outcomes involves design thinking and implementation science skills, these tools will result in less meaningful results without strong foundational work in Leading from Within and Leading Together. Basing the work in relationships, we can test interventions that are actually meaningful to the people who need them the most. Getting to results is one of the best ways to build lasting bonds with people. The satisfaction of accomplishing change together keeps communities progressing and ultimately facilitates Leading for Sustainability.

### **Leading for Equity for Relationship Building**

This focuses on health improvement for those who need it most while also addressing equity at a structural level. Equity is defined as a set of conditions in which all people have the opportunity to attain their highest possible level of health and well-being, without barriers that prevent them from doing so. In the Community of Solutions framework, Leading for Equity is nearly impossible without the pre-relationship steps related to Leading from Within and Leading Together. The time devoted to this stage ensures that our communities are addressing equity in a meaningful way and designing solutions that make sense for those most affected by inequities.

### **Leading for Sustainability for Relationship Building**

This facilitates an ongoing process of transformation in a community through four key elements: environmental (physical, political, cultural); resources (will for change, financial support); people (cultivation of leaders); and change (growth in the change process). Our relationships with people and communities influence all of the elements within Leading for Sustainability. Health improvement work that started as a new idea or project may actually transform into a practice or policy. Our goal in Leading for Sustainability is to transform the work into fundamental and lasting systems change. Such change will never happen without foundational pre-relationship work with people with lived experience.

## Landmine Challenges to Avoid in Pre-relationship and Relationship Building

Although there are many joys in the pre-relationship and relationship building process, the process can still have complications. Collaboration between individuals with intersecting identities can allow for new ideas to emerge; yet working with individuals from different backgrounds can lead to questioning one's value in a collaborative space. Challenging individuals to grow together can lead to intersecting strengths as well as insecurities. A few examples of common responses are highlighted in the image below:



### Why can't we all just get along? Why can't we all agree?

Often in meetings, differing opinions emerge. Acknowledging and working constructively with these differences can lead to exceptional insights and strong solutions. It is important to understand the techniques and resources available to navigate these dynamics at the beginning of the process and as it continues. We will see this point explained further as a teachable moment from the Livewell Kershaw Access to Care workgroup.

#### Tools for Action:



- [Engaging People with Lived Experience of Inequities: Meeting Facilitation Guide](#)
- Community of Solutions Skill(s): Leading from Within; Leading Together

## Is it safe to share?

Once a meeting is planned and an agenda is set, there is often little flexibility. When meetings are tightly focused on getting through the agenda, people may be reluctant to share important information or feelings. When a person has something to contribute in a meeting that was not previously approved to discuss, too often it will go unaddressed or will be allowed but managed in a way that makes sharing uncomfortable. Sometimes even when your opinion has been solicited, you may be unsure whether sharing comes with a cost. Questioning whether you can feel safe to share is fueled by lack of trust in the group, seeing poor outcomes for others when they speak up, and having experienced or witnessed subtle and/or overt retaliation for speaking one's own truth.

### Lived Experience Story from the Field: Is it safe to share?

**Problem:** A community member did not feel that their community environment was a safe place to share. When this community member shared their story in the past, others began using the story to get money from funders, while this individual did not receive any of these benefits. The individual lost control and ownership of their own narrative and felt further isolated from the work in the community. Eventually, the individual and their family heard a presenter share their story in front of an audience. The family felt uncomfortable hearing the story presented to this audience without their consent. The presenter did not recognize that this individual was in the room.

This problem highlights how organizations profit from individual stories of oppression. In this specific example, this individual was able to grow and become a leader. Yet the community members felt as if only their stories of oppression were valued instead of the unique contributions they have made to further the work. The fact that an organization can receive funding to improve the lives of individuals who have experienced inequity, and yet those very individuals are often exploited for their stories, brings up a unique power dynamic to consider when conducting this work.

It is important to prevent exploitation in the pre-relationship and relationship building process. This means receiving permission to share stories and photos and keeping equity at the forefront in terms of funding and shared decision making. It includes frequently checking for consent, compensating individuals as appropriate, and seeing value in a range of contributions and skill sets.

### Tools for Action:



- Touchstones<sup>4</sup> & [Habits of the Heart](#)
- Engaging People with Lived Experience of Inequity: Assessment Tool & Resource Guide<sup>5</sup>
- [Engaging People with Lived Experience of Inequities: Meeting Facilitation Guide](#)
- Community of Solutions Skill(s): Leading for Equity, Leading from Within, Leading Together, Leading for Sustainability, Leading for Outcomes

## Is my work valued?

This feeling may arise when there is a lack of relationship and trust, even though trust building is in progress. This feeling also arises when responsibilities are not equitably shared, when organizational hierarchy is present, or when workers/partners feel that their contribution is not appreciated.

<sup>4</sup> 100 Million Healthier Lives Touchstones for Collaboration. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

<sup>5</sup> Rumala BB, Coleman SE, Roary Y, Canedy C, Turk A, Knuckles D, Glaze E, FallCreek S. *Engaging People with Lived Experience of Inequity: Assessment Tool and Resource Guide*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

## Lived Experience Story from the Field: Valuing presence but not compensating for time

“As a community member with lived experience, I remember working with existing and new community organizations that wanted to connect with the community and include the community in its redevelopment process. The organizations received a lot of kudos and accolades for such wonderful efforts to connect with the community, which helped them get access to more funding. However, there seemed to not ever be an opportunity to be compensated for my work in its success. I was asked frequently to facilitate meetings and speak, until I spoke up about feeling undervalued. I would prepare and present packages of how my engagement work could be done better with more than the \$100 a month compensation I was currently receiving. I felt they would listen to my ideas but choose someone else to do the work or hire more reputable engagement firms instead. I also felt that I wasn’t invited into the meetings where money was involved, just the meetings to get the community on the ‘same page.’” - Shemekka Coleman

When beginning the journey of engaging community members, look hard and creatively at how your organization can ensure value-based compensation for community members wanting to support community improvement. This may mean reallocating the current budget. Creating Communities of Solutions must begin with everyone at the table being seen as a valuable contributor.

### Tools for Action:



- [DVHSC Advocates Program Sample Compensation Policy](#)
- Touchstones<sup>6</sup> & [Habits of the Heart](#)
- [Reinventing Organizations, by Frederic Laloux](#)
- Engaging People with Lived Experience of Inequity: Assessment Tool & Resource Guide<sup>7</sup>
- Community of Solutions Skill(s): Leading Together; Leading for Equity; Leading for Sustainability

## Does my opinion matter?

In some organizational partnerships, there are moments when partners may feel that they have no voice. Feelings of insecurity may stem from being new to the team, or from recalling negative consequences for others who exercised their voices in the past. New collaborations should consider developing touchstones reflecting that everyone has value.

### Tools for Action:



- [Interview with Suzette Shaw, Lived Experience Expert](#)
- Community of Solutions Skill(s): Leading for Equity; Leading from Within

<sup>6</sup> 100 Million Healthier Lives Touchstones for Collaboration. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

<sup>7</sup> Rumala BB, Coleman SE, Roary Y, Canedy C, Turk A, Knuckles D, Glaze E, FallCreek S. *Engaging People with Lived Experience of Inequity: Assessment Tool and Resource Guide*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))



## What do we do if harm occurs in the group?

If the group is an established one where harm has previously occurred, it is good to acknowledge the harm as a “fail forward” moment and attempt to learn from it together. The group should acknowledge the history of harm and gain a shared understanding of how harm as well as growth have manifested over time. The River of Life activity can be used to help acknowledge one’s history of harm in a visual way. After the group documents this shared history, they may hold a truth and reconciliation roundtable session to engage with individuals who have lived experiences of inequity. If individuals are not aware of historical harms in the space, a mediated restorative justice session can help promote community healing.

If harm happens through an interpersonal dialogue within the group, begin by acknowledging the instance of harm. If the group is facilitated, acknowledge the harm in front of the group, either in the moment (if this group does not meet regularly), or after a conversation with the affected individuals. After acknowledging the harm, connect this instance to ground rules and revisit any adopted frameworks to re-center the space. Check in with the affected individual(s), make sure that they feel supported in the space, and ask if any other steps could be taken to increase that support. Check in with the individual who has committed the harm so that they understand what happened and its impact on the community. If the individual is interested in a path toward healing, begin connecting that individual with appropriate tools and resources.

A tip for group relationship building is to co-lead with vulnerability. By identifying neutral team members who can serve as “safe leaders” during meetings, communities can address harms as they come up. These members should be trained through a trauma-informed lens so that others can approach them at any time. These safe leaders offer support during triggering or difficult activities.

### Tools for Action:



- [River of Life Activity](#)
- [Truth and Reconciliation with Healthcare Leaders](#)
- [Restorative Justice Framework](#)
- [Trauma-Informed Facilitation](#)
- Community of Solutions Skill(s): Leading from Within; Leading Together; Leading for Equity; Leading for Sustainability



"Joy in Co-Design." Ziva Mann and Shemekka Ebony Coleman began their pre-relationship journey in a conversation on a bus at a Community Health Improvement and Leadership Academy (CHILA) in 2016.



## Bright Spots and Teachable Moments

**Bright spot:** A set of activities, an intervention, or a program that a community is working on to improve health, well-being, and equity and that has shown success. It is scalable and shows evidence of the impact of the work on the population or subpopulation in the community.

**Teachable moment:** An event or experience that presents a good opportunity for learning something about a particular aspect of life.

**Community Champions** in SCALE were defined as community members who were also leaders or aspiring leaders in their community. During SCALE, Community Champions were appointed as members of the leadership group or core transformation team in their community. These individuals indicated that they were ready to be actively involved in efforts to improve the health and well-being of their community. They were informal or emerging leaders in their community, or they were ready to step into a leadership role. Most importantly, Community Champions were connected to a group of peers with shared lived experience. One Community Champion's perspective is shared below.

### INSIGHT FROM A COMMUNITY CHAMPION: Teachable Moment

#### DeAngelo Knuckles

##### Who I am:

I am a father. A son. An entrepreneur. A community advocate.

My name is Aaron De'Angelo Knuckles. My first and middle name became interchangeable based on the circle I was hanging in—one was linked to doing things that were bad and the other was linked to good in me. My last name, Knuckles, is a name not allowed to be tarnished because it was not my own. My name also represents family, past and present. A name that has to be honored. I now realize that both my first and second names are just as important to honor because the more I learn about myself, the more I am all of them, DeAngelo and Aaron. Today, I am able to stand up and fight for someone else — an all-important tool. A tool that I did not put into place before.

My people are diverse, falling into no specific categories. My people are based on who I surround myself with. Some of the people that I surround myself with have a thirst to move forward but lack the drive to do so. Some of those that have the drive to move forward but lack the know-how.

Before the SCALE initiative, I already was fighting to get the community healthy. It was the realization of the lack of equity in my neighborhood and community that brought me fully on board to be a change agent. Through SCALE, I could see how equity brings people towards a healthy lifestyle. I wanted that!

Understanding what equity means allows you to see disparities. It's more than just jogging around the corner in your neighborhood. It's so much more than that. My SCALE work is important to me because it provides tools to understand the importance of being healthy. Those same tools help me understand who my allies are and improve my ability to acquire new allies (with relationships).

## SCALE

The most impactful and fondest memory of my SCALE experience began at CHILA 1. We participated in the “Stare” activity, where we had to stare into the eyes of someone that we were paired up with. I was paired up with Somava Saha. I had no idea who she was, nor she of me. The fact that I didn't know who she was made this activity easy for me. Nothing doing, just stare into her eyes. To my surprise, everything came out of that stare! Doubt. Insecurity. Fear. What also culminated from that stare activity was a friendship that will last a lifetime. It was the fastest, most intimate relationship (building) that I ever had! Participating in that activity opened me up to my own judgment of self, worries about self, and hurt from self.

On a SCALE meeting level, no one particular meeting stuck out for me. I'm like a sponge, absorbing so much that no one meeting hit home, just the experience with the people telling me their own stories. The concept of “failing forward” was not apparent to me, not in the way that I live my everyday life. To be able to take someone's failure and to see how they use it to teach others allows us to possibly miss that stumbling block in our own lives, things we can't ever learn in a book.

*An “aha” moment for me* was coming into SCALE. I came with limited knowledge based on working out — being physically active in my own community. I began to see how social injustice affects my community and those of others. I saw how multiple factors contribute to injustice. I realized how my community is considered a minority when it comes to application of finding ways to be healthy and stay healthy. The big “aha” is being able to see first-hand how people accept injustices as truths, not even knowing that they are injustices.

### What I learned:

After SCALE, I am fighting to keep the injustices from allowing the community to be unhealthy! I have learned to use the SCALE processes, tools, and people to help me set up for success so that I can help my community thrive in an equitable environment. I feel empowered by SCALE.

*My vision for myself* is that I am dependable, committed, and faithful to my community.

*My vision for my community* is that it will someday be a community full of networks, local champions, and change agents fighting for equality and to cut out disparities. A community that is thriving to get to the next level by looking through a community lens without color. A community that is warm and inviting. A community that has access to resources as well as people to fight for the resources they lack.

*My vision of my contribution* to a Culture of Health and 100 Million Healthier Lives is simply this: talk about it and be about it! It is important to be seen being healthy and assisting organizations with implementation. It is important not only to advocate for fresh food and local food co-ops in the community but also to eat healthy.

I want to be the motivation for people who want to work out and be healthy. I want to create a movement of exercise gurus — people who totally dedicate their lives to being healthy and empowering other people to get to the next level. I want for people to not be afraid of having conversations about the impact of chronic illnesses in our community and then to be activated by those conversations, taking the pain and stain out of it by being healthy.

“It's easier to build strong children than to heal broken men.” - Frederick Douglas

## The 100MLives Way of Conducting Meetings as a Form of Pre-Relationship Building: Bright Spot & Teachable Moment

**Bernice B. Rumala**

Having been used to professional meetings with rigid structures, I was first exposed to a different way of conducting meetings at the 100MLives 2018 Fall Gathering in San Diego, California. In what would be my first of many subsequent meetings with 100MLives (in person and virtual), there was dedicated time for everyone to check in, be present in the moment, and express how one was feeling. I had only heard of this being done at “retreats.” However, with 100MLives, this was meaningfully incorporated into the agenda for each meeting.

This simple incorporation of checking in at the beginning helped to build camaraderie among those present (including myself) for the in-person and virtual meetings I participated in. It helped to create a bond and helped us to understand more about individuals in the meeting beyond the professional side. In essence, it enabled people to bring their lived experience and whole selves to the meeting as part of pre-relationship building instead of wearing only a “professional hat” as is often advocated as part of the professional ethos for many work environments.

This also enabled the group not to have to dissect the myriad identities and lived experiences that we bring to the space in an effort to improve equity. I recall that at one of the check-ins, one of the questions asked was “What brings you joy?” Each person began to share.... One person said taking nature walks, another reflected on how she was glad to spend time with her grandchildren. Sharing during check-ins also became a space for healing and sharing of resources between group members. On one particular occasion, someone had a loss in her family and she was able to share the grief she was feeling while team members provided space for listening and reached out to her with resources. This was unique and truly transformative for me in terms of a gold standard for conducting meetings.

A safe space was also created through sharing of norms and guidelines in the meeting so that individuals were able to share and contribute their lived experiences. We as a group were able to contribute by co-designing elements of the norms, guidelines, and agenda that were important. Most of all, I loved the semi-structured nature of the agenda to enable flexibility, growth, and a deeper dive into elements that may not have been on the original agenda.

In some of the meetings, there was dedicated time to debrief at the end on what worked well and opportunities for improvement. It enabled a richness in discourse that otherwise would not have happened if the agenda were very rigid. As a result, I have seen the success and utilized this meeting format for different populations including PhD students, executive leadership meetings, community meetings, and one-to-one meetings.

I recall in the first meeting I attended, I wondered if it was possible for people to truly bring their whole selves into a meeting and fully share for the benefit of equity. I now know that it is possible as long as a space is created for sharing, co-designing, and co-leadership. One of the first lessons shared, and one that has stuck with me, is “We are all in this together” as we continue this work towards equity.

## Downtown Women’s Center Relationship Building Leads to Co-Design of an Advocates Program: Bright Spot

### Amy Turk

The Downtown Women’s Center (DWC) leads the cross-sector Domestic Violence and Homeless Services Coalition to increase access to safe housing and supportive services for survivors of domestic violence and homelessness. Survivors of homelessness and gender-based trauma are driving the work at all levels of the Coalition. After a year exclusively devoted to building relationships with women who have lived experience, the idea of an Advocates Program emerged. The Coalition fostered relationship building by infusing principles of Habits of the Heart and Community of Solutions into monthly workgroups, quarterly large Coalition meetings, and three day-long CHILAs in Los Angeles. Based on this foundational work, the Advocates decided to design a program comprising four components:

1. Monthly skills-based training in effective advocacy, policy history and context, and how to publicly present their stories.
2. Monthly “business” meetings to study policies, plan for upcoming advocacy efforts, and coordinate logistics with speaking schedules.
3. Monthly peer support group to sustain each other through the emotional aspects of advocacy work.
4. Monthly check-ins with an Ally. Each Advocate is paired with an Ally to help support their learning and create opportunities for mutual growth in our work together in the Coalition.

**Program Theory:** Sharing personal trauma narratives is both an empowering tool for healing and a potential trigger for re-traumatization. With the support of peers and service provider staff attuned to survivor needs, the Advocates Program utilizes co-design principles of *Leading from Within* and *Leading Together* to bolster the healing of Advocates through individually tailored supports, peer support, skills-based training, and systems change advocacy.

**Keys to Implementation:** In the first year of program implementation, we learned that the most important aspects of our work together were attention to readiness to participate, financial compensation (see Relationships and Finances sections), and sufficient peer and staff support. Regarding attention to readiness, the women’s housing and safety needs are currently met, although their healing journey continues. In the relationship building stages of our work together, Advocates frequently mentioned concerns that social service staff were paid for their work in the Coalition while the Advocates were volunteering their time. Financial compensation became non-negotiable for the women, and they are now compensated for their time. Staff set initial compensation parameters based on private grant funding, and the Advocates finalized the compensation policy to match their needs. Lastly, it was important to the women to foster an environment that encourages peer and staff support; they initiated a peer support group and asked to be paired with Allies who were seasoned in their careers to further support their growth.

**Time to Implement:** The program requires 10-20 hours per month of staff time to coordinate and facilitate. Advocates commit to hours ranging from 4-15 per month. Implementation duties include outreach and engagement, agenda setting, reminder correspondence for meetings, meeting facilitation, advocacy education, coordination of advocacy efforts (e.g., meetings with elected officials), scheduling trainings, and communication/coordination with Advocates and Allies. Additional time is needed to help prepare Advocates for conference presentations, media interviews, press conference statements, and signature advocacy events.

**Cost to Implement:** Flexible funding is needed to compensate the Advocates. \$24,000 supports Advocates' time for a year. Payments included \$25.00 for attending monthly educational meetings, \$50.00 for making public comments at City Council or other public meetings, and \$1500.00 per month for one Advocate intern who helped coordinate the advocacy action items, set the agenda for educational meetings, and kept all of the Advocates informed about upcoming advocacy actions. Additional costs include the time of two staff members, one who spent about 20 percent of their time as a coordinator of the Advocates Program and another who provided about 15 percent of their time as a Director who oversaw the content and helped set the strategic direction of the program.

**Partnerships:** Leading together with other Domestic Violence Homeless Services Coalition members is crucial. One key partner is the Corporation for Supportive Housing, a technical assistance housing agency with a strong track record of training advocates with lived experience. They support the program by sharing their curriculum and leading meetings with the Advocates. Other partners include the Allies, such as executive directors and system leaders of nonprofit and government entities.

**Measurement and Evaluation:** Outcomes of the Advocates' experience in the program are measured using the 100MLives Well-being Survey Tool. Advocates use it as a quarterly pulse-check regarding their overall well-being. They discuss the results in the peer support group and in one-on-one meetings with their Allies.

### Tools for Action:



- 100 Million Healthier Lives Well-being Survey Tool (Adult)<sup>8</sup>
- Engaging People with Lived Experience of Inequity: Assessment Tool & Resource Guide<sup>9</sup>
- Community of Solutions Skill(s): Leading from Within; Leading Together



Domestic Violence Homeless Services Coalition Advocates power-pose before making public testimony to the Los Angeles Board of Supervisors for increased funding for housing and services.

<sup>8</sup> Stiefel MC, Riley CL, Roy B. *Well-being Assessment (Adult - 12 items)* — 100 Million Healthier Lives. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

<sup>9</sup> Rumala BB, Coleman SE, Roary Y, Canedy C, Turk A, Knuckles D, Glaze E, FallCreek S. *Engaging People with Lived Experience of Inequity: Assessment Tool and Resource Guide*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))



## Downtown Women’s Center Relationship Building and Finances: Teachable Moment

### Amy Turk

When working with people with lived experience, compensation is crucial in order to respect their time and labor, and to create mutuality in Leading Together practices. Community groups and social service organizations need to factor methods of compensation into their work with PLE. Without financial compensation, hierarchies of power are reinforced. Some PLE may start to feel used, may feel uncomfortable speaking up to staff in paid positions, and, in the worst-case scenarios, may be further traumatized by inequities that play out directly in community work. Many PLE have survived generations of institutional racism and marginalization. They deserve to not feel ostracized, even second-class, without it, and they should not have to ask for it. Social services risk exploiting people for their stories if they do not have financial capacity to support the emotional and skilled labor of PLE.

There are many complexities in this sphere. Social service programs, especially those predominantly funded through government contracts, may not have flexible general funds to provide gift cards, stipends, or paid positions for PLE. Most government contracts require personnel to have credentials or higher-level education, which may preclude some PLE from applying for positions. Further complicating matters, for people with lived experience, accepting paid work may jeopardize their eligibility for affordable housing and health care programs. Although some social service programs are recognizing that they cannot fulfill their mission without hiring PLE, it is challenging to find funders who agree, and the field is moving too slowly to serve the actual needs and interests of people with lived experience.

Regarding the Domestic Violence Homeless Services Coalition Advocates, the compensation is still very modest. Downtown Women’s Center (DWC) aspires to provide more, and, when possible, raises general fund dollars to support additional stipends or solicits gift card donations from their supporters. These limitations were shared with the Advocates at the beginning of the program, and the Advocates weighed in on how to make the best of the resources. For example, they chose their preferred gift cards, and they receive individualized assistance, such as bus transportation cards, based on their unique needs. DWC also provides food and pays for transportation when we do advocacy work in the field together with PLE. Additionally, DWC pays for professional development certifications and conference attendance to help the Advocates advance their career opportunities and ensures that they have clothing appropriate to the setting of their advocacy work. These offerings help close the gap a little, but finances can still be an area of tension. Coming into the work with that awareness helps all parties prepare for crucial conversations so they can try to prevent concerns from festering into insurmountable conflicts.

#### Tools for Action:



- [DVHSC Sample Compensation Policy](#)
- Community of Solutions Skill(s): Leading for Sustainability; Leading for Outcomes; Leading for Equity

## Health Improvement Partnership of Maricopa County Veterans and Housing Insecurity: Teachable Moment

### Erica Glaze

During the Equity Action Lab (see definition in [Glossary](#)), we relied heavily on our partners who had trusting relationships with residents. We asked them to include people with lived experience in the Equity Action Lab and they made it happen. As a result, we were able to do a focus group for one of the teams with veterans experiencing housing insecurity. The teachable moment was the rich conversation that we had at the Midpoint Meeting. We asked the group to reflect on where they were and how they could move up the spectrum. This led to an important discussion about realistic expectations. For example, when someone is in crisis, trying to keep a roof over their head and put food on the table, is it realistic to ask them to attend a series of meetings?

We agreed that even with appropriate compensation, this is fundamentally a different ask than, say, asking someone with diabetes or high cholesterol to attend a workgroup addressing medication management programs. In addition, we recognized that we must be thoughtful and intentional about how we engage those who are currently experiencing housing insecurity, those who previously experienced housing insecurity, and those who have experienced the veteran housing system. Given the different levels of complexity, using a one-size-fits-all approach may not be appropriate.

#### Tools for Action:



- Equity Action Lab Implementation Guide<sup>10</sup>
- Engaging People with Lived Experience of Inequity: Assessment Tool & Resource Guide<sup>11</sup>
- Community of Solutions Skill(s): Leading for Equity

## Livewell Kershaw Coalition Community Champion Steward for Youth Mental Health: Teachable Moment

### Yolanda Roary

From the beginning, our shared goal was to engage youth at all four high schools in Kershaw County while creating healthier lifestyles. Kershaw County School District officials attended a meeting with us where we discussed our aim and reviewed Parker J. Palmer's Habits of the Heart along with Community of Solutions skills. While we were able to create goals for our work, the students remained unengaged. After a scheduled event with the youth, soliciting their opinion and insight, we were amazed to find out their definition of what it takes to create a healthier lifestyle. Each group of students (four per high school) verbalized that mental health counselors were nonexistent in their schools. The students felt as if they had no one to confide in, and the stress of demanding course work and schedules became a weighted beam on their shoulders. Hearing about their lived experience, along with the experience of parents attempting to encourage a child that is overwhelmed, yet full of hidden success, was an indescribable

<sup>10</sup> Douglas, W., Fritsch, S., Howard, P., Muiga, R., Munene, E. Equity Action Lab Implementation Guide. Boston: Institute for Healthcare Improvement; 2019. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

<sup>11</sup> Rumala BB, Coleman SE, Roary Y, Canedy C, Turk A, Knuckles D, Glaze E, FallCreek S. *Engaging People with Lived Experience of Inequity: Assessment Tool and Resource Guide*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

feeling. One student shared his six-word story of self: “Foundation of rock, built upon sand.” This story embodied their lack of support, their mistakes, as well as flaws...but also their strength within.

Now, each school has a mental health counselor available to students daily. Student-led clubs have received grant funds to provide fresh fruit and vegetables for all students during school hours. Lived experience is not limited to adults. These teenagers suffered from a lack of support in the school system, and the residue of its impact spilled onto their parents. They now have satisfaction in knowing that their voices were heard, and systemic changes were made.

### Tools for Action:



- Overview of SCALE<sup>12</sup>
- [Habits of the Heart](#)
- Community of Solutions Skill(s): Leading Together

## Regional Municipality of Waterloo: Bright Spot

### Yolanda Roary

The municipality of Waterloo, Canada created a [lived experience practice manual](#). This manual is composed of practices that organizations can implement when they partner with PLE. One example of these practices is called the Rotating Chair. While carrying the title of Rotating Chair, each member is able to voice their perspective. This practice empowers members to develop facilitation and leadership skills while solidifying the belonging of all group members. Group members are reminded of the importance of their perspective, knowledge, and skills. This reminder is reiterated continually to reduce the chances that big egos will dominate the group. The resulting sense of inclusion promotes the motivation needed for continued action, despite differences of opinion.

This implementation by the citizens of Waterloo carries the potential to serve as a model for a national way of doing and being when PLE are included. Their commitment to hearing and respecting every voice exudes an inclusiveness that should be emulated.

### Tools for Action:



- [Lived Experience as Expertise](#)
- Engaging People with Lived Experience of Inequity: Assessment Tool & Resource Guide<sup>13</sup>
- [Engaging People with Lived Experience of Inequities: Meeting Facilitation Guide](#)
- Community of Solutions Skill(s): Leading from Within; Leading Together

<sup>12</sup> Saha S. *Overview of SCALE and a Community of Solutions: SCALE 1.0 Synthesis Reports*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement, 2017. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

<sup>13</sup> Rumala BB, Coleman SE, Roary Y, Canedy C, Turk A, Knuckles D, Glaze E, FallCreek S. *Engaging People with Lived Experience of Inequity: Assessment Tool and Resource Guide*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))



## Pre-Relationship and Relationship Barriers to Co-Leadership and Co-Design: Teachable Moment

**Bernice B. Rumala**

Oftentimes the issue of equitable voice in decision making for partnerships arises. In the pre-relationship building stage, some of the unspoken barriers that may lead to inequitable partnerships involve resources. Individuals or organizations that are more resource-rich may have unspoken power. For example, in the process of co-designing the agenda, the party that is more resource-poor might have wonderful ideas to share but feel less inclined to provide them for fear of sharing a different point of view which could result in losing access to valuable resources and funding.

To mitigate this issue, it is important to create an atmosphere that enables shared decision making and input. It is also important to address any unacknowledged barriers such as power dynamics and resource inequity at the outset of the pre-relationship and relationship building process. There are strong benefits in having a diversity of input, shared leadership, and a process of co-design for better and more equitable outcomes.

### Tools for Action:



- Touchstones for Collaboration<sup>14</sup>
- Engaging People with Lived Experience of Inequity: Assessment Tool and Resource Guide<sup>15</sup>
- [Engaging People with Lived Experience of Inequities: Meeting Facilitation Guide](#)
- Co-Design/Distributed Leadership Debrief Template<sup>16</sup>
- Community of Solutions Skill(s): Leading Together; Leading for Equity

## Livewell Kershaw Coalition Access to Care Workgroup: Teachable Moment

**Yolanda Roary**

During our SCALE journey, we were taught ways of being/doing called Habits of the Heart. The third habit is the capacity to hold tension creatively. We have adopted a slightly different name, calling the habit “an ability to hold tension in life-giving ways” to reflect the internal transformation that can occur when processing conflict or tension. The creator of Habits of the Heart, Parker J. Palmer, explains that our lives are filled with opposing views from those who may see things from a different perspective. He believes that if we fail to see the importance of holding our tension, we ignore the possible value of the opposer’s experience and knowledge. Parker states: “The genius of the human heart lies in its capacity to use these tensions to generate insight, energy, and new life.”

<sup>14</sup> 100 Million Healthier Lives Touchstones for Collaboration. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

<sup>15</sup> Rumala BB, Coleman SE, Roary Y, Canedy C, Turk A, Knuckles D, Glaze E, FallCreek S. *Engaging People with Lived Experience of Inequity: Assessment Tool and Resource Guide*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

<sup>16</sup> Brennan L, Mullin F, Hayes H. *Co-Design/Distributed Leadership Debrief Discussion Tool*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

The [Livewell Kershaw coalition](#) held a meeting with City of Camden government officials and Health Services district employees. A total of 15 individuals attended this meeting. The goal was to create a Community Health Improvement Plan for getting adequate, quality care to the rural residents of Kershaw County. When the topic of trust came up in the conversation, I began to explain the importance of trust, and the lack thereof with community members. If community members have a sense of distrust, your efforts are null and void. Your countless hours of planning and organization have been wasted. PLE need to feel involved in the decision-making process, and most of all they need to KNOW they can trust that you will not fail them as other systems have. Basically, other topics overshadowed my trust explanation.

Again, I spoke up. At that time, I had a person with lived experience with me who had recently relocated from Egypt. Due to her limited familiarity with English, I shared her story of inequity. Some in attendance continued to boldly express their feeling that trust should be a sub-topic. I HELD THE TENSION as others in the meeting downplayed the importance of trust. As my soft voice turned firm, I looked to the organizers and gave examples of the homeless individuals and less fortunate residents in our city who have been neglected and devalued. I reminded them of our mission to serve the whole person. At that moment, the facilitator removed the sub-topic of trust and it became a priority.

### Tools for Action:



- [Habits of the Heart](#)
- [Livewell Kershaw Community Health Improvement Plan](#)
- Community of Solutions Skill(s): Leading from Within; Leading Together

## Downtown Women's Center Investment in Relationship Building Results in Better-Informed System Solutions: Teachable Moment

### Amy Turk, CEO, Downtown Women's Center

When Downtown Women's Center first started our SCALE journey, three Community Champions joined the work. Pre-relationship building was a crucial stepping stone to ensure that the women remained involved despite some challenging life situations, and it built the foundation for mutual respect among all the partners involved in our health improvement work. Pre-relationship building included, along with the formal monthly community meetings, additional meetings and touchpoints to review content and discuss any areas that needed further clarification. During this phase, we put our focus more on Leading from Within techniques than Leading from Outcomes techniques, so that we all could build a trusting foundation.

To facilitate this stage, we reflected on poems and quotes to help us all think more deeply about the work and get to know each other better. With more time to build relationships, we were able to turn to more meaningful and deeper work in anti-racism and areas of implicit bias. This foundational work was especially important, as all three Community Champions encountered unexpected life circumstances during the process. One had heart surgery, one had a baby while navigating housing instability, and one needed to relocate to new affordable housing due to unsafe conditions in her apartment. These circumstances required flexibility and additional support from staff members to ensure that the voices of the Community Champions were sustained in ways that also responded to their time constraints and other life realities.

Everyone appreciated how resilient they were to be able to stay engaged in the work despite significant challenges. Because of the safety that was created in the coalition, they were able to share their experiences and challenges with navigating large systems of care, including health care, housing, and child care. In real time, we were all witness to how systems ostensibly set up to help people actually caused harm and unnecessary challenges.

These real-time experiences allowed us to co-create solutions together. For example, we learned from one Community Champion how helpful it was to have her mental health care provider meet with her directly after her primary care physician appointment. Because she shared this positive experience, Downtown Women’s Center implemented the same practice in our onsite health clinic. The time invested in this pre-relationship stage helped ensure that the women felt comfortable attending to their external circumstances while also participating in the system-change work. They utilized their personal experience to be able to communicate systemic solutions and work together to implement change.

## Failing-Forward: 100 Million Healthier Lives Shemekka Ebony Coleman

“Failing Forward” is the concept that mistakes are not only inevitable in improvement projects, but should often be viewed as critical opportunities for learning and strengthening the improvement process. According to this concept, teams that recognize failures can learn faster, reach higher levels of performance, and create a safe environment for a wide variety of ideas, including innovative, high-risk/high-gain ones.

When building relationships with communities, there will be moments of Failing Forward. These are situations when we don’t get it right, we mess up, and do things wrong while learning. “Failing: first attempt in learning,” as we affectionately call it, leads to learning how to do better. 100MLives has been a great example of community organizations pursuing learning to improve from fail-forward moments. When we fall short, we should still fall forward, getting us closer to our shared goals. When creating safe spaces for community members to share and try new ideas, there will be times when you don’t get it perfect. It’s OK: be brave, fail forward often and fast, and most importantly, try again.

### Tools for action:



- [I Am Brilliant Engagement Strategy](#)
- Engaging People with Lived Experience of Inequity: Assessment Tool & Resource Guide<sup>17</sup>
- Community of Solutions Skill(s): Leading from Within; Leading Together

<sup>17</sup> Rumala BB, Coleman SE, Roary Y, Canedy C, Turk A, Knuckles D, Glaze E, FallCreek S. *Engaging People with Lived Experience of Inequity: Assessment Tool and Resource Guide*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

## SCALE Synthesis Report & Engagement Toolkit Testimony

### Will Douglas, Tenderloin Health Improvement Partnership

The following interview is a Q&A with a leader in a SCALE community. This reflective interview was initiated by the People with Lived Experience Co-Leadership Team to ask about this SCALE community member's awareness and use of the SCALE 1.0 synthesis report<sup>18</sup> and the [Engaging People with Lived Experience toolkit](#).

**Q: Have you reviewed the SCALE 1.0 Synthesis Report or Engaging People with Lived Experience Toolkit?**

A: I have reviewed them both!

**Q: Have you found them useful?**

A: I have found both of the tools useful. They've helped me feel more confident in my own ability to partner and work with individuals with lived experience, because I see that it comes down to communication and trust.

**Q: In what ways have you applied the tools?**

A: They both have provided me with useful documentation to share with our partners and others who work with people with lived experience so that we are all using best practices and learning together. I also have worked to facilitate the same skill building in other organizations and use these practices as recommendations. I try and model that for others too in order to dispel the mystery of what it boils down to. And I also try and uplift and showcase examples of others in our community who do it well, to have them shine as teachers for others.

**Q: Have you experienced any obstacles in using the resources, and if so, what are they?**

A: At times I have forgotten about where they are, and so they might have been more useful but if I didn't share them or pull them up, we might not have thought to use them. I also think that a lot of the skills need to be practiced over time. Clear communication, being able to meet on nights and weekends. Also, in our community there are a lot of linguistic barriers. There are many large proportions of individuals who speak languages other than English. There are challenges specific to engaging individuals with lived experience in those situations too.

Also, a big hurdle is the reporting requirements that required extensive reading and/or writing, particularly online or computer-based. Part of co-design means co-reporting so it's not just one person's voice or perspective. That part was challenging for me. But interviews and one-on-one meetings helped. And I would take lots of notes to be able and go back and hear their perspective clearly.

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<sup>18</sup> Coleman S, Byrd K, Scaccia J, Saha S, Schall M, Callender S, Anderson J, Behrman N, Budnik A, Smith D, Brown L, Douglas W, Bussey R, McDermott E, Munene E, Mullin F, Hatchett L, Pohorelsky J, VanLanen T, Pairolo B, Mann Z. *Engaging Community Members with Lived Experience: SCALE 1.0 Synthesis Report*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2017. (Available at [www.ihl.org/100MLives](http://www.ihl.org/100MLives))

## Glossary

Words can have different meanings to different people. To be clear about the concepts used in this guide, a brief glossary is included below. For more definitions, please refer to the [100MLives Glossary](#).

| Word or Phrase         | Definition   |
|------------------------|--|
| Assessment             | A tool used to identify specific opportunities for a person/community/organization.  |
| Case Study             | A process or record of research in which detailed consideration is given to the development of a particular person, group, or situation over a period of time.   |
| Co-Leadership          | Leadership shared among group members. Roles, responsibilities, and participation are shared among leaders based on strengths and gifts.   |
| Community Institution  | An institution working to improve health and well-being, lead complex change, and improve health equity in the community.  |
| Community Organization | Organization working to improve health and well-being, lead complex change, and improve health equity in their community.  |
| Engagement             | The process of establishing communication between an organization/institution and the target community.  |
| Implementation Guide   | A guide providing an overview of processes and best practices for implementing improvement.  |
| Listening Sessions     | A method of gathering information by asking a series of open and honest questions, with follow-up questions asked for further clarity.   |
| Lived Experience       | Expertise that doesn't come from training or formal education. Knowledge from an experience in a person's past or present with an issue or challenge. People with lived experience know a system, process, or issue from the perspective of those affected by it or trying to engage with it. They know what works, what doesn't work, and what resources (formal or informal) are available. They know what's needed to make things better. |

|                       |   |
|-----------------------|---|
| Relationship Building | The process of connecting with organizations and community members with lived experience. |
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