

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



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

This Assessment Tool & Resource 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 Inequities: Relationship Building

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

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## Background & Statement of Intent to Lead for Equity

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“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

“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

Our leadership practice is centered upon equity. To inform our practice, we utilize Touchstones for Collaboration<sup>1</sup> and [Habits of the Heart](#). This Assessment Tool and Resource Guide is designed to provide communities with tools to engage people with lived experience. We developed this guide with an intention to assess where individuals and organizations are and to share best practices for engaging those who are experiencing inequities as well as those who benefit from privilege and relative power. Each of the items in the assessment will guide individuals and organizations to reflect on existing partnerships and to build stronger relationships with the ultimate goal of systems transformation.

The shared experiences of the People with Lived Experience (PLE) Co-leadership Team lead us to prioritize the experience of individuals who are systematically marginalized. This prioritization in turn improves the potential for meaningful pre-relationship and relationship building, for creating community engagement, and for driving improvements desired 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 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.

Members of this team understand the inequities that underpin the need for this guide. From experiencing housing insecurity (homelessness), food insecurity, job insecurity, financial insecurity, racism, discrimination, and myriad personal, family, and health obstacles, this group understands the many dynamics that should be considered when working with marginalized people. Our own lived experience,

<sup>1</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))

and the experiences we carry from our communities, constitute our expertise. These challenges helped the PLE Co-leadership Team pour our hearts into change.

Building on the Community of Solutions (CoS) framework<sup>2</sup>, in the context of relationship building and anchored in co-design, supports communities to nurture behaviors, processes, and systems that will, over time, sustain improvements in health, well-being, and equity. The CoS framework, along with this Assessment Tool and Resource Guide, will support efforts to achieve more meaningful relationships with your community and your team. 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 skills involves best practices for engagement and illustrates how to partner effectively by prioritizing and building on the lived experience of community members.

This Assessment Tool and Resource Guide grew out of a collaborative team of both organizational leaders and leaders with lived experience of inequities across multiple communities nationwide. This team committed to digging deeper into how best to engage people with lived experience as partners in community improvement as part of 100MLives. This document builds on Engaging People with Lived Experience of Inequity: Relationship Building<sup>3</sup>, which focuses on building relationships and putting engagement tools into practice with a Community of Solutions framework in mind.

## Introduction

Pre-relationship building entails preparation and the intentional early-stage connections that are formed in the relationship building process, 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 the community. They would identify early-stage opportunities to build familiarity, commitment, and trust, and to introduce activities leading to stronger, more advanced relationship building. Relationship building is the nurturing of ongoing relationships from the initial collaboration meeting and beyond (Roary, Rumala, Coleman et al., 2020).

## Overview

This Assessment Tool and Resource Guide is designed to provide communities of all sizes and kinds with user-friendly tools for engagement. It can be used to assess readiness for pre-relationship and relationship building, especially for people with lived experience of inequities. It also provides easy access to existing and emerging resources, as well as guidance about how to move forward and navigate next steps.

The PLE Co-Leadership Team, comprising people with lived experience of inequities, conducted listening sessions and workgroup meetings with community members through a process of co-leadership and co-design. The purposes of the listening sessions and meetings were to identify barriers to relationship

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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 <http://www.ihl.org/100MLives>)

<sup>3</sup> Roary Y, Rumala BB, Coleman SE, Knuckles D, Turk A, Glaze E, Canedy C, FallCreek S. Engaging People with Lived Experience: Relationship Building. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2020. (Available at <http://www.ihl.org/100MLives>)

building, determine what is working and what is not working, and devise strategies to enable effective relationship building.

From these sessions, several recurring themes emerged. These included the need for an assessment and the need to further understand lived experience, process, co-design, co-leadership, resources, voice, value, equity, and ownership at the pre-relationship building stage. Several community partners mentioned that when initially engaging organizations and individuals, it was difficult to determine their readiness level.

According to feedback from partners in the listening sessions, as well as associated feedback in leadership meetings, a tool to assess pre-relationship building at the individual and organizational level would be useful. Partners also agreed that it would be helpful to have guidance from the PLE Co-Leadership Team on navigating existing and emerging resources and on facilitating meetings.

To address this need, this guide and an accompanying [action worksheet](#) were developed. These provide a space to have open and honest conversations and further strengthen partnerships.

## Lived Experience and Relationship Building

People with lived experience bring an important perspective to the relationship building process as a result of having a personal understanding of inequities and of solutions to bridge these. They play an integral role in co-designing and co-leading the relationship building process. Lived experience is defined as expertise that does not come from training or formal education but from an experience in a person's past or present 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. Lived experience experts know what is likely to work and not to work.

The *Engaging People with Lived Experience of Inequity: Relationship Building* guide (Roary, Rumala, Coleman et al, 2020) explores common landmine challenges and teachable moments in relationship building. Examples include: safe sharing, valuing of work, time compensation, barriers in co-leadership and co-design, engaging the unengaged, equitable voice in meetings, and group harm. This assessment provides an avenue to engage in meaningful conversation about challenges at the outset of partnerships using a Community of Solutions framework.

## Gaps and Needs

A variety of stakeholders could benefit from user-friendly tools at the pre-relationship and relationship building stages. Once identified, the tools can be used to address various needs of the group while engaging people and organizations. This Assessment Tool and Resource Guide provides a framework for individuals and organizations to deeply reflect on the stage they are in and to access existing and emerging resources, and navigational guidance toward next steps.

## Better Results with Coaching, Technical Assistance, and Workshops

To promote Leading for Equity, Leading for Outcomes, and Leading for Sustainability, this Assessment Tool and Resource Guide is accompanied by offerings of technical assistance, coaching, and workshops from the PLE Co-Leadership Team. Recognizing that all organizations and individuals are different, we

offer a tailored approach to authentically engaging people with lived experience and to fostering sustainability of practice at the individual and organizational levels. To us, the Co-Leadership Team, it is imperative that the tools are utilized in a way that does not cause harm to communities impacted by inequities. Hence, we are pleased to partner with individuals and organizations for effective utilization of the tools to achieve better results. For more information, see the Resources section at the end of this document.

## Assessment Categories

We offer two assessments. The first is for people with lived experience and the second is for organizations/collaboratives. The assessment categories and questions were partly informed by the PLE Co-Leadership Team's listening sessions and meetings. The areas of assessment include: lived experience, process, co-design, co-leading, resources, power dynamics, voice (ensuring that everyone's voice is heard), value (ensuring that everyone's value is recognized), social capital (people, resources, power, knowledge), ownership, and equity. Links to resources for each area of assessment are provided at the end of this document.

## Assessment Tool and Resource Guide

This contains two separate assessments. You may provide your response to one or both assessments as applicable.

1. [Assessment for people with lived experience](#)
2. [Assessment for individuals who are part of organizations or collaboratives](#)



## Resource List

Below is a list of resources referenced in the Assessment Tool & Resource Guide:

### 100 Million Healthier Lives Tools

*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))

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))

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))

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

### External Links

[Engaging People with Lived Experience of Inequities: Meeting Facilitation Guide](#)

[Habits of the Heart](#)

[Interview with Suzette Shaw, Lived Experience Expert](#)

[Toolkit for Engaging Community Members with Lived Experience](#)

### Workshops & Coaching

**People with Lived Experience Co-Leadership Team Workshop:** This workshop will help organizations and individuals learn how to authentically engage people with lived experience in co-designed efforts to improve health, well-being, and equity. For more information, please email [pwleadership@gmail.com](mailto:pwleadership@gmail.com).

**People with Lived Experience Co-Leadership Team Coaching:** Coaching is available for individuals and organizations interested in achieving better results through authentic engagement of people with lived experience. For more information, please email [pwleadership@gmail.com](mailto:pwleadership@gmail.com).

## Action Worksheet

The action worksheet enables individuals and organizations to chart actionable next steps in the assessment areas with guidance from the PLE Co-Leadership Team as part of a workshop. This worksheet, coupled with the Assessment Tool, enables open and honest conversations about individual and organizational next steps.

Areas	Actionable Next Steps for Yourself/Your Organization
Process	
Voice	
Power Dynamics	
Equity	
Value	
Co-Leading	

<b>Co-Designing</b>	
<b>Lived Experience</b>	

Rumala BB, Coleman SE, Roary Y. *People with Lived Experience Action Worksheet*. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2019.

## 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](#).

Words & Concepts	Definitions & Explanations
Assessment	A tool used to identify specific opportunities for a person/community/organization.
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, to lead complex change, and to improve health equity in their community.
Community Organization	An Organization working to improve health and well-being, to lead complex change, and to improve health equity in their community.
Engagement	The process of establishing communication between an organization/institution and the target community.
Listening Sessions	A method of gathering information by asking a series of open, 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 people with lived experience and organizations in the community.

## References

- Berg B, Francoeur N, Morrison N. *Lived Experience as Expertise: Considerations in the Development of Advisory Groups of People with Lived Experience of Homelessness and/or Poverty*. Waterloo, ON; 2012. [www.socialservices.regionofwaterloo.ca](http://www.socialservices.regionofwaterloo.ca).
- Cahn ML. Community Health Improvement Plan, *Chronicle-Independent*. May 24, 2019. <https://www.chronicle-independent.com/news/healthcare/community-health-improvement-plan-released/>.
- Canedy C, Rumala B.B, Coleman SE, Roary Y. *Engaging People with Lived Experience of Inequities: Meeting Facilitation Guide for Relationship Building*. People with Lived Experience; 2020. <https://img1.wsimg.com/blobby/go/195c6b57-b4f2-4124-bd4c-a660c8b3a6eb/downloads/Final%20PLE%20Meeting%20Facilitation%20Guide%2003%2027%20202.pdf?ver=1585614684725>.
- 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))
- Coleman S. *I Am Brilliant Strategy: 6 Tips for Beginning Community Engagement* [Video file]. June 16, 2018. [https://youtu.be/r\\_eXzL-C2aA](https://youtu.be/r_eXzL-C2aA).
- 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))
- Downtown Women's Center. *From Expert Panelist and Poet Suzette Shaw, DWC Community Leader* [Video file]. <https://youtu.be/6Sr7xuKdK5I>.
- Five Habits of the Heart that Help Make Democracy Possible, adapted from Parker J. Palmer, *Healing the Heart of Democracy: The Courage to Create a Politics Worthy of the Human Spirit*. Seattle, WA: Center for Courage and Renewal, 2011. <http://www.couragerenewal.org/habitsoftheheart/>.
- Roary Y, Rumala BB, Coleman SE, Knuckles D, Turk A, Glaze E, Canedy C, FallCreek S. *Engaging People with Lived Experience: Relationship Building*. 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 Toolkit for Engaging Community Members with Lived Experience. Boston: 100 Million Healthier Lives, convened by the Institute for Healthcare Improvement; 2017. <https://www.communitycommons.org/collections/Engaging-Lived-Experience-Toolkit>

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