



SUCCESSFUL ENGAGEMENT WITH PEOPLE WHO HAVE LIVED EXPERIENCE



National **MCH** Workforce
Development Center
Advancing Health Transformation



Welcome!

The purpose of this workbook is to provide detailed steps for professionals who seek to authentically engage with people who have lived experience to improve policy, services, supports, systems of care, health outcomes, etc. This document provides guidance for setting the stage in order to create trusting relationships and engage individuals with lived experience at the beginning of your work.

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COMMON SENSE

This workbook is divided into three sections:

Preparing

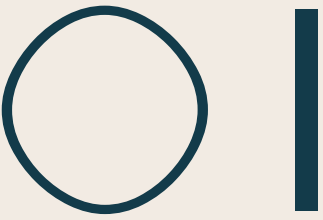
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DEFINITION

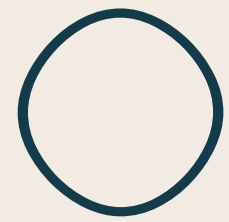
All humans have lived experiences that provide them with specific insights. In the context of public health, the engagement of “people with lived experience” aims to identify and amplify those voices, being inclusive of those heard less often.

A person with lived experience has knowledge and expertise derived from components of their personal identity and perspective, such as parenting, pregnancy, living in poverty, having a disability, experiencing structural disadvantages such as racism, ableism, classism, etc., which is then employed in service to a population-level goal or objective.

In public health practice improvement, persons with lived experience can offer insight into the operations and impact of programs, services, policies and systems on themselves, their peers, and their communities. They can serve in multiple roles, including as peer mentors or coaches, partners in program and policy planning, implementation and evaluation, and as leaders and advocates for systems change.

Their knowledge and expertise can help ensure that programs and policies meet the real-world needs of the population served, assist in avoiding unintended negative consequences, and by extension improve the cost-effectiveness of decision-making.





SHARED UNDERSTANDING

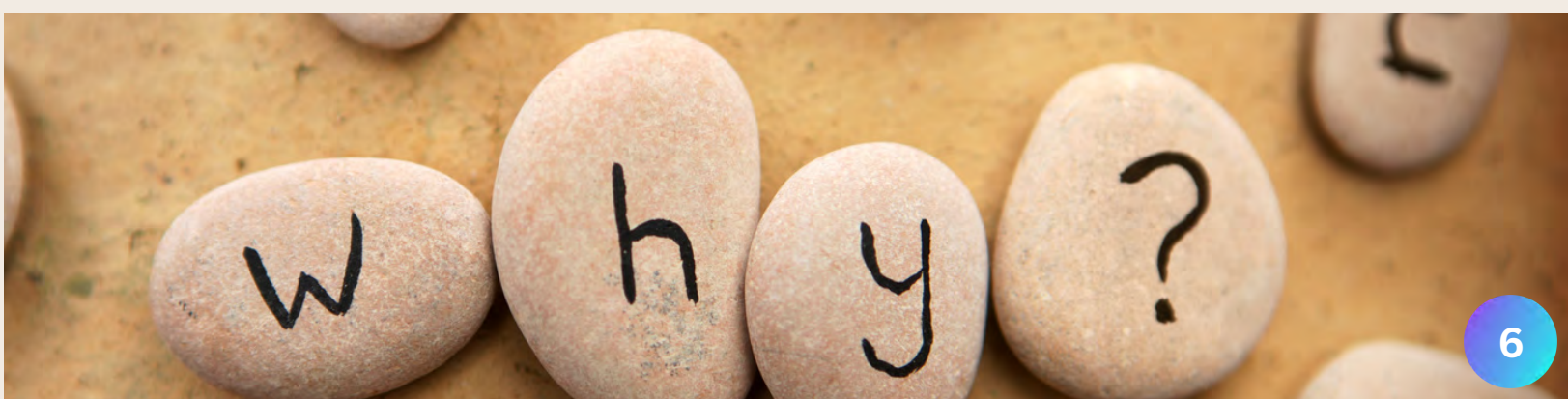


One must be clear about what they are asking from people with lived experience. Although the project may change direction overtime, there needs to be at least a shared understanding of what is needed from the onset.

With as much detail as possible, describe your project or activity:

What are you seeking from people with lived experience?

- Partnership in project
- Project consultant
- Advisor
- Ideas
- Discussion
- Buy In
- Preferences
- Something else: _____

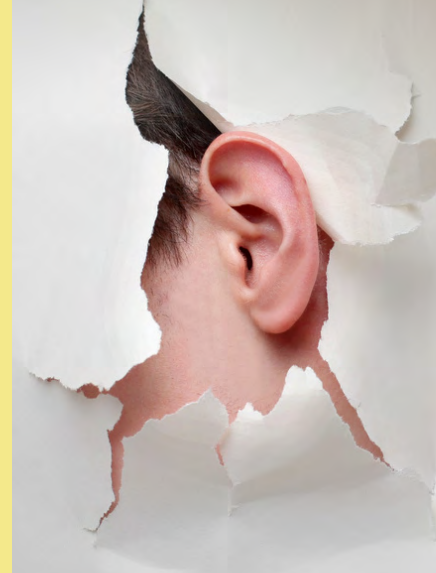


03



ORGANIZATIONAL READINESS

The only way to hear the voices of community members is if the people representing the program listen and share power. Is the organization ready to set aside their own hierarchy to hear the ideas from people with lived experience?



Shared Power:

- **Respect me:** Take me seriously and treat me fairly.
- **Include me:** Involve me in decisions that affect me.
- **Collaborate:** Work with me to solve problems and reach goals.
- **Let me lead:** Create opportunities for me to take action and lead.

START



3

ORGANIZATIONAL READINESS

Has everyone who will be working on this project identified and addressed their own unconscious bias(es)? There are many online opportunities to help highlight implicit biases and trainings to work towards awareness of bias(es).

<https://implicit.harvard.edu/implicit/takeatouchtestv2.html>

Is everyone able to release control to the wisdom of the group as a whole? Regardless of position or title, is everyone ready to accept the decisions the group makes rather than promoting or accepting only their own ideas or decisions? This requires a focus on consensus rather than individual resolutions. Of course some decisions made by a group may be limited by other factors, like grant requirements, everyone's contributions to the conversation deserve consideration.



Does everyone in your project group have an open mindset? Are they ready to learn from the collective thinking of the group? Sometimes this is referred to as a growth, learner's, or beginner's mindset. It is about coming to a discussion without any preconceived expectations, or past experiences that limit the view of a situation or possible solutions.

Do all staff, at all levels within your organization, agree that fully supporting engagement is a priority?



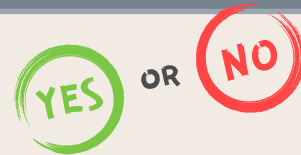
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ORGANIZATIONAL READINESS

Is everyone prepared to agree to an action that they may not be 100% comfortable with? It is imperative that staff do not intentionally or unintentionally sabotage an agreed upon solution or action plan. Working in collaboration with others requires that everyone works towards the same goal.

Does your organization recognize the need to compensate people with lived experience for their time/effort to engage/participate/contribute to your work? Is your agency leadership agreeable to providing this support? This topic will come up again later, but it is important to know that compensation shows that the organization truly values people with lived experience and should be a component of all engagement efforts. People with lived experience will want to know if and how they will be compensated.

Does the organization have the authority to make changes? If not, make sure the people who can make changes are at the table. Or ensure the people who are engaged are informed about what changes are feasible, and what may be limitations. Be transparent about what is reasonable and what may be bigger dreams or long-term goals.



Many answers to these questions are likely more complex than a simple Yes or No. If there are items that you have not addressed, keep working towards a resolution to remove any stumbling blocks down the road. Consider if your funding source supports this work as well.

When it comes to comparable compensation, learn from people with lived experience what is best for them. Sometimes it will be financial, other times it will look different. Bottom line, there should never be a cost incurred by people with lived experience who are offering their expertise. This means things like travel, parking, meals and other expenses should be covered or reimbursed by the program or organization.

03



ORGANIZATIONAL READINESS

Examples of challenging situations

01

The front-line staff are all in for engaging with people but management or leadership doesn't support this idea. This will need to be addressed for the greatest success. Part of the work will be finding ways to communicate the value of working with others. This may be done by having people with lived experience help you in this process.



02

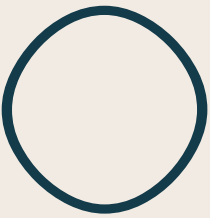


The program isn't planning to pay for the contributions of those with lived experience. There are many ways to acknowledge and support volunteers without the explicit paying for their expertise, although this still needs to be addressed over time. See chapter 12, "Support" for compensation options.

03

Everyone likes the idea of engagement, but it becomes apparent that what they think engagement is having people agree with decisions already made rather than true, genuine engagement. If you can address any anticipated barriers to authentic engagement, it will be easier to help others understand why it's so important.





4



IDENTIFY WHO



Sometimes staff in an organization have lived experience, but their opinion may be biased or their willingness to share their personal opinion at work may be challenging, or it may be a conflict of interest or they may be hesitant to share their personal experiences. It is best to include additional representatives from the community who do not also work in the field.

With as much detail as possible, describe the people who will be most impacted by the project outcome or decisions.



4



IDENTIFY WHO

Race / Ethnicity



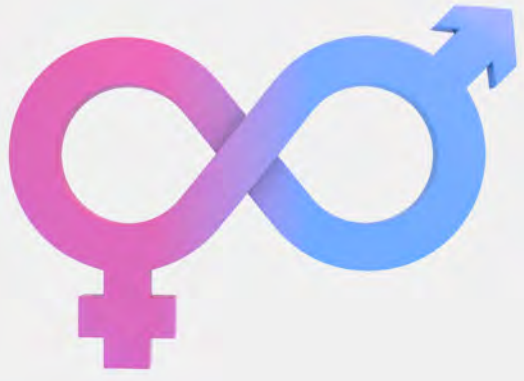
- White
- Black or African American
- Hispanic or Latino
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander
- All
- Other: _____

Sexual Orientation

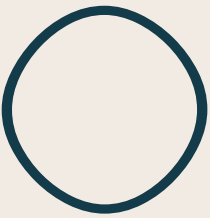
- Heterosexual
- Gay / Lesbian
- Bisexual
- All
- Other: _____



Gender / Sex



- Male
- Female
- Transgender
- Nonbinary
- All
- Other: _____



4



IDENTIFY WHO

Age

- 0- 5
- 6-12
- 13-18
- 19-24
- 25-39
- 40-65
- Over 65
- All
- Other: _____

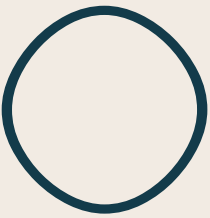


Additional Considerations

- | | | |
|--------------------------------------|--|---------------------------------------|
| <input type="checkbox"/> Education | <input type="checkbox"/> Language - written & spoken | <input type="checkbox"/> Geography |
| <input type="checkbox"/> Occupations | <input type="checkbox"/> Family size and relationships | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Income | <input type="checkbox"/> Disability | |

Consider what history people with lived experience need to have with your program or service.

- People currently using the program
- People who have used the program in the past
- People who have no connection to the program
- People who live in the community where the program is located
- People most impacted by the decisions being made
- A variety of people



4



IDENTIFY WHO

Examples of how to use the categories from above to be more specific about who to engage.

Rather than families who have a child with a special health care need, it might be:

Families who have a child under the age of five with a special health care need who are Hispanic and have never received your services in the past.

Rather than mothers of color, it might be:

Mothers of color who experienced a C-Section within the past 2 years who live in a particular part of your state.

Rather than Title V staff, it might be:

Title V staff who have been in their positions for more than five years and are under 40 years of age.

With as much detail as possible, describe the specific lived experience you are seeking.

05

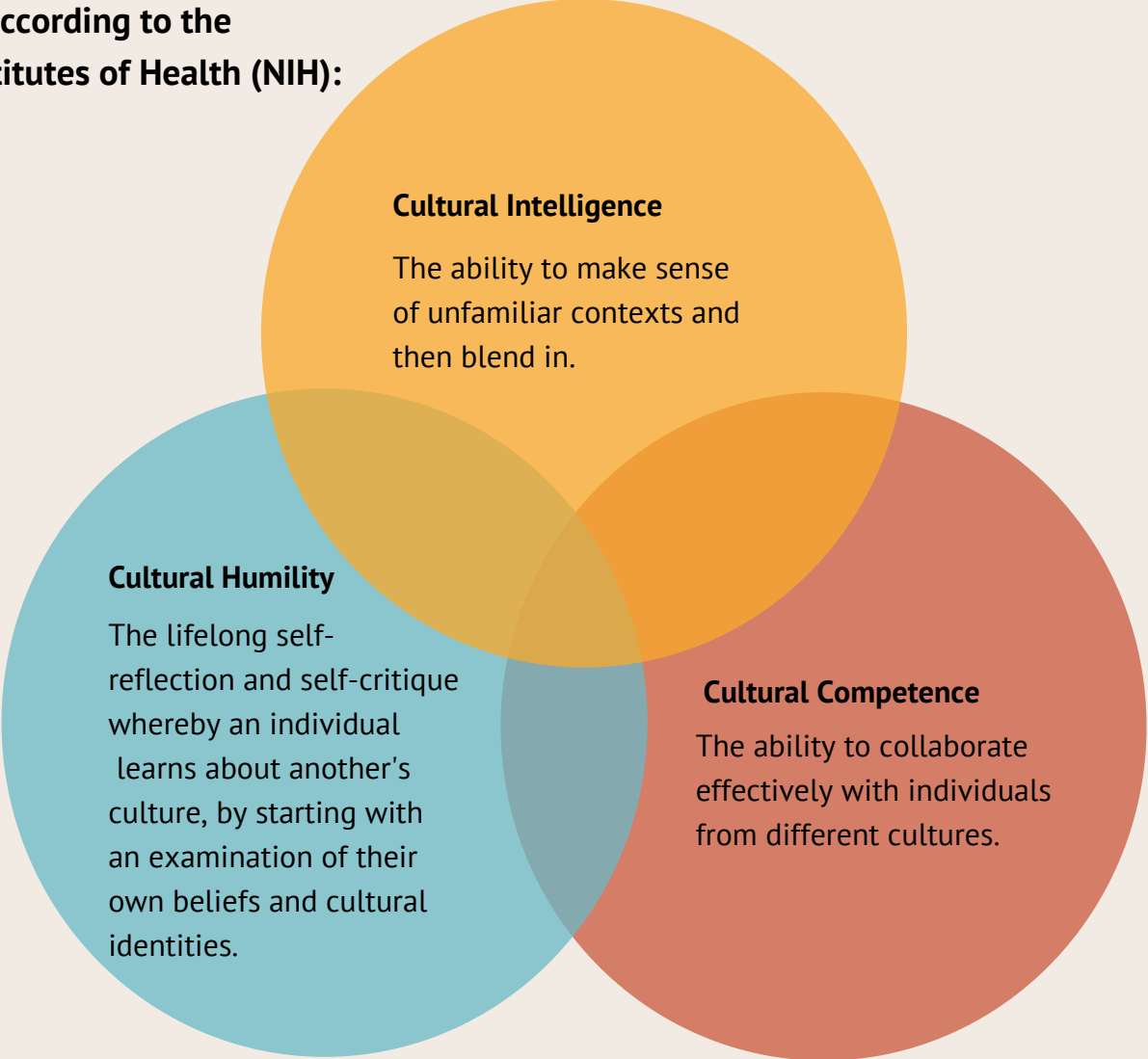
CONSIDER CULTURE



Relationships with community members are more positive when their culture is known and honored. This includes current culture as well as historical aspects.



Definitions according to the National Institutes of Health (NIH):



05

CONSIDER CULTURE



It would be ideal to live in a world where everyone understands the history and culture of all populations, but we are not there right now. Start by learning about the populations with whom you will be building a relationship. Include current and historic values and beliefs. Discover what the relationship has been between your agency and different communities. Think about connecting with local historians or librarians to learn more. Or, if a relationship already exists, chat with the community's leaders to learn more.

Reflect on your agency's culture. Talk with people who have been at the agency a long time to learn about past dynamics. Keep in mind when working with government agencies that they have a culture all their own. That culture is influenced by politics, the current administration, and has a historical approach to solving problems can be transactional rather than focusing on transformation. You carry the history of that government everywhere you go.



Creating trusting relationships may be driven by taking the time to learn about and understand others' cultures. If you want to shift from mere engagement to equitable engagement, this may be where there is really an opportunity for you to grow. Find ways to create dialog with people from cultures other than your own. You can do this at social events, community circles, and community cultural events. Likewise, you can invite people from another culture to an event you are hosting and spend time talking, and more importantly, listening to them.

05

CONSIDER CULTURE



Dates to consider and acknowledge

January

- The 3 Kings Day
- Martin Luther King Day
- International Holocaust Remembrance Day

February

- Black History Month
- National Freedom Day
- International Day of Zero Tolerance for Female Genital Mutilation
- World Day of Social Justice
- International Mother Language Day

March

- Women's History Month
- Nat'l. Developmental Disabilities Awareness Month
- Zero Discrimination Day
- International Women's Day
- Remembrance Day of the Victims of the Transatlantic Slave Trade
- Int. Day of Trans Visibility
- Persian New Year
- Passover (or early April)

April

- Celebrate Diversity Month
- World Autism Awareness Day
- World Health Day
- Day of Silence

May

- Asian-American and Pacific Islander Heritage Month
- Jewish American Heritage Month
- Cinco de Mayo
- World Press Freedom Day
- Vesak or Buddha Day
- Int. Day of Families
- International Day against Homophobia, Transphobia, and Biphobia (IDAHOTB)

June

- Lesbian, Gay, Bisexual, and Transgender Pride Month
- World Environment Day
- Pulse Night of Remembrance
- Juneteenth
- Stonewall Riots Anniversary

July

- International Non-Binary Day
- Nelson Mandela International Day
- Disability Independence Day

August

- International Day of the World's Indigenous Peoples
- World Humanitarian Day
- International Day for the Remembrance of the Slave Trade
- Women's Equality Day

September

- Hispanic Heritage Month (Mid-Sept to Mid-Oct)
- International Day of Peace

October

- LGBT History Month
- National Indigenous People's Day
- National Coming Out Day
- World Mental Health Day
- International Pronoun Day
- Intersex Awareness Day

November

- National Native American Heritage Month
- Trans Awareness Week
- Transgender Day of Remembrance
- The National Day of Mourning

December

- World AIDS Day
- International Day of Disabled Persons
- International Human Rights Day
- Yule
- Kwanzaa
- Christmas

05

CONSIDER CULTURE



Holidays that fall on different dates each year

- 🎉 Ramadan
- 🎉 Mardi Gras
- 🎉 Hanukkah
- 🎉 Ash Wednesday
- 🎉 Diwali
- 🎉 Passover
- 🎉 Rosh Hashanah
- 🎉 Yom Kippur
- 🎉 Easter

Additional Cultural Considerations:

- Muslims pray five times a day, with their prayers being known as Fajr (dawn), Dhuhr (after midday), Asr (afternoon), Maghrib (after sunset), Isha (nighttime), facing towards Mecca.
- Consider the use of Land Acknowledgement and Honor.
- Jewish holidays start at sunset the evening before the date on the calendar. Some holidays are observed for more than one day.
- Ramadan lasts a full month. It wouldn't be a good idea to schedule a luncheon or event during that time if possible.
- Think about how you describe the community – do you use terms like "our" or "we" or "those people" or "these people" vs. "this community."



05

CONSIDER CULTURE



Cultural Considerations for Meetings:

“How to Run a Meeting of People from Different Cultures”
<https://hbr.org/2015/12/how-to-run-a-meeting-of-people-from-different-cultures>

Key Take-aways:

- It can be helpful to develop norms and agreements to govern the meeting and share in advance so everyone knows the expectations.
- Communication styles vary from culture to culture as do notions of authority and hierarchy, which only heightens the potential for misunderstanding and hard feelings.”

There are differences in terms of

- How and where people sit (to convey authority/status);
- The speed in which they get down to business (expectations of social engagement; value placed on punctuality);
- Willingness to provide feedback or argue (disagreement can be perceived as disrespect; perceived power dynamics may inhibit honest feedback). Silence does not necessarily mean agreement.
- Research and share material on cultural differences.
- Think about how behavior is viewed by others and make adjustments.
- Solicit feedback from everyone (e.g. go around the room). Another method to hear from everyone is to ask team members to email their ideas and thoughts to you and then you can share once everyone is together.



Please note: the examples given are not necessarily relevant to everyone in the cultural group



DISCOVER DIVERSITY



Even within sub-groups, diversity still exists (intersectionality). It is important to hear from people impacted by programs, decisions and policies.

What types of diversity will you need to consider?

- ♥ Races
- ♥ Ethnicities
- ♥ Sexual Orientations
- ♥ Gender Identities
- ♥ Religions
- ♥ Languages
- ♥ Disabilities
- ♥ Incomes
- ♥ Age
- ♥ Geography
- ♥ Other: _____

What adaptations may you have to make?

- ♥ Interpreters
- ♥ Translation
- ♥ Pronouns
- ♥ Identify class differences
- ♥ Accessibility
- ♥ Closed captioning
- ♥ Antiracist or implicit bias training
- ♥ Recognize power differences
- ♥ Other: _____





DISCOVER DIVERSITY



What do we know about different communities?

“The Essence of Culture”

<https://www.yumpu.com/en/document/read/11717026/the-essence-of-culture-a-peek-at-hispanics-college-of-agriculture->

Key Take-aways:

- 🌈 The persevering processes African Americans use to face adversity include many character strengths, such as positive outlook (hope), spirituality, religiousness, meaning-making, forgiveness, expression of empathy (social intelligence), compassion (kindness), gratitude, and humility (Mattis et al., 2016).
- 🌈 Latino/x/e and Hispanics, more than any other culture, have a high regard for family. When interacting with others, Latino/x/e and Hispanic prefer being closer to each other in space than non-Hispanic whites do.
- 🌈 Asian-American traditions emphasize family solidarity, discipline, hard work and schooling. They value educational achievement, responsibility for relatives, and respect for authority. Along with respect for authority, there is also a strong sense of respect for the elderly.

WHEN IN DOUBT, LISTEN TO UNDERSTAND!



DISCOVER DIVERSITY



- Native Americans emphasize a nonverbal communication style. Moderation in speech and avoidance of direct eye contact are nonverbal communicators of respect by the listener, especially for respected elders or authority figures. Traditional Native American Indian people are not rewarded for asking questions or verbally analyzing situations. Rather they are expected to learn through patience and observation. Native Americans usually speak softly and take ample time to reflect before responding. Direct confrontation is avoided because it disrupts the harmony and balance that are essential to being.
- The amount of space between you and the person you are talking to can say a great deal in the Middle East. It is common to sit very close to the person you are talking to. Not doing so may show that you are uninterested in the conversation and may offend the other person.
- The emphasis on personal relationships in Islam and the Middle-East mean that the person is valued greatly for whom he is and for what he does for the benefit of the whole, be it family or society.
- LGBT communities are defined by identities based on gender and sexual orientation. Their sense of culture emerges in their experiences in life due to core differences from the cultural norms surrounding gender and sexuality.
- The way people relate to one another in rural communities is more personal, emotional, direct and socially supportive. Everybody knows everybody. There is a feeling of belonging and fellowship. Even relationships with authority figures are softened or tempered by social constraints and niceties.



Please note: the examples given are not necessarily relevant to everyone in the cultural group



YOUR ASK



People can only offer relevant experience if they have a clear understanding of the issue(s) and the specific ask. It is easier for a team to make progress when everyone starts on the same page.



What?

- What is the project?
- What is the goal?
- What is the scope of the project?
- Over describe and be abundantly clear. Provide a clear description, using plain language and spell out any acronyms.

When?

- Time commitment
- Dates
- Duration of involvement

Where?

- In-Person or Online
- Location



07

YOUR ASK



Type of Engagement?

- Inform/Educate
- Gather
- Discuss
- Involve
- Partner

Engagement Categories		Definition and Methods
PARTNER		<p>An ongoing joint venture, involving people in every aspect of decision-making – from the early stages of defining the problems to developing and selecting the most promising solutions. People with lived experience are full partners with program staff. They are fully engaged from the start of a discussion around policy, programming, implementation, etc.</p> <p>Examples include members of a team, governance boards, and improvement initiative work groups.</p>
INVOLVE		<p>People play an important role in innovation/quality improvement efforts, but are still viewed as “advisory,” with no role in decision-making. People with lived experience are advisors to program. They are provided program challenges to problem solve.</p> <p>Examples include Advisory Councils, world café and town halls.</p>
DISCUSS		<p>Providing information so that people can respond with their viewpoint. The team commits to consider the input, not to incorporate people’s perspectives into ultimate decisions and strategies. People with lived experience and staff discuss issues. The program provides opportunities for input and programs. The input is used in the program or activities. Typically input is offered through discussions which include give and take with opportunity for clarification.</p> <p>Examples include focus group, interviews and discussions.</p>
GATHER		<p>Collecting information from people and listening to their insights. People with lived experience are informers. Their input is solicited through opportunities to provide feedback. Input may not always be incorporated.</p> <p>Examples include surveys, interviews, and suggestion boxes.</p>
INFORM/ EDUCATE		<p>Communicating to the people you serve, and educating them about innovation efforts. People with lived experience are recipients of information and education. They are informed about the program and activities.</p> <p>Examples include brochures, posters, and newsletters.</p>

Types of Engagement, from the UW Madison Center for Patient Partnerships

07

YOUR ASK



Method of Engagement?

- Interview
- Focus group
- Webinar with Q&A
- Survey
- Meeting
- Advisory committee
- Feedback panel
- World Café
- Be part of a work team
- Retreat
- Town hall

		Inform/ Educate	Gather	Discuss	Involve	Partner
Methods	High Touch	<ul style="list-style-type: none"> • Face-to-face education • Newsletter • Brochure • Posters 	<ul style="list-style-type: none"> • Face-to-face inquiries • Suggestion boxes • In-person interview • Shadowing • Mystery shopping 	<ul style="list-style-type: none"> • Targeted meetings to clarify input • Focus group • 1:1 in-person discussion 	<ul style="list-style-type: none"> • On-going feedback panels • People occasionally join program meetings • Town halls • World Café 	<ul style="list-style-type: none"> • People join ongoing program meetings • People learn content and help decide what changes to make • Retreats
	High Tech	<ul style="list-style-type: none"> • Website • Mass Media • Email/ Texts • Social Media 	<ul style="list-style-type: none"> • Electronic surveys • Phone interview • Webinars with Q&A 	<ul style="list-style-type: none"> • Google hangouts • 1:1 phone discussion • Online forums 	<ul style="list-style-type: none"> • Virtual town halls • Panels via video conferencing 	<ul style="list-style-type: none"> • Use collaborative documents • Use video conferencing

Method of Engagement from the UW Madison Center for Patient Partnerships

07

YOUR ASK



Support Provided?

- Logistics
- Compensation
- Staff support

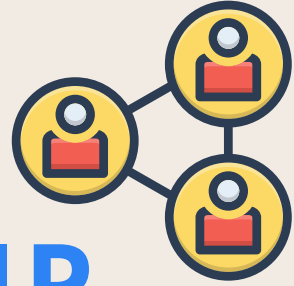
How to Ask?

- Letter
- Social Media
- Email
- PSA (Public Service Announcement)
- Phone call
- Over lunch

Why Me?

- What experience are you asking me to share?
- How is this information going to be used?
- What skills are you seeking?





RELATIONSHIP



"I DON'T KNOW ANYONE FROM CULTURAL GROUPS DIFFERENT FROM MY OWN"

Does someone in your agency/program have an existing relationship with people who have lived experience from different cultures?

Does someone in your agency/program have an existing relationship with someone who does have a relationship with people who have lived experience from different cultures that could introduce you?

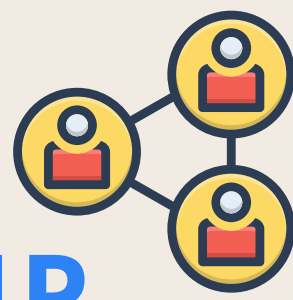


Does someone in your agency/program know how the people who have lived experience from different cultures gather or communicate within their community?

Can you ask the community what supports they might need as a way to get to know more about them and develop relationships?



RELATIONSHIP



When building a new relationship with a community, finding a community connector is a good place to start. It is often valuable to have a trusted community leader introduce you to a community. Think about people you may already know through board or committee members.

Community Connectors

- Spiritual or Faith Communities
- Community Leaders
- Cultural Events & Celebrations
- Community Meetings
- University Cultural Unions or Services
- Community Centers (neighborhood, LGBTQ+, public health)



Other Avenues



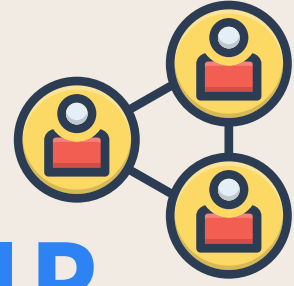
- Community Newsletter
- Community Radio Shows
- Community Health Center
- Social Media / Listservs
- Volunteer

Example

An agency wanted to connect with African American/Black fathers of children with special health care needs. The staff made a connection with a African American/Black faith community through attending a black history course. It turns out that this community's church had a men's group. Through the spiritual leader, a message was sent to the men's group asking if any of them were fathers of children with special health care needs who might be interested in helping out a service program. Through that process, four people with lived experience were identified and introductions were made.

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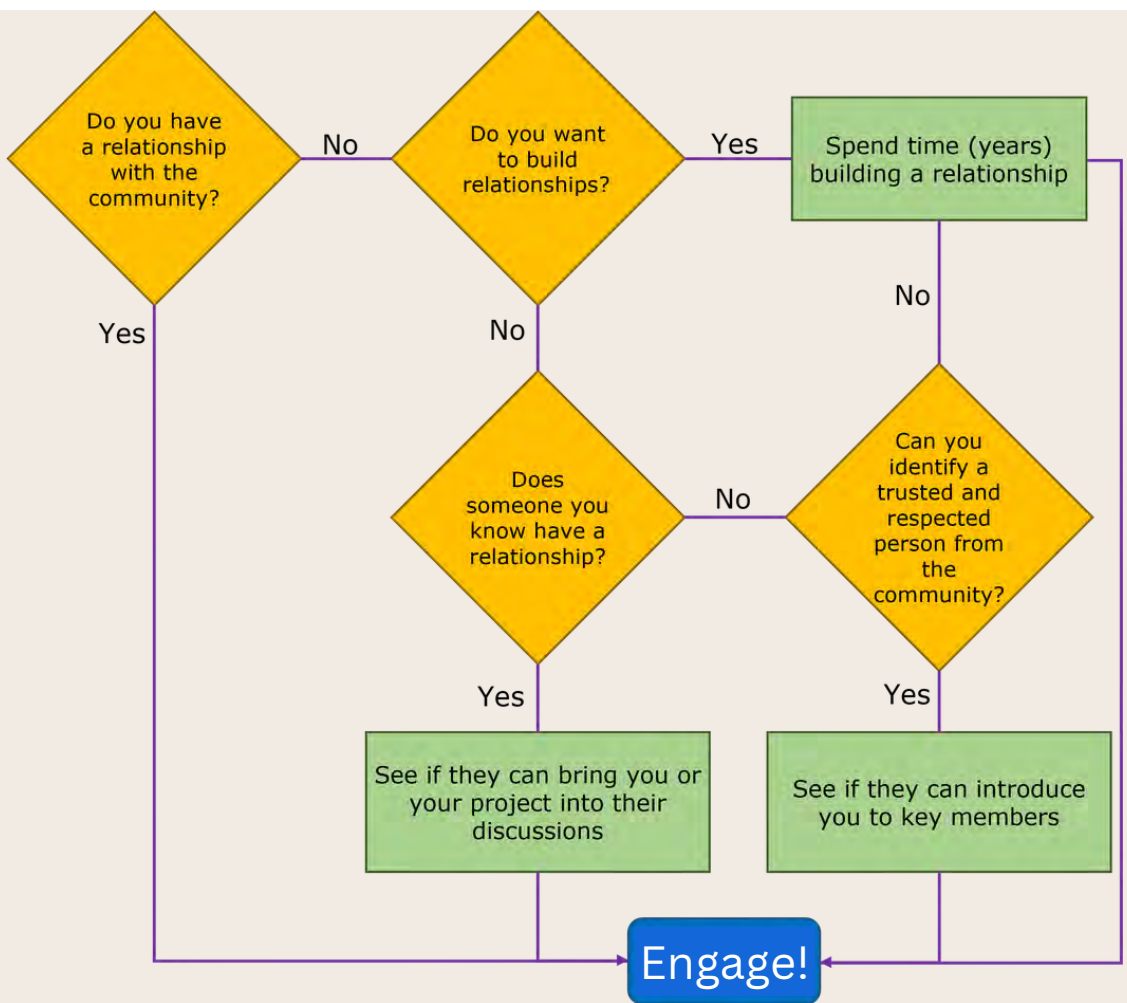
RELATIONSHIP



“I don't know anyone, but I know a program that has that relationship!”



If you/your agency does not have the relationship or the connections to build a relationship, then start looking at who already has the relationships. Find programs that are trusted in the community already and forge a partnership with them to better meet the needs of the community. Think about health care, public health or social service programs. **Can you barter with a program to carry your message to the community?** That is, offer something that supports their program if they help carry your message to the community. Most often, both programs can benefit from the partnership.





WHEN



The best time to engage is the moment you realize you need others to impact a decision and never after the decision has been made.



Inviting people with lived experience from the beginning of an activity or project is best practice. If you don't invite the people served at the beginning, it deprives them of the relationship building that may have gone on among the other program people who are working together. If invited later, people with lived experience will need the back-story about the project when they join the discussion. If you invite people too early, they may wonder why they are there and feel as though their time is being wasted or, worse yet, as though the invitation was merely so the program could check a box. If you wait too long, then people may feel like their ideas do not really matter. Programs must be *intentional* and *thoughtful* when engaging with the community.

Project Design

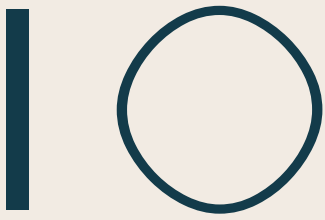
Executing

Evaluation

Planning

Monitoring

Dissemination



EFFECTIVE CONNECTIONS



It is important to connect people with lived experience to opportunities for which they are well suited.

Know people well enough to always connect them to opportunities in areas where they feel they can have an impact.

Family

Being a leader in one's own family – advocating for one's own child or situation.



Peer

Connect with and support others in one's community and beyond that have a shared experience.



Agency

Participate in decision-making related to policy, program development & evaluation, professional education, hiring processes & support/service delivery.



Systems

Contribute to improving the quality of supports and services that are essential for effective policies and practices at all levels of care and systems planning.



SELF DETERMINATION



Self-determination is the process by which a person controls their own life. They set their own goals and can pick and choose why, when, and where to share their lived experiences to help redesign systems of care.



People with lived experience have the right to say “No” without fear of retribution or a change in their services or supports. Programs must respect the boundaries of what a community member can offer. Provide a graceful way for people with lived experience to decline the opportunity.



People with lived experience must be able to share experiences, especially negative ones, without having to worry about retribution or changes in their services.

Life happens to everyone and circumstances change. It's important to understand that not everyone, even staff, may not be able to participate for the duration of a project. Thank them for their contributions to date and wish them well.



12

SUPPORT

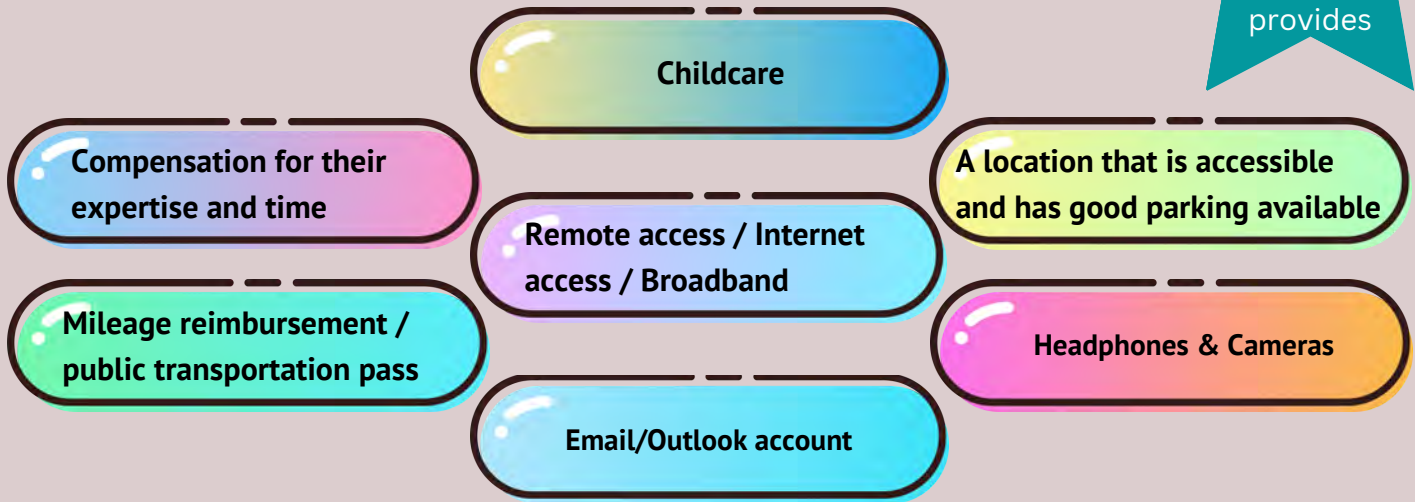


A key attribute of successful engagement is providing support to reinforce the experience of engagement and reduce disparities between people with lived experience and those representing an organization or program.



Logistics

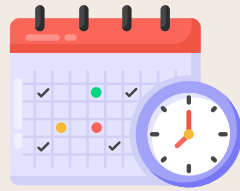
Things a program pays or provides



SUPPORT

12

SUPPORT



Scheduling

1

Start by asking people with lived experience about their availability.

2

Consider meeting times in the early morning, over the lunch hour, evenings, or weekends.

3

Identify a clear start time and end time and honor that decision.

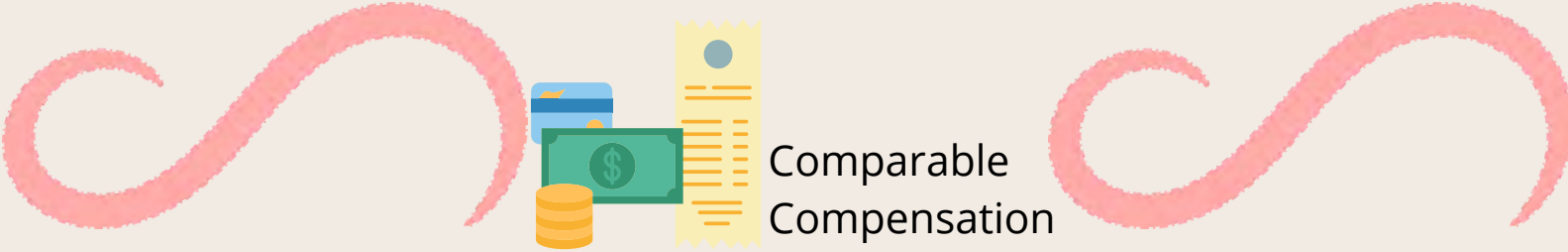


Communication

- Determine why people with lived experience are at the table – to share their story, participate as an equal member, just listen, provide feedback later, etc.?
- Offer mentorship and support for people with lived experience to learn how to best communicate their expertise.
- Meet with community members 15-30 minutes prior to the meeting to orient them to the discussions likely to take place and answer any questions they may have.
- Ask people with lived experience to contribute to the agenda. If you don't ask, their concerns and priorities may not be addressed.
- Offer appropriate (non-jargon-y) background information on the topic.
- Include everyone on all communications related to the project.
- Provide an agenda and documents a week in advance to any meeting.
- Designate consistent team member connectors to support people with lived experience. Make sure the people with lived experience know how to connect with them before, during, and after the meetings.

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SUPPORT



Comparable
Compensation



Small acts of kindness

- ♥ Remember a participant's name and use it when you greet them.
- ♥ Say 'thank you' often.
- ♥ Be interested in others' personal lives and share your story too.
- ♥ Celebrate everyone's birthdays.
- ♥ Send heartfelt, personalized thank-you notes.
- ♥ Give holiday gifts, other than cash or gift card equivalents, with a low fair market value, such as an ornament.
- ♥ At meetings, offer occasional snacks (coffee, fruit, candy).

For some people with lived experience, **it is best to bring them on staff as a paid consultant.** For others, they may either not want that level of commitment or financial reimbursement may impact other benefits. There are many ways to acknowledge and be reciprocal with people who have lived experience – ask them what works best.



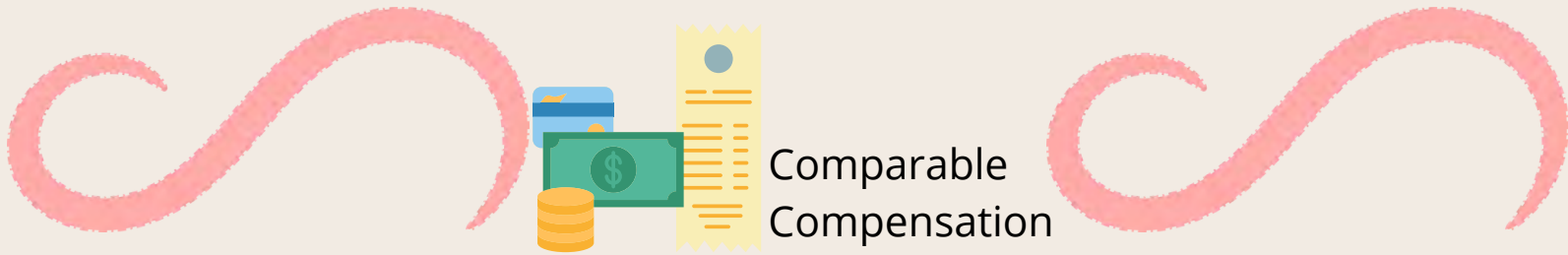
For an individual

- #1 Offer to write letters of recommendation for school or future employers.
- #1 Encourage volunteers to include their work with your organization on their resume.
- #1 As appropriate, nominate volunteers for community awards and recognition.
- #1 Offer plaques or similar mementos honoring their service.



12

SUPPORT



Comparable
Compensation



For everyone

- + Use special days e.g., 'Volunteers Week' or 'Make a Difference Day' to publicize their work and the time put into your projects.
- + Annually organize a social event, outing, or party to say thank you.
- + Post appreciation photos and videos highlighting volunteers on your organization's social media site (get permission first).
- + Write newspaper articles about volunteers' group achievements.
- + Celebrate major achievements, perhaps with an award ceremony to which you invite prominent local people.
- + Create and distribute a volunteer scrapbook.
- + Mention the effort put in by your volunteers in any newspaper or radio coverage.



13

STRENGTHS AND ASSETS



By leading with an asset-based approach, the outcome is more likely to be a good fit for the community. The best way to identify issues and concerns is to ask the people in the community. Always remember, the challenges that exist are not a reflection of the people in that community.



Strength based leadership pays attention to everyone's strengths and uses those strengths to support the project. Asset-based thinking means you look at yourself and the world through the eyes of what is working, what strengths are present, and what the potentials are. It is founded on the belief that communities and neighborhoods thrive when built upon the knowledge, interests, and capacities of their residents, groups, and institutions.

Tips to generate ideas from everyone

- ☀️ Begin each meeting with a not too personal ice-breaker.
- ☀️ Go around the group asking each person in the meeting to make a comment.
- ☀️ Use 1-2-4-all or pair shares as a technique to allow people time to formulate their ideas.
- ☀️ Consider general norms and agreements, like listening with an open mind, being non-judgemental, using "I" vs "You" statements, not interrupting, etc.
- ☀️ Invite the quieter people to take a particular role within the meeting, if they are comfortable.
- ☀️ Acknowledge the desire to hear from everyone openly in a meeting, and invite the more vocal people to try to speak less often.
- ☀️ Use Brainwriting when you think you want to use Brainstorming – it involves more ideas from everyone.
- ☀️ To keep communication open, invite everyone to share additional thoughts and ideas after the meeting - as this may be an option for quieter folks rather than having them speak during a meeting which may not be comfortable for them.



13

STRENGTHS AND ASSETS



Donna Hicks' Dignity Model

"The Dignity Model provides a framework for understanding how the experience of dignity can help strengthen relationships, resolve conflicts, or make organizations more successful, and how violations of dignity inevitably damage relationships, incite conflicts, or undermine organizational cultures."

Ten Essential Elements of Dignity

1. Acceptance of Identity
2. Recognition
3. Acknowledgment
4. Inclusion
5. Safety
6. Fairness
7. Independence
8. Understanding
9. Benefit of the Doubt
10. Accountability







Ten Temptations to Violate Dignity

1. Taking the Bait
2. Saving Face
3. Shirking Responsibility
4. Seeking False Dignity
5. Seeking False Security
6. Avoiding Conflict
7. Being the Victim
8. Resisting Feedback
9. Blaming and Shaming Others to Deflect Your Own Guilt
10. Engaging in False Intimacy and Demeaning Gossip



Create leadership opportunities, for example, to:

-  Serve as a co-chair or chair of a meeting.
-  Take the lead on a project or the evaluation.
-  Lead the discussion on an agenda item.
-  Connect to community resources.



14

TRUST



The more a program can be transparent, the greater the trust will be with the community. The greatest ideas for change are voiced in an atmosphere of trust.

“13 Behaviors of High Trust Leaders” by Stephen M. R. Covey

Character

- Talk Straight** – Be honest. Tell the Truth. Let people know where you stand in a polite and honest manner.
- Demonstrate Trust** - Care for others and show it. Treat everyone with respect, especially those who can't do anything for you.
- Create Transparency** - Tell the truth; be real, genuine, open and authentic. This may involve making meeting notes and decisions publicly available.
- Right Wrongs** - Admit when you're wrong, apologize quickly, show humility, don't let pride get in the way of doing the right thing.
- Show Loyalty** - Give credit to others, speak about people as if they're present and represent others who aren't there.

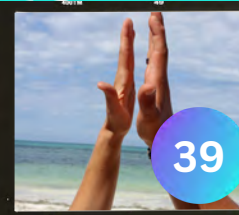
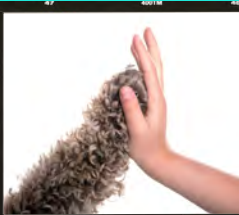
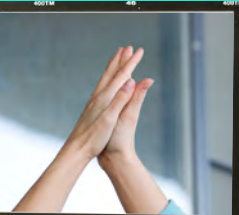
Competence

- Deliver Results** - Establish a track record of getting the right things done. Make things happen, on-time and within budget. As Yoda says, “Do or do not, there is no try.”
- Get Better** - Continuously improve. Increase your capabilities. Be a constant learner. Don't consider yourself above feedback.
- Confront Reality** - Tackle all issues head-on, even the “undiscussables.” Address the tough stuff directly. Confront the reality, not the person.
- Clarify Expectations** - Disclose, reveal and validate expectations. Don't assume they're clear or shared. Renegotiate if needed/possible.
- Practice Accountability** - Hold yourself accountable first, others second. Take responsibility. Be clear on how you'll communicate how you're doing and how others are doing. Don't blame.

Character + Competence

- Listen First** - Listen before speaking. Understand, diagnose, listen with ears, eyes and heart.
- Keep Commitments** - Say what you'll do, then do it. Make commitments carefully and keep them. Don't break confidences.
- Extend Trust** - Extend trust abundantly to those who've earned it, conditionally to those who are still earning it.

Think about who is in the room. Your truth should not harm others.

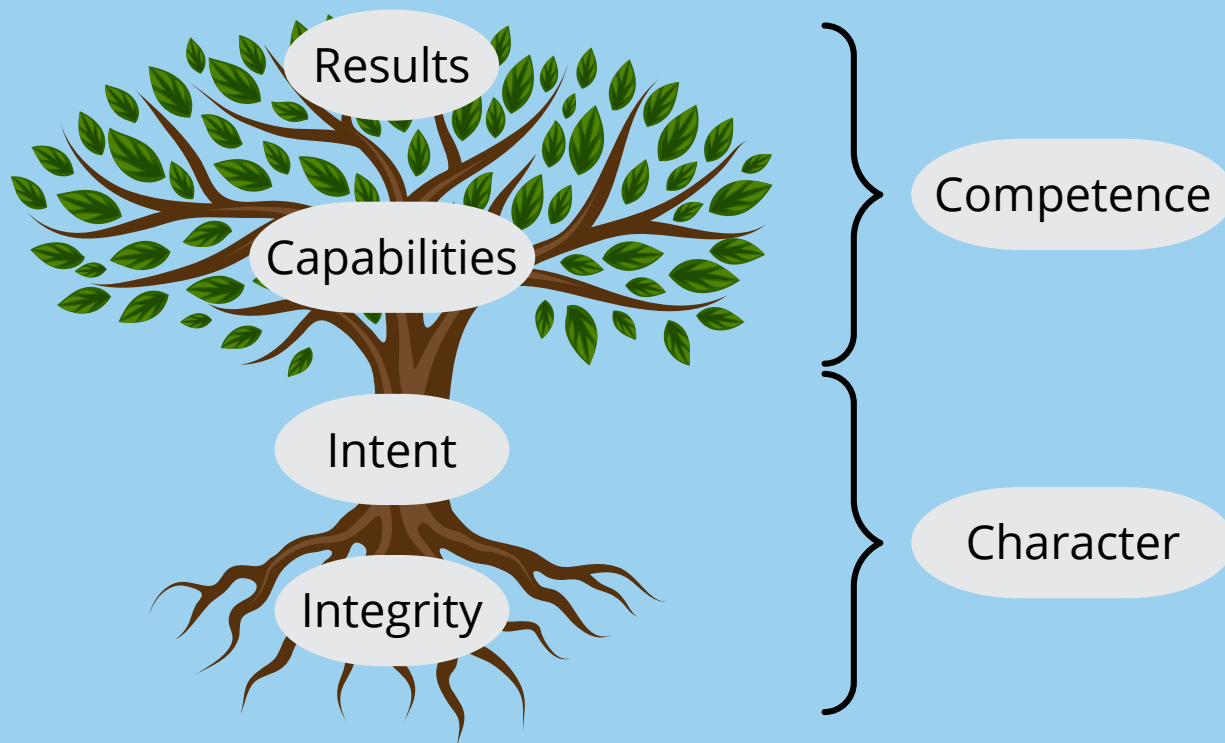


14

TRUST



“13 Behaviors of High Trust Leaders” by Stephen M. R. Covey



Other Tips

- Build in time to get to know each other as human beings who may have common interests or experiences.
- Create a culture where people feel they can bring problems to the group; use meetings as a place to solve problems, not just a place to report activities. This can be encouraged by reporting on activities via email and using meeting time to discuss ideas and solutions.
- Make sure everyone feels comfortable asking for help, sharing suggestions informally, or challenging the status quo without fear of negative social consequences. At times, people in traditional leadership roles are blind/deaf to power dynamics that others experience.
- Learn to recognize times when you need to go off the planned agenda in order to address people's underlying concerns.
- Realize that being your own worst critic does not actually improve the work; if you are constantly criticizing yourself in your relationships with others, you focus the attention on you, on support for you, rather than on the issue at hand.
- Engage in the simple act of using "I" statements, which leads us to claim our own experience rather than generalizing from our experience in ways that can exclude those who have a different experience or perspective.

15 COLLABORATIVE PROCESS



Once a group is gathered, the group creates the purpose moving forward. Everyone can learn from others and when this is a shared understanding then more creativity is fostered.



The Agenda:

- ➔ Create opportunities for people who have lived experience to lead the process and create the agenda.
- ➔ Review the agenda prior to a meeting with a small group that includes community representatives.
- ➔ Share the process about how to get time on the agenda or who to talk with.
- ➔ Have five minutes at the beginning or the end of the meeting for additional items or sharing thoughts or ideas.
- ➔ Recognize the importance of the issues for the people with lived experience and have the agenda prioritize those issues.
- ➔ Review and confirm mutually agreed upon “next steps” and “to do” items, especially if they have been assigned to particular individuals, before concluding the meeting.
- ➔ Set the next agenda at the end of the current meeting, including the date and time.
- ➔ Request agenda items a few weeks in advance of the meeting.



5 COLLABORATIVE PROCESS



Behavior:

- ➔ Once a group has made a decision, honor that decision and see what you and others can learn from making that decision, even and especially if it is not the way you would have chosen.
- ➔ Notice when you or others use 'either/or' language and make time to come up with more than two alternatives. When you stop after two ideas have been offered, you miss out on the third or fourth idea people were thinking about.
- ➔ When a sense of urgency arises, slow down and encourage people to take a pause, a breath, restate the goal, and dive deeper into alternatives.
- ➔ Acknowledge that collaboration takes more time, particularly at the front end and yields a better result with higher buy-in and higher ability to take shared risks.
- ➔ Recognize the power dynamics in the situation and respond thoughtfully.
- ➔ Welcome discomfort and learn to sit with discomfort before responding or acting.
- ➔ Leave rank and egos at the door. Only use first names and not titles.
- ➔ Share group agreements or norms, avoid office talk, and avoid acronyms.
- ➔ Include everyone in the process.



16

COMMITMENT



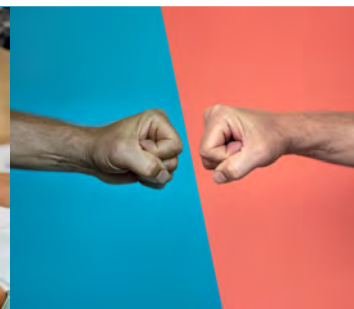
Building authentic relationships and creating an environment of trust takes time. When the process ends early, mistrust is created.

Support the Process:

- ★ Everyone will deepen the relationship and continue to work together for the long haul, fostering an atmosphere of trust.
- ★ Provide infrastructure, technical assistance, and support. Invest in developing leadership skills and building capacity for community members to effectively address their current and future challenges. For example, partner with a family-led or community based organization to provide training.
- ★ Develop a culture of appreciation; take time to make sure that everyone's work and efforts are appreciated. Be specific about what someone did that you are grateful.
- ★ Ensure communication is ongoing and everyone is getting the same message. Decide as a group how information is going to be shared (email, text, what's ap, etc.)

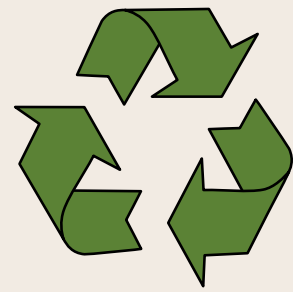
Evaluate the Process:

- ★ Have a safe person who will check in with participants following the meeting to see how the meeting went.
- ★ Use Plus/Delta (+/ Δ) at the end of meetings to evaluate the meeting.
- ★ Follow through and “close the loop.”
- ★ Dedicate funding for evaluation and dissemination of findings to monitor whether initiatives are working as intended and promote community buy-in and sustained investment in interventions.



17

SUSTAIN ENGAGEMENT



People with lived experience continue to have opportunities to share their expertise, make a difference, and are provided with new experiences to hone their skills.

Current Participants:

- ▶ Publicly recognize their involvement.
- ▶ Express gratitude, it goes a long way.
- ▶ Acknowledge people's participation in the final product.
- ▶ Ask and support people with lived experience to share the product (at conferences, posters, etc.).

Future Opportunities:

- ▶ Broaden the base of people with lived experience by repeatedly identifying new community members to be involved in projects or programs. Consider pairing newly involved individuals with more seasoned people with lived experience as mentors.
- ▶ Provide technical assistance and institutionalize support mechanisms for people with lived experience to be engaged and supported as leaders.
- ▶ Promote policies and practices to support engagement and leadership within organizations.
- ▶ Be honest about the future of the project. Sometimes grants simply end and there are not future opportunities in the same way or with the same group.



National **MCH** Workforce
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Advancing Health Transformation

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