

Spectrum of Engagement: Assessment of Meaningful Engagement of People with Lived Experience in the Healthy Start Community Consortia

Organization and/or Team: _____ Date: _____

Purpose

This assessment of the different ways of engaging individuals with lived experience in the Healthy Start (HS) Community Consortium has been adapted from The *Lived Experience Inclusion Ladder*.¹ The Lived Experience Inclusion Ladder is a way to think about a commitment to increasing the highest levels of meaningful (rather than tokenizing) lived experience engagement in decision-making and leadership that are possible and realistic for people with lived experience. For the HS Community Consortium, individuals with lived experience include community members who are enrolled HS participants and women of reproductive age, mothers, fathers, or partners, and other people with lived experience living in the project area.

The first five levels in the table below describe the goals at each level for engaging individuals with lived experience. The sixth level, “structures,” describes the organizational processes that facilitate engagement and can help with planning activities.

Level	Description
Inform	Provide information
Consult/ask	Obtain feedback on program and/or decisions
Involve	Work with community members to hear concerns and feedback and incorporate input in decision-making
Collaborate	Partner with community members in decision-making throughout planning
Empower	Place decision-making authority on new initiatives, activities, or services in the hands of community members
Structures	Work plan of activities and assignment of community member roles and responsibilities to achieve its goals

Instructions

Use the table below to assess your organization’s level of engagement. Circle 0 for no (N), 1 for some/sometimes (S), 2 for yes (Y). Circle X for “unknown” (U) if you do not know the answer to this question based on your experiences with the organization.

Your “score” on this assessment is less important than what you do with its results. The scores on the assessments do not tell you whether or not you are succeeding or failing, or whether or not you should be proud or ashamed. They give you information that you can use to have a more impactful strategy. The goal is to evaluate your own strategy of meaningfully engaging individuals with lived experience in your Healthy Start Community Consortium, identify and prioritize follow-up actions, and develop a strategy for implementing changes. This is continual quality improvement (CQI).

¹ See original inclusion ladder developed for the meaningful engagement of people with lived experience of human trafficking: [Meaningful-Engagement-of-People-with-Lived-Experience.pdf \(gfems.org\)](https://www.gfems.org/meaningful-engagement-of-people-with-lived-experience.pdf)

Assessment of the Level of Engagement of People with Lived Experience in the Healthy Start Community Consortia

Engagement Activities		N	S	Y	U	Score
INFORM						
1	Are our public materials (e.g., websites, newsletters, social media, and reports) written in plain language, accessible, with acronyms or terms explained?	0	1	2	X	
2	Do we provide information in an easily understandable way about how positive feedback or complaints from people with lived experience are addressed?	0	1	2	X	
3	Do we consistently provide overall project updates to Community Consortium members with lived experience?	0	1	2	X	
4	Do we have safeguarding/protection/ complaints policies that are easy to access and understand? Do they inform people how complaints are addressed?	0	1	2	X	
5	Do our public materials avoid perpetuating stereotypes or bias against impacted people or using sensational imagery that dehumanizes them?	0	1	2	X	
6	Do our public materials utilize impacted people's stories or images only with consent and only as necessary to tell the story of our organization?	0	1	2	X	
7	Do we have a process for people to revoke consent later if they no longer want their stories or images used?	0	1	2	X	
Totals					X	Total Score on Inform:
Percent						___/___(___%)
CONSULT/ASK						
8	Do we regularly survey our existing Community Consortium members with lived experience for both positive and critical feedback and incorporate that feedback for continuous quality improvement?	0	1	2	X	
9	Do we have a clear and accessible grievance policy and protocol for reviewing and addressing grievances from current members?	0	1	2	X	
10	Do we incorporate feedback from Community Consortium members with lived experience and/or responses to surveys of current clients in deciding what kinds of funding to apply for and/or offer and are they informed about how and why their feedback is reflected?	0	1	2	X	
Totals					X	Total Score on Ask:
Percent						___/___(___%)

Engagement Activities		N	S	Y	U	Score
INVOLVE						
11	Do we engage organization, program, or project-specific lived experience advisory teams that provide input at key stages throughout the work or project?	0	1	2	X	
12	Are Community Consortium members with lived experience offered opportunities to learn skills they might need to have more opportunities to participate at the “involve” level?	0	1	2	X	
13	Are participants for advisory positions selected/ invited based on both knowledge and interest, rather than solely because they are Community Consortium members with lived experience?	0	1	2	X	
14	Do we evaluate members’ experiences of working with our Community Consortium at the “involve” level and have clear procedures in place for using the feedback for continuous quality improvement?	0	1	2	X	
Totals					X	Total Score on Involve:
Percent						___/___(___%)
COLLABORATE						
15	People with lived experience are in leadership positions in our Community Consortium such as working group chair. (0: 0%, 1: up to 25%, 2: over 25%)	0	1	2	X	
16	Our Community Consortium has advanced equity in our work, and it has demonstrated a willingness to change the way the Consortium operates to be inclusive and equitable. (0=No, 1= this is in progress, 2=we are well along our journey)	0	1	2	X	
17	Our Community Consortium considers potential power imbalances that may exist with organizations we partner with, and it has ways of working together fairly to share decision-making.	0	1	2	X	
Totals					X	Total Score on Collaborate:
Percent						___/___(___%)
EMPOWER						
18	Our organization scored well on the “Collaborate” section of this assessment. (0=up to 50%, 1=50-75%, 2=over 75%)	0	1	2	X	
19	Members with lived experience report similar levels of satisfaction with the Community Consortium compared to those who do not disclose lived experience.	0	1	2	X	
20	Our board and executive leadership demonstrate a commitment to support, develop, and empower the people in leadership positions who have lived experience.	0	1	2	X	
Totals					X	Total Score on Empower:
Percent						___/___(___%)

Engagement Activities		N	S	Y	U	Score
STRUCTURES						
21	Our Community Consortium uses the highest level of engagement that is possible for each project based on staffing and the interest, expertise, and strengths of people with lived experience in our networks.	0	1	2	X	
22	When a project of the Community Consortium does not have people with lived experience as part of the project team, people with lived experience are engaged at the ask or involve level to fill gaps in knowledge.	0	1	2	X	
23	Lived experience expertise is engaged in the development of initial program/project design, implementation, and evaluation.	0	1	2	X	
24	Our Community Consortium ensures members with lived experience have similar workloads to those without lived experience in similar roles and are not expected to take on extra work or unpaid overtime.	0	1	2	X	
Totals					X	Total Score on Structures:
Percent						___/___(___%)

Analysis

- Calculate the percentage for each level of inform, consult, involve, collaborate, empower, structure:
 - Identify the total possible for each level, that is, add all the “2s” in each level. Exclude questions marked “X” (unknown) when calculating this total.
 - Identify the total score for each level based on your rating.
 - Divide the total score for each level by the total possible for each level and multiply by 100.
- Do you have 75 percent on Inform? If so, look at your score for Consult/Ask–do you have 75 percent? Continue through the sections’ scores until you identify the first level at which you fail to score 75 percent. This is your target level for your first actions.
- Are there any questions that could be brought to a score of two with little or no funding in less than a month? These are your “low-hanging fruit.” You can knock them off the list and improve them easily. Give yourself up to one month to address any low-hanging fruit.
- Are you at 75 percent now? If so, you can move on to the next level that has a score of lower than 75 percent. Remember, you can continue to work on any remaining indicators even in levels that you “passed” as ongoing projects.
- If resolving your low-hanging fruit does not get you to 75 percent, you will need to do a mid-level analysis for that level to determine the next steps.