

Welcome!

We are so glad you are here!

We will get started shortly.
In the meantime, we invite you to intentionally enter this space.



Silence your cell phone



Stretch



Close the door



Take a few deep breaths



Close browser windows



Emotionally release your to-do list



Check your audio and video



Take a bio break

Healthy Start Evaluation Webinar
Engaging People with Lived Experience in the Community Consortium

Wednesday, November 6, 2024 || 2:00pm – 3:00pm ET



Healthy Start Evaluation Webinar: Engaging People with Lived Experience in the Community Consortium

WEDNESDAY, NOVEMBER 6, 2024
2:00AM – 3:00PM ET

THE HEALTHY START TA & SUPPORT CENTER IS OPERATED BY THE NATIONAL INSTITUTE FOR CHILDREN'S HEALTH QUALITY (NICHQ). THIS PROJECT IS SUPPORTED BY THE HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA) OF THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) UNDER GRANT NUMBER 1 UF5MC327500100 TITLED SUPPORTING HEALTHY START PERFORMANCE PROJECT.

NICHQ
National Institute for
Children's Health Quality

**HEALTHY
start**
TA & SUPPORT CENTER





THIS SESSION IS BEING RECORDED.



ALL PARTICIPANTS ARE MUTED UPON ENTRY. WE ASK THAT YOU REMAIN MUTED TO LIMIT BACKGROUND NOISE.



PARTICIPANTS ARE ENCOURAGED TO SHARE COMMENTS AND ASK QUESTIONS USING THE CHAT BOX.



Welcome & Introduction

Ada Determan

DIVISION OF HEALTHY
START & PERINATAL
SERVICES

*HEALTHY START EVALUATION WEBINAR
HOSTED BY THE HEALTHY START TA & SUPPORT CENTER AT NICHQ*

NICHQ
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HEALTHY
start
TA & SUPPORT CENTER

Engaging People with Lived Experience in the Community Consortium

New Measure to Include in Healthy Start Non-Competing Continuation Progress Reports

Healthy Start TA & Support Center
November 6, 2024
Presented by Westat

Objectives

1. Understand the performance measure for engaging people with lived experience in the Community Consortium that Healthy Start grantees will have to describe in the annual Non-Competing Continuation (NCC) progress report.
2. Use the spectrum of engagement to plan the meaningful engagement of people with lived experience.
3. Be able to assess and document progress on the engagement of people with lived experience for continuous quality improvement.

Community Consortium Members

- At least **25% of Community Consortium members** are expected to be enrolled Healthy Start participants and women of reproductive age, mothers, fathers, or partners, and other **people with lived experience** living in the project area.
- Other representatives of the Community Consortium to include:
 - Title V
 - Public health departments
 - Hospitals
 - Health centers
 - State substance abuse agencies
 - Other significant sources of health care services
 - Other partners (e.g., community leaders; representatives from service agencies; community-based organizations; state/non-profit organizations/faith-based organizations addressing housing, employment, education, transportation, and health care)

Source: HRSA's Notice of Funding Opportunity (HRSA-24-033, Healthy Start Initiative: Eliminating Disparities in Perinatal Health)

Poll

For the returning grantees, how did you encourage HS participants and community members to participate in the Community Consortium (formerly Community Action Network or CAN)? (Select all that apply)

1. Financial incentive/compensation (e.g., gift cards)
2. Meal/refreshments offered at the meeting
3. Childcare
4. Transportation reimbursement
5. Bonus points that could be redeemed through incentive program (e.g., for baby goods, diapers, etc.)
6. Some other way (please provide examples in the chat)
7. Did not provide any incentive

Poll

For the returning grantees, how did you engage Healthy Start participants and community members in your Community Consortium (formerly the Community Action Network or CAN)? (Select all that apply)

1. Provided them educational sessions and information (e.g., about CAN activities, community services, or a particular topic)
2. Obtained their feedback on products (e.g., for educational materials and resources)
3. Heard their concerns and feedback and incorporated input in decision-making (e.g., in strategic planning, program activities, or mentoring)
4. Partnered with them in decision-making throughout planning activities (e.g., for CAN initiatives)
5. Gave them decision-making authority on new initiatives and activities such as for the CAN
6. Engaged them in other ways (please provide examples in the chat)

Community Consortium Members: Engagement of Persons with Lived Experience

HRSA DGIS Activity Form: In the coming year, HS grantees will have to report on the measure for Engagement of Persons with Lived Experience:

- *During the reporting period, did your program support engagement of persons with lived experience?*

DGIS or the Discretionary Grant Information System is HRSA's web-based system that collects data from grantees on the performance of their programs. The data is used to assess the effectiveness of the programs, identify gaps, and inform future planning.

Engagement of Persons with Lived Experience: Definition in DGIS

Individuals with knowledge and experience on health or social issues relevant to a particular program that is gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people.

Community-based organizations, for example, would not be included under this definition. For the purposes of this form, engagement of persons with lived experience is measured through two categories: “Family Engagement” and “Other Persons with Lived Experience.” Family members often navigate systems and services on behalf of individuals, so their lived experience is collected separately. Therefore, for data collection purposes, the term “Other Persons with Lived Experience” is used to delineate from family engagement and avoid duplicated counts.

Source: HRSA/MCHB DGIS, Attachment B, OMB Clearance Package (page 29-35)
[DGIS 0915-0298 Exp 12.31.26 Full Package \(hrsa.gov\)](#)

Report in DGIS What Your Program Did to Engage Persons with Lived Experience

- 1) *Whether*** your program supported engagement of persons with lived experience (Yes/No)
- 2) *Areas of engagement:*** Program Development, Planning and Evaluation; Leadership Training; Active Leadership (Yes/No for each and number engaged)
- 3) *Race and ethnicity*** - number engaged
- 4) *Underrepresented groups*** - number engaged
- 5) *Compensation*** - whether they were compensated for their engagement and number compensated
- 6) *Resulting changes to program*** - whether engagement resulted in changes and types of changes noted (program priorities; program quality; program's messaging; enrollment; funding/resources; buy-in for goals; implemented shared goals; other)

Source: HRSA/MCHB DGIS, Attachment B, OMB Clearance Package (page 29-35)
[DGIS 0915-0298 Exp 12.31.26 Full Package \(hrsa.gov\)](#)

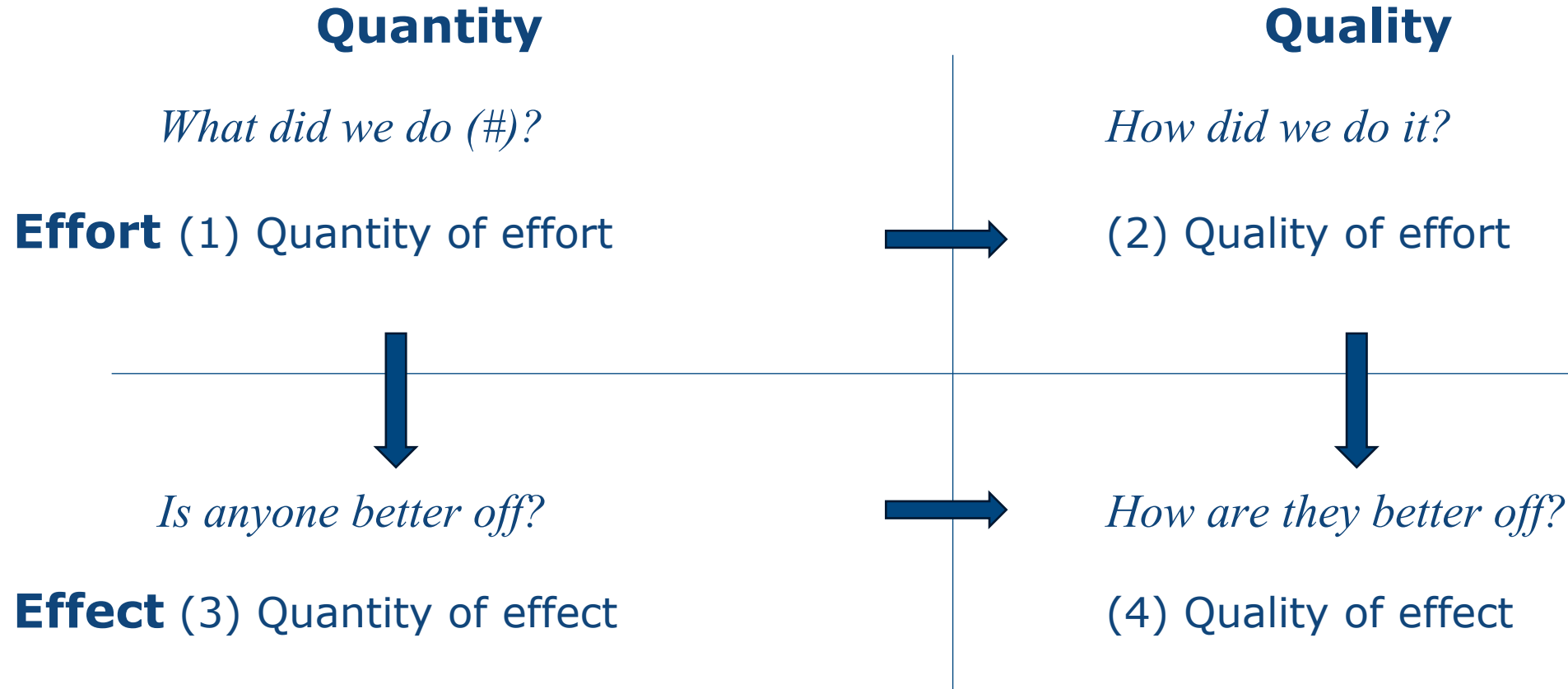
In the NCC Progress Report Describe How Your Program Engaged Persons with Lived Experience

In addition to reporting *what* you did in the DGIS, you will be asked to describe *how* you did it in the NCC progress report:

- *What was your process of engagement?*
- *To what extent did you engage people with lived experience?*
- *What does success look like?*

In today's session, we will focus on addressing these question for reporting in the NCC progress report.

Four Quadrants of Measurement for Effort and Effect



Meaningful Engagement

People impacted by an issue know

- Whether a program or service is helpful
- How it might be improved

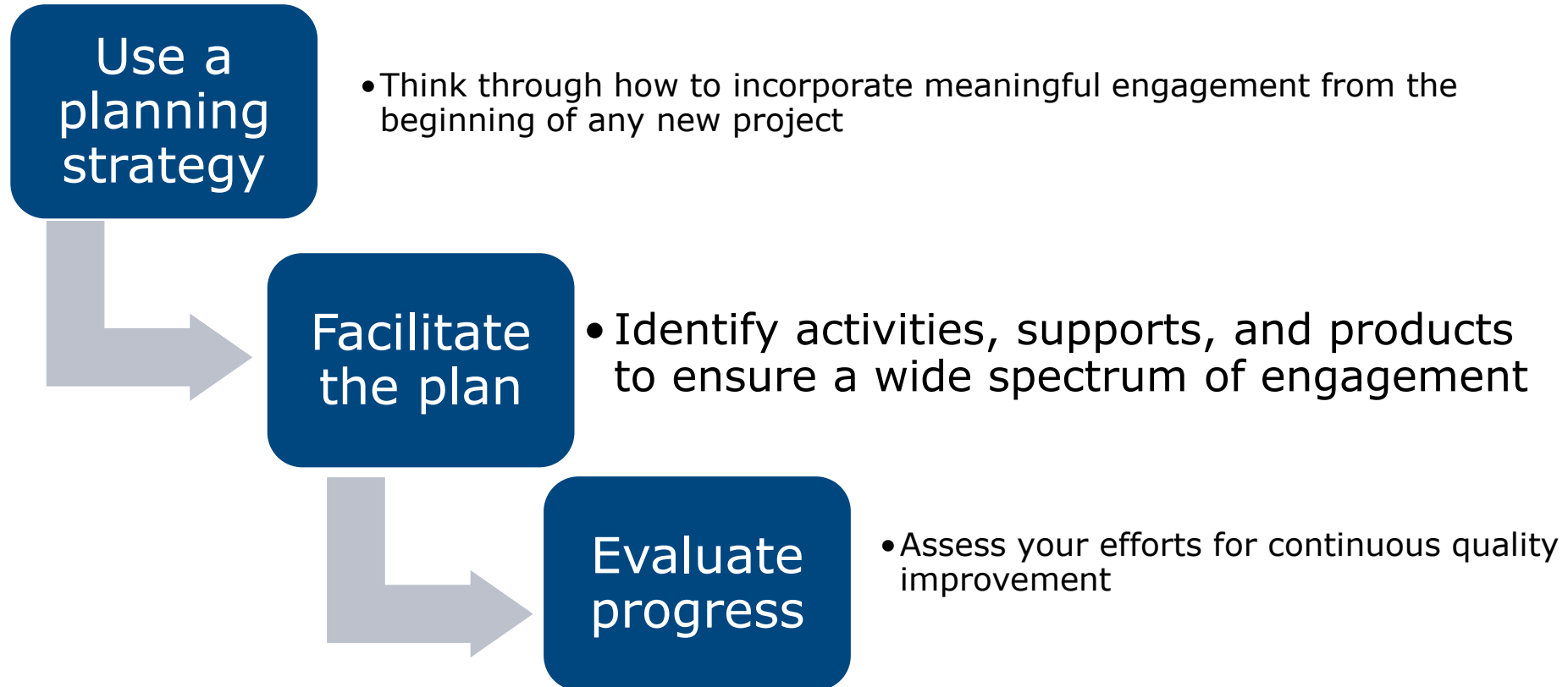
People with lived experience

- Are experts of their experience

Meaningful engagement of people with lived experience

- Ensures that people impacted by an issue are involved in developing, implementing, and evaluating the effectiveness of strategies to address the issue

Planning and Assessing Meaningful Engagement



Spectrum of Engagement: Strategy to Engage People with Lived Experience at Different Levels



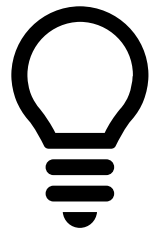
Source: IAP2 ([IAP2 Federation - P2 Pillars.pdf \(ymaws.com\)](https://www.ymaws.com/iap2-federation.org/PDFDocs/P2_Pillars.pdf))

Planning Engagement of People with Lived Experience in the Community Consortium

Under each level of engagement, list ways you can incorporate multiple ways to meaningfully engage people with lived experience in the Community Consortium. Consider completing for different projects during the planning process. You may not have something in every block.

Inform	Ask/Consult	Involve	Collaborate	Empower

For each level, think about:



- What are the processes that support this level of engagement?
- What are the tools we may need to implement this level of engagement?
- What are the supports we can put in place to be successful at this level?

Spectrum of Engagement: Tools to Meet Goals at Each Level

Inform

- Goal: Provide information
- Tools: fact sheets, websites, newsletters

Consult

- Goal: Obtain feedback on program and/or decisions
- Tools: Surveys, public meetings, focus groups, community forums

Involve

- Goal: Work with community members to hear concerns and feedback and incorporate input in decision-making
- Tools: Workshops, community meetings

Collaborate

- Goal: Partner with community members in decision-making throughout planning
- Tools: Advisory committees with community members; funding as partners

Empower

- Goal: Community members have decision-making authority on new initiatives, activities, or services
- Tools: Support of leadership and partnership

Source: IAP2 ([IAP2 Federation - P2 Pillars.pdf \(ymaws.com\)](http://ymaws.com))

Spectrum of Engagement Assessment Worksheet

Spectrum of Engagement Assessment of Meaningful Engagement of People Adapted for Healthy Start Communities

Organization and/or Team: _____

Purpose: This assessment of the different ways of engaging Healthy Start (HS) Community Inclusion Ladder has been adapted to the highest levels of meaningful (rather than tokenizing) making and leadership that are possible and realistic for Community Consortiums, individuals with lived experience enrolled HS participants and women of reproductive age people with lived experience living in the project area.

The table below describes the levels of engaging in the assessment. The level, "structures," describes engagement.

Level	Description
Inform	Provide information
Consult/ask	Obtain feedback on program
Involve	Work with community members to incorporate input in decision-making
Collaborate	Partner with community members to make decisions
Empower	Place decision-making in the hands of community members
Structures	Work plan of activities and responsibilities to achieve goals

Instructions: Use the table below to answer (N), 1 for some/sometimes (S), 2 for yes/always (Y), 3 for no/never (X) to this question based on your answer to this question based on your assessment. Your "score" on this assessment is the number of "2"s you have. If you have 0 "2"s, you should be proud or ashamed. They are the assessments do not tell you why you should be proud or ashamed. They are the goal is to evaluate your experience in your Healthy Start Community Consortium and develop a strategy for implementation.

* See original inclusion ladder description at <https://www.hhs.gov/health-equity/meaningful-engagement/>

Assessment of the Level of Engagement		Engagement Activities	N S Y U					Score
INFORM		INVOLVE						
1	Are our public materials, social media, and reports accessible, with accurate information, and easy to understand?	11 Do we engage organization members with lived experience at key stages through our work?						
2	Do we provide information about our work to people with lived experience?	12 Are Community Consortium members offered opportunities to have more of the "involve" level?						
3	Do we consistently provide information to our Community Consortium members?	13 Are participants for advisory based on both knowledge and lived experience?						
4	Do we have safeguard policies that are easy to understand and they inform people with lived experience?	14 Do we evaluate members of our Community Consortium for continuous quality improvement?						
5	Do our public materials or bias against individuals with lived experience?	Totals						
6	Do our public materials or images or necessary to tell the truth?	COLLABORATE						
7	Do we have a process later if they no longer used?	15 People with lived experience in our Community Consortium chair. (0: 0%, 1: 25%, 2: 50%, 3: 75%, 4: 100%)						
	Totals	16 Our Community Consortium work, and change the way we work?						
	CONSULT/ASK	17 Our Community Consortium members share decisions?						
8	Do we regularly solicit feedback from our Community Consortium members?	Totals						
9	Do we have a clear protocol for reviewing current members?	EMPOWER						
10	Do we incorporate Community Consortium members' responses to our work into our work plan?	18 Our organization's work plan is informed by the needs of our members?						
	Totals	19 Members are satisfied with their experience?						

Analysis

- Calculate the percentage for each level of inform, ask, involve, collaborate, empower, structure:
 - Identify the total possible for each level, that is, add all the "2s" in each level.
 - 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% on Inform? If so, look at your score for Consult/Ask - do you have 75%? 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% now? If so, you can move on to the next level that has a score of lower than 75%. 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%, you will need to do a mid-level analysis for that level to determine the next steps.

- We have developed a worksheet to assess your organization's level of engagement to share with you.
- Your "score" on this assessment is less important than what you do with its results.
- You can use the results 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.

Assessment of the Level of Engagement of People with Lived Experience: Example Questions in the Worksheet

Level	Example of Activity	N	S	Y	U	Score
INFORM	Are our public materials (websites, newsletters, social media, and reports, for example) written in plain language, accessible, with acronyms or terms explained?	0	1	2	X	
CONSULT/ ASK	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	
INVOLVE	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	
COLLABO- RATE	Are people with lived experience in leadership positions in our Community Consortium such as co-chair of a meeting? (0: 0%, 1: up to 25%, 2: over 25%)	0	1	2	X	
EMPOWER	Do 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	
	<i>Calculate the score for each level separately to assess which level of engagement you are at.</i>				X	Total Score __/__(__%)

N=No; S=Sometimes; Y=Yes; U=Unknown

Spectrum of Engagement Assessment to Plan and Document Progress for Continuous Quality Improvement

Be clear and transparent about your position on the spectrum and fulfill the promises of being there.

- Complete the assessment at the beginning of a project to identify the engagement level you are at and decide which level you want to reach.
- Identify and implement the activities of the level you plan to reach. Use the tools relevant for each level.
- Complete the assessment again periodically to assess your progress.
- Based on what you learned, modify or expand your approach and activities that you implemented.

Evaluate the quality of your effort and its effect: How did you do? How are people better off?

Continuous Quality Improvement
Cycle



[Plan-Do-Study-Act \(PDSA\) Worksheet | Institute for Healthcare Improvement \(ihi.org\)](#)

Poll

How likely are you to use the Spectrum of Engagement to guide the meaningful engagement of persons with lived experience in your Community Consortium?

1. Not at all likely
2. Not very likely
3. Somewhat likely
4. Very likely

Poll

What levels may be challenging for engaging community members with lived experience in the Community Consortium? (Select all that apply)

1. Inform: Provide them educational sessions and information
2. Consult: Obtain feedback on Consortium activities and decisions
3. Involve: Work with them to hear concerns and feedback and incorporate input in decision-making
4. Collaborate: Partner with them in decision-making throughout planning
5. Empower: Place decision-making authority on new Consortium initiatives, activities, or services in their hands

Discussion

What challenges engaging community members with lived experience can you share?

How do you select a diverse group of Healthy Start participants to participate in the Community Consortium?

Resources

- C. Ash and S. Otiende. Meaningful Engagement of People with Lived Experience: A framework and assessment for increasing lived experience leadership across the spectrum of engagement. Global Fund to End Modern Slavery and National Survivor Network- Cast, Washington, DC (2023). <https://gfems.org/wp-content/uploads/2023/01/Meaningful-Engagement-of-People-with-Lived-Experience.pdf>
- Collective Impact Forum: Community Engagement Toolkit. <https://collectiveimpactforum.org/wp-content/uploads/2021/12/Community-Engagement-Toolkit.pdf>
- International Association for Public Participation. Spectrum of Public Participation. [https://cdn.ymaws.com/sites/iap2.site-ym.com/resource/resmgr/files/IAP2_Federation - P2 Pillars.pdf](https://cdn.ymaws.com/sites/iap2.site-ym.com/resource/resmgr/files/IAP2_Federation_-_P2_Pillars.pdf)

Thank you

For more information reach us at:

HSEvalSupport@westat.com



Healthy Start Evaluation Webinar 2: Engaging Community Members in Data-Related Decisions

*Wednesday, November 13
3-4pm ET*



*HEALTHY START EVALUATION WEBINAR
HOSTED BY THE HEALTHY START TA & SUPPORT CENTER AT NICHQ*

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Thank you!