



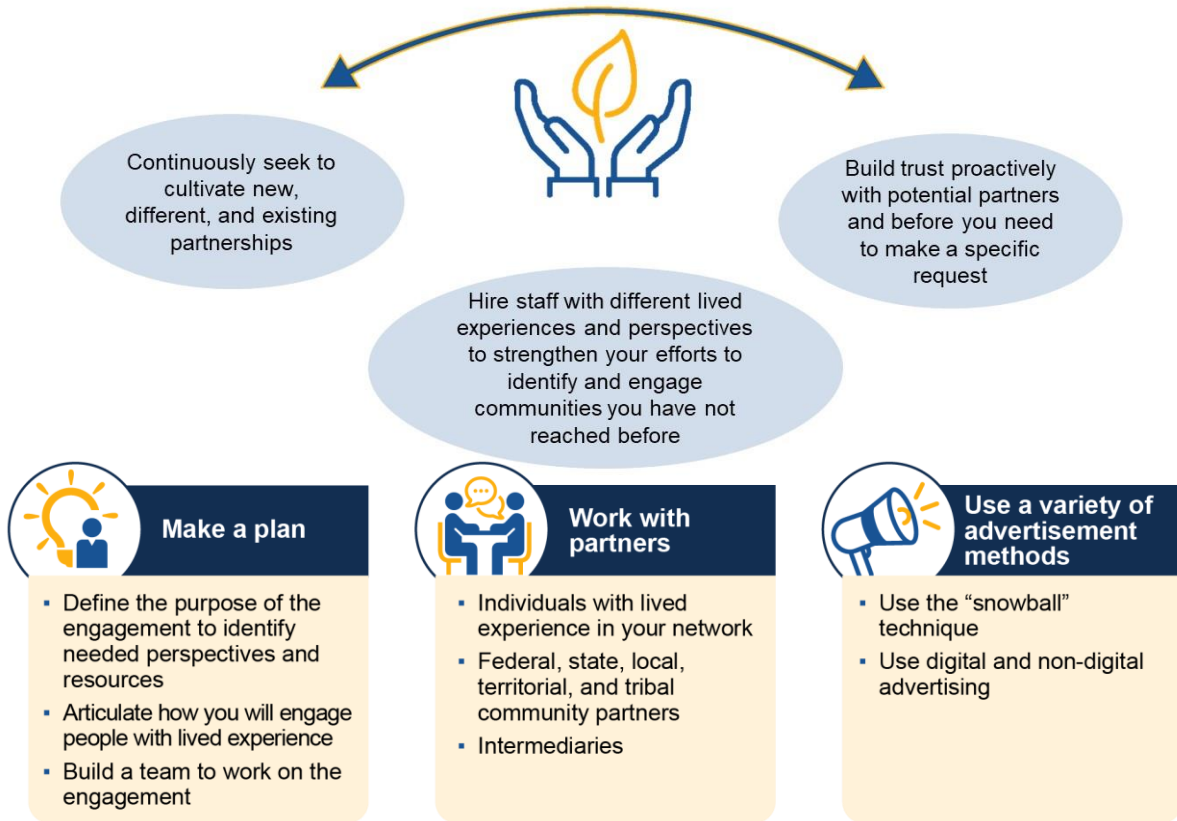
# Strategies to Identify People with Lived Experience

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## Purpose

It is vital to engage people with lived experience in developing and informing health and human services programs, policies, and research to ensure that they reflect the perspectives and needs of the communities we aim to serve. People with lived experience are those directly affected by social, health, public health, or other issues and by the strategies that aim to address those issues. This gives them insights that can inform and improve research, policies, practices, and programs. This tool provides concrete strategies—making a plan, working with partners, and using a variety of advertisement methods—for identifying people with lived experience to engage in health and human services work.<sup>3</sup>

**National, regional, state, tribal, and territorial health and human service groups can use a range of strategies to identify people with lived experience from unreached communities. The graphic shows three strategies discussed in this resource and highlights an overarching, continuous strategy of cultivating partnerships with different communities:**



<sup>1</sup> Suggested Citation: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. “Strategies to Identify People with Lived Experience,” by Grace Guerrero Ramirez, Lauren Amos, Annalisa Mastri, Ryan Ruggiero, Dana Jean-Baptiste, Nkemdirí Wheatley, Tonyka McKinney, Kataney Prior, Roger De Leon, Madison Sandoval-Lunn, Wilnisha Sutton, and Eric Washington. Washington, District of Columbia: 2022.

<sup>2</sup> ASPE would like to thank and acknowledge the insights of numerous HHS staff who contributed to the content in this guide.

<sup>3</sup> For more information on how to engage people with lived experience, see <https://aspe.hhs.gov/lived-experience>.

## Strategies



**Make a plan.** Before you identify people to recruit, formulate a plan to help you identify and ultimately engage a group with the varied perspectives you need.

- ▶ **Define the specific purpose of the engagement—the “why”—to identify the perspectives you need, those you are missing, and the resources you will need to engage everyone.** Before identifying people with lived experience, consider:
  - What is the **goal** of the engagement?
  - What **types of perspectives, identities, experiences, and expertise are you seeking** to represent and why? Ensure that those perspectives reflect populations central to the engagement’s goals.
  - What **perspectives are typically under- or overrepresented** in your information-gathering and decision-making processes? For example, which communities have not been reached in earlier engagements, such as those that may distrust government, those that have been traditionally excluded, and/or those facing burdens to attaining their optimal health, well-being, and economic goals? Which communities tend to benefit from engagement opportunities, and which have been denied such opportunities?
  - **Which groups might you overlook or exclude** when recruiting individuals with lived experience, such as individuals from communities that have openly reported negative perspectives about the policy or program in question?
  - To what extent have you **proactively sought new and opposing perspectives**? To what extent do you routinely recruit and engage the same individuals?
  - What strategies and processes can ensure that you **hold yourselves accountable for achieving your goals for engaging varied perspectives**? Consider whether you need to develop tools to track how well you are meeting goals. For example, you may use a rubric or spreadsheet to identify key skills you are seeking or capture characteristics of potential experts (e.g., area of lived experience).
  - What **resources** (such as budget and staff skills and knowledge) do you **need to identify**, recruit, and, ultimately, engage individuals? Include ample staff time for effective engagement. Train staff on the skills needed to effectively engage, such as by reflecting on their context and attitudes, and by training on topics such as trauma-informed engagement.
- ▶ **Articulate how you will engage people with lived experience** by outlining the engagement **methods you will use** and **how you will act** on individuals’ input. Plan to be flexible about engagement methods and transparent about constraints on their potential influence and impacts that individuals can have by engaging.



- Be **open to new and opposing perspectives**—remember, **communities are not monolithic.**
- Consider conducting a **relationship mapping activity** to identify individuals whom you have and have not engaged. Mapping can also help you explore individuals’ level of influence in their communities, helping you broaden your reach.

► **Put together a team to work on the engagement.**

- **Identify roles for staff** (e.g., who will be primarily responsible for identifying people with lived experience who are not staff, who will communicate with those you engage).
- Consider bringing in **external partners such as contractors or technical assistance providers who specialize in recruitment and engagement** of people with lived experience to consult on or oversee your identification process. Brief external partners on your goals and engagement plan.



**Work with partners.** Collaborate with a wide variety of partners to help identify people with lived experience whom you can potentially engage. If you are conducting large-scale recruitment, partners can help promote the opportunity. Partners may include:

- **Individuals with lived experience in your network.** Ask people with lived experience in your network for recommendations, outreach assistance, and any perspectives you may overlook. If appropriate, seek recommendations from those you engaged for other efforts. It is **important not to rely solely on connections with people you already know**, although such individuals can offer **valuable recommendations** to complement other efforts.
- **Federal, state, local, territorial, and tribal community partners.** Contact community partners, especially trusted leaders who may act as credible messengers in the community or have connections to individuals with lived experience. Consider the following types of partners:
  - **Community leaders** with lived experience who can connect you with their networks
  - **Community partners** that can connect you with informal groups relevant to your goals, such as interest groups, parent groups, or veterans groups
  - **Places of worship** and **faith-based** organizations
  - **Trusted providers**, such as community health workers, job training and adult education centers, service coordinators, or religious organizations
  - **Groups that have effectively reached communities during past efforts** to gather input (e.g., census counts) or to distribute information
  - **Local, regional, and family foundations**
  - **Advocacy** groups
  - **Parent organizations** (e.g., parent centers in each state's department of education, Head Start parent advisory councils)
  - **Chambers of Commerce**
  - **Federal, state, local, territorial, and tribal government or service agencies**, such as housing authorities, Temporary Assistance for Needy Families offices, or public health agencies
- **Intermediaries.** Ask national and intermediary groups for contacts, including:
  - **Affinity or advocacy groups that conduct direct engagement**, such as patient advocacy organizations, survivor-led coalitions, or state peer coalitions
  - **Allied professional groups**, such as professional associations, direct service providers, or authors/researchers involved with the community
  - **Educational partners**, such as colleges or sororities and fraternities

- **Existing advisory groups**, such as employee groups or patient boards
- **Disability organizations**, such as Centers for Independent Living (CIL), Councils on Developmental Disability (DD Councils), or University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD)
- **Area Agencies on Aging (AAA)**
- **Health care entities**, such as medical advisory committees, health care practitioners or clinical investigators, or health centers
- **Individuals with widespread influence**, such as celebrities, who can highlight your interest in identifying people
- **Attendees or speakers from relevant conferences** that reach different audiences



**Use a variety of advertisement methods.** If you are seeking to identify a broad range of experts from communities to which you are not already connected, explore methods below.<sup>4</sup> Tailor strategies to your context and consider promotional partners.<sup>5</sup>

- ▶ **Use the “snowball” technique.** Ask potential participants to identify other partners or individuals to engage, especially if they are interested but unable to participate. **Use digital advertising.** Explore social media, online community groups, newsletters and listservs, webinars, and virtual flyers.
- ▶ **Use nondigital advertising.** Consider potential nondigital outreach methods:
  - **Post flyers in public places in potential communities**, such as bus stops, relevant community-based organization offices, and local schools
  - **Publish media advertisements**, relying on platforms that are popular with relevant audiences
  - **Use local service access or complaint lines**
  - **Conduct door-to-door outreach** in potential communities
  - **Advertise** at local gathering places such as health fairs or community centers, community events (e.g., festivals), sporting or entertainment events, or local businesses (e.g., barber shops, nail and beauty salons, social clubs)



- **Find ways to thoughtfully ask those who previously declined** to engage why they were not interested or able to engage, noting that as part of your work you hope to learn and improve your engagement efforts. Then, adapt your outreach strategy to address the feedback.
- **Conduct outreach through oral, manual (e.g., signs, gestures), and written (e.g., words, images) means** to make outreach accessible.

<sup>4</sup> Most strategies in this section are relevant when recruiting broadly rather than when recruiting from a small, curated group. These strategies are most likely to be implemented when promoting an opportunity for which individuals would apply.

<sup>5</sup> For detailed strategies on recruiting people with lived experience, see <https://aspe.hhs.gov/lived-experience>.