



# Strategies for National and State Groups to Equitably Identify People with Lived Experience

Authors and contributors: Mathematica staff (Grace Guerrero Ramirez, Lauren Amos, Annalisa Mastri, Ryan Ruggiero, Dana Jean-Baptiste, Nkemdirí Wheatley, Tonyka McKinney); experts with lived experience (Kataney Prior, Roger De Leon, Madison Sandoval-Lunn, Wilnisha Sutton, Eric Washington); and ASPE project officers (Laura Erickson, Amanda Benton).<sup>1,2</sup>

*This content was initially created to inform federal staff at the U.S. Department of Health and Human Services. In an effort to increase collaboration and share promising practices, the Office of the Assistant Secretary for Planning and Evaluation has made this tool available for both public and private partners. Potential audiences that may be interested in these materials include, but are not limited to, state and local governments, tribal governments, and other private or non-profit organizations focused on programs and policies relating to health and human services.*

## Purpose

It is vital to equitably 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>

## What is equity?

The consistent and systematic, fair, just, and impartial treatment of all individuals, including individuals who belong to underserved communities that have been denied such treatment, such as Black, Latino, and Indigenous and Native American persons, Asian Americans and Pacific Islanders and other persons of colors; members of religious minorities; lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI+) persons; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality. *Definition adapted from [Executive Order 13985](#).*

<sup>1</sup> Suggested Citation: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. “Strategies for National and State Groups to Equitably 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, Eric Washington, Laura Erickson, and Amanda Benton. 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 equitably engage people with lived experience, see <https://aspe.hhs.gov/lived-experience>.

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



### Make a plan

- Define the purpose of the engagement to identify needed perspectives and resources
- Articulate how you will engage people with lived experience
- Build a team to work on the engagement



### Work with partners

- Individuals with lived experience in your network
- Federal, state, local, territorial, and tribal community partners
- Intermediaries



### Use a variety of advertisement methods


- Use the “snowball” technique
- Use digital and non-digital advertising

## Strategies



**Make a plan.** Before you identify people to recruit, formulate a plan to help ensure that you are able to equitably identify and ultimately engage a diverse group of perspectives.

- ▶ **Define the specific purpose of the engagement—the “why”—to identify the groups whose perspectives you need, those you are missing, and the resources you will need to engage a diverse group.** 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? What dimensions of diversity and inclusion, such as racial, gender, or geographic breadth, are you seeking? 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 been excluded from earlier engagements, such as those that may distrust or have perhaps been harmed by government or systems, those that have been traditionally excluded, and/or those facing systemic barriers to attaining their optimal health, well-being, and economic goals? Which communities tend to benefit from engagement opportunities (e.g., people with social, educational, and economic privilege), and which have less access to 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 equity, diversity, and inclusion goals**? Consider whether you need to develop tools to track how well you are meeting equity 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, relevant demographic information).
  - What **resources** (such as budget<sup>4</sup> and staff skills and knowledge) do you **need to equitably 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, power, attitudes, and biases and by training on topics such as trauma-informed engagement.
- 
  - 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.
- ▶ **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.
  - ▶ **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 diversity, equity, and inclusion** to consult on or oversee your identification process. Brief external partners on your goals and engagement plan.

<sup>4</sup> Grant recipients must check with the funding agency before using federal dollars for this purpose.



**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 or homelessness support 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 leaders
  - **Groups that have effectively reached communities during past efforts** to gather input (e.g., census counts) or to distribute information (e.g., vaccine access)
  - **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 (especially Minority-Serving Institutions, such as Tribal Colleges and Universities, Historically Black Colleges and Universities, and Hispanic-Serving Institutions) 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 diverse 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>5</sup> Tailor strategies to your context and consider promotional partners.<sup>6</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 shelters, 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., Pride 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>5</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>6</sup> For detailed recruitment strategies on recruiting people with lived experience, see <https://aspe.hhs.gov/lived-experience>.