OFFICE OF HUMAN SERVICES POLICY

Recruiting Individuals with Lived Experience

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Purpose

This guide highlights questions to consider and discuss as a team before recruiting individuals with lived experience from outside of your organization to be a part of a health and human services program or policy effort.[3] We use lived experience to mean knowledge based on someone's perspective, personal identities, and history, beyond their personal or educational experience. 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. It may **not be necessary to answer each question in this guide**, depending on your context. The team should consider what constitutes a satisfactory response to a question before initiating outreach.

Planning for Recruitment

Reflect on lessons from previous engagements and identify areas for improvement.

- Have we previously engaged individuals with lived experience? If so:
  - What worked well before and why? How do we know it worked well?
  - What needs improvement? Whom did we not include?
- What could we learn from other health and human services initiatives outside of our organization that have recruited people with lived experience?

Identify recruitment goals and engagement roles.

- What goals do we want to accomplish by recruiting individuals with lived experience?
- Whom do we want to recruit?
  - What types of experiences or backgrounds should be represented for the engagement to succeed?
  - Can we recruit individuals from groups who have been overlooked or excluded from the type of work we are engaged in?
  - Do we need to develop an application process for individuals to apply for an engagement? If so, why?

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[1] Suggested Citation: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. "Recruiting Individuals with Lived Experience," by Jasmine Forde, Sonia Alves, Lauren Amos, Ryan Ruggiero, Annalisa Mastri, Kate Bradley, Nkemdiri Wheatley, Tonyka McKinney, Dana Jean-Baptiste, Jeremiah Donier, Madison Sandoval-Lunn, Wilnisha Sutton, Roger De Leon, Kataney Prior, and the HHS staff peer learning community on engaging people with lived experience. Washington, District of Columbia: 2022.

[2] ASPE would like to thank and acknowledge the insights of numerous HHS staff who contributed to the content in this guide.

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

- What would an application process involve and how do we ensure it recruits those with untapped perspectives and supports our goals?

- What will be the role(s) and responsibilities of individuals with lived experience?
  - What do we want to learn that we cannot learn from our colleagues?

TIP

If your strategy requires an application process, consider a rubric with well-defined criteria to assess applicants, helping ensure that you are meeting your goals. Avoid burdensome or unnecessary requirements that may deter potential applicants, and be clear with applicants about your criteria.

- What do we expect from people with lived experience who participate? How much time and effort will it take to participate in the engagement? How can we honor that commitment and ensure that we respect their time?

Consider the impact of trust and decision-making.

- How can we address the potential lack of trust that people with lived experience may have in government, programs, and systems? Can we validate that early on and work to regain trust?
  - How can we earn trust from community leaders connected to people with lived experience?
- How will we ensure that the knowledge and input of people with lived experience is valued like the knowledge and input of staff?
- How do we prioritize the insights of constituents and communities in decision-making processes?
- How will we provide realistic, meaningful opportunities to influence decision making?
- How will we collect and act on feedback?
  - How will we handle conflicting input from those with lived experience and staff?
  - Are there types of feedback that we know in advance are not actionable because of time or resource limits, legislative or program guidance, or other constraints? How can we be transparent about these constraints in advance?
- How will we follow up after an engagement to describe the impact of feedback from people with lived experience?

Identify the infrastructure and resources needed to engage individuals.

Budgeting considerations

- Are there partners we can engage to determine appropriate budgeting levels, including adequate compensation for people with lived experience who are not staff (see compensation considerations below)?
- What percentage of the budget should be allocated to the engagement, including planning; identifying, recruiting, engaging, and compensating people with lived experience who are not staff; and following up?
- Are there flexible funding arrangements to allow for budget shifts if engagement costs exceed expected levels?

- Does our budget allow us to ensure that the engagement is fully accessible? Have we planned for translators, interpreters, captioning, and other strategies to make the engagement accessible to all?

Compensation considerations for people with lived experience[4]

- What flexible mechanisms are in place for the timely compensation of individuals with lived experience who are not staff? Can the mechanisms accommodate any budget, timeline, and process changes?
- How much time will compensation take? Does our timeline allow for executing an available funding mechanism, determining an appropriate rate, identifying a possible method (e.g., direct deposit), helping individuals complete paperwork (e.g., W-9, Automated Clearing House), and tracking payable hours and disbursements?
- Does the compensation align with the amount of time and effort we are seeking?

TIP

It is extremely important to compensate those with lived experience who are not staff at similar rates as other experts. It helps ensure that people with varied views can participate. In addition to (not instead of) compensation, consider your ability to provide nonmonetary benefits (e.g., transportation, networking) and meaningful recognition, such as authorship credit and collaboration on presentations, as well as advance per diem, where appropriate.

Preparation considerations

- Do we have the skills needed to engage people with lived experience? Is training available to prepare organizational staff on topics such as trauma-informed approaches?
- What information, orientation, or background materials could help prepare people with lived experience to participate in our engagement?

Ensure flexibility and accommodation.

- Can we be flexible with meeting times or days outside typical work hours to ensure people with lived experience can fully participate?
- Can we be flexible with location? Do individuals prefer to engage in-person—including in their community—or virtually? If the engagement is virtual, are participants comfortable with and able to access the virtual platform we will use? If not, are non-Internet options viable?

TIP

Consider offering “office hours” that allow participants to test virtual platforms and ask questions before an engagement officially begins.

- Is the engagement accessible to everyone, including people with disabilities? Are materials or discussions presented in a way that is understandable to everyone? Is accessibility a central principle?
- How will we solicit and act on feedback about how the engagement is working?

Recruitment Methods

Identify a group that represents the intended communities.

[4] Grant recipients must check with the funding agency before using federal dollars for this purpose.

Consider providing critical resources such as stipends to cover transportation costs or Internet costs. Ask people what they need to participate.

- Are those we plan to recruit representative of the communities we serve? For example, consider demographics, geography (e.g., rurality, state, region), and major life experiences (e.g., parenting, substance use).
- Whom might we have overlooked? Who is most affected by our program, policy, research, or issue area? Whose perspective is often excluded from our decision-making process?
- Can we use a "snowball" technique by asking individuals with lived experience already in our network to recommend additional individuals to recruit?
- Have we sought guidance and recruitment support from other partners, such as community-based organizations, faith-based groups, foundations, advocacy groups, technical assistance providers, and/or government partners?

Identify effective outreach methods aligned with the intended audience.

- Have we connected with staff members who want to lend their own lived experience?
- Which national, state, tribal, or territorial health and human services partners (e.g., advocacy or peer organizations, foundations, grant recipients) can connect us with individuals with lived experience? Can they help us identify individuals, promote recruitment opportunities, host information sessions, and/or share their recruitment channels? Draw on existing partnerships and consider connecting with new partners, such as community leaders, advocacy groups, and allied professionals.
- Which contact methods are most effective for intended participants? Personalized outreach can be particularly valuable. Consider:
  - Connection through a trusted contact
  - Text
  - Social media
  - Email, including listservs
  - Phone call
  - Flyers posted in community spaces
- What advertising opportunities have we considered to reach the intended audience?
  - Sporting or entertainment events
  - Media ads on platforms that are popular among relevant audiences, such as free or low-cost public service announcements

Consider working with liaisons or partners who are approachable and can connect with and understand the communities you are trying to reach. They may be best positioned to communicate with those you are recruiting.

  - Community or neighborhood listservs
  - Local service access or complaint lines

Determine follow-up procedures.

- What is the best way to follow up with individuals who do not respond to initial outreach?

- How long do we wait before following up with those who do not respond initially? How many times do we follow up?

> **Build in extra time to work with partners on recruitment and outreach to ensure that your communication method is appropriate. For example, social media can be useful for recruiting youth, whereas the most effective approach to recruit tribal populations might be to present recruitment information to a trusted contact, such as a tribal leader.**

- Are we prepared to answer questions from interested individuals via email and phone?
- Have we identified additional individuals to recruit if initial recruits decline participation?
- Can we ask why people decline (e.g., to learn what burdens exist) to inform future efforts?

Content for Recruitment Communications

Include various types of information in outreach materials.

Below is key information that you should be prepared to provide to recruits. It is important to consider how best to make the information available so that recruits have the critical information to decide whether to participate. For example, some details may be included in upfront outreach while other details may be available upon request or in follow-up communication.

Topics to include in initial outreach:

- **Engagement goals**, including why you need input and the expected reach of the engagement
- **Why and how the person was chosen** (e.g., acknowledge the individual's unique expertise or note who recommended the person), the type of expertise/perspective sought, who other participants are, and whether they can invite others to participate as well
- **Time commitment**, including duration/timing of engagement activities
- **Compensation and nonmonetary supplements** (e.g., transportation subsidy, professional networking) and the timeline for compensation
- **Activities and format/location** (e.g., number/type of meetings, in-person or virtual)
- **Deadline** for decision to participate
- **Accessibility of the engagement** (e.g., captioning)
- **Contact** methods for questions (e.g., phone, mail, email), including non-Internet options for those with limited access to or familiarity with technology
- **Links** to more information on the project

> **Try to avoid jargon and excessive acronyms. Where possible, use active voice and strengths-based language. Use images that showcase the strengths of the intended audience and do not reinforce stereotypes. Use a title that captures the intended audience's interest.**

Additional topics for either initial outreach or early discussions:

- **Scope of engagement** (i.e., topics within scope)

- **Engagement roles and responsibilities** for participants and staff
- **Principles** guiding the engagement, including a commitment to treating people with lived experience as partners and assurances of plans for confidentiality and privacy
- **Expectations for how we will use input**, including intended benefit(s) to communities; transparency about limitations imposed on your team for acting on input; plans for communicating how your team uses input, such as dissemination of final products or decisions; and assessment or measurement of engagement’s impact
- **Expected preparation or training** provided to participants to ensure that they have the information they need to engage meaningfully and effectively