



Methods and Emerging Strategies to Engage People with Lived Experience

Improving Federal Research, Policy, and Practice

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About This Document

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Overview of Findings

This brief identifies lessons learned and key considerations from a range of methods for engaging individuals with lived experience to improve federal research, policy, and practice. The findings are based on a comprehensive environmental scan, key informant discussions, and consultations with lived experience experts.

Reported impacts of engagement: Key informants shared anecdotal evidence that engaging people with lived experience has helped improve the outcomes and impacts of federal systems, programs, and initiatives. They also reported benefits for both individuals with lived experience and for individual federal staff, including increased understanding of the needs of the people they serve.

Approaches for effective engagement: While individual federal leaders and staff have varying degrees of control over important engagement considerations, agencies, their staff, and partners may wish to consider the following strategies:

- Define **clear expectations, roles, and limitations** of engagement through policies and operating procedures and, where possible, set internal policies that require the engagement of people with lived experience.
- Build in **enough time** to allow space for people with lived experience and staff to engage meaningfully.
- Allocate federal **resources to equitably compensate** people with lived experience commensurate with their role in the engagement. Provide logistical support and dedicated staff to support implementation of lived experience engagement activities.
- Ensure the engagement is **person and healing centered, trauma and survivor informed**, respectful of varied personal histories, and transformational rather than transactional.
- Start with **equity as a goal and expectation** when planning to proactively ensure historically excluded populations can meaningfully participate in opportunities to lend lived experience expertise.
- **Recognize and examine disparities in power** that exist among federal staff, their partners, and individuals with lived experience. Work collaboratively to share power by ensuring individuals with lived experience not only have a seat at the table but also can meaningfully contribute to decision-making throughout the full program lifecycle.
- Avoid the risks of exploiting and/or tokenizing lived experience by ensuring **thoughtful, intentional, inclusive, and purposeful engagement** with federal agencies.
- Involve people with lived experience **throughout the entire decision-making process**, including at the conceptualization, implementation, and evaluation levels to the fullest extent possible.

What Is Lived Experience?

Lived experience in the context of this study is “representation and understanding of an individual’s human experiences, choices, and options and how those factors influence one’s perception of knowledge”¹ based on one’s own life. Lived experience provides insight into patterns, common behaviors, challenges, and barriers among individuals who share similar experiences.

Roles for Individuals with Lived Experience in Federal Initiatives

- Storytellers
- Advisors
- Grantees
- Partners
- Staff

Effective Engagement Strategies for Federal Agencies to Use

- Prepare and plan for engagement
- Consider the duration of the engagement
- Dedicate sufficient resources, including compensation
- Ensure flexibility and accommodation
- Provide ongoing training and support for collaboration and bidirectional learning
- Create supportive policies, procedures, and protocols
- Conduct continuous quality improvement
- Integrate people with lived experience into the agency workforce

Federal Agency Conditions for Greatest Success

- Prior experience with engagement
- Committed leadership

¹Given, L. M. (Ed.). (2008). *The SAGE encyclopedia of qualitative research methods* (Vol. 2). SAGE Publications. <https://dx.doi.org/10.4135/9781412963909>

Introduction

This brief identifies lessons learned and experiences of federal initiatives that engage youth, young adults, and adults with lived experience to improve federal research, policy, and practice. By illuminating how federal agencies have engaged individuals with lived experience and the reported impacts of such engagement, we hope to provide federal leaders and partners with emerging models, practices, and considerations that agencies can use to effectively engage people with lived experience across a broad array of human services initiatives.

In the context of federal agencies, lived experience helps to develop a deeper understanding of the conditions affecting certain populations, the solutions that are most appropriate for those impacted by the issue, and the potential harmful unintended consequences of the current and past actions taken by the existing system on the people it aims to serve. This brief uses the term “lived experience” broadly to describe many different human services areas and experience, but people may prefer different terminology depending on programmatic context and personal preference.

Engaging people with lived experience represents one key way that federal agencies gather important information, shape programming and policy, and help improve outcomes for those served. Other information gathering methods include listening sessions, requests for information, and other methods of research and seeking feedback from program constituents, as well as other research methods such as analyses of program records and survey data, and formal program evaluation—all of which may be enhanced by including people with lived experience. In particular, insights informed by lived experience can help highlight the following:

- Patterns, common behaviors, challenges, and barriers among individuals who share similar experiences.
- Changes in the context surrounding social issues of interest over time.
- Intersections and interdependencies among participatory practices and democratic and empowerment program design and evaluation in each stage of a program’s lifecycle.
- Ways to effectively support individual behavioral and practice changes among federal staff and individuals with lived experience.
- Improvements to services and programs yielded by teaching agency staff and decision-makers about the priority population and its needs and facilitating the application of those learnings.

Defining Lived Experience

Lived experience is defined here as “representation and understanding of an individual’s human experiences, choices, and options and how those factors influence one’s perception of knowledge”² based on one’s own life. *People with lived experience* in the context of this research is defined as individuals directly impacted by a social issue or combination of issues who share similar experiences or backgrounds and can bring the insights of their experience to inform and enhance systems, research, policies, practices, and programs that aim to address the issue or issues.

This brief uses *lived experience* as an umbrella term encompassing many different human services areas and experiences, but context is important when defining *lived experience*. Specific definitions differ by sector, and it is important for different human services systems that partner with people with lived experience to refine their terminology in collaboration with program participants and constituents. For example, *lived experience* may carry different connotations in the mental health context than in the child welfare system, and in some cases other terms may be preferred. It is important to ask people how they want their experience reflected as part of an engagement, particularly since the term may be stigmatizing in some cases when used as a label. For example, labeling someone as a person who uses substances may unintentionally cause stigma, or a parent with child welfare involvement may prefer to be referred to as simply a parent rather than a parent with child welfare involvement.

²Given, L. M. (Ed.). (2008). *The SAGE encyclopedia of qualitative research methods* (Vol. 2). SAGE Publications. <https://dx.doi.org/10.4135/9781412963909>

While the Federal Government's history of engaging individuals with lived experience to contextualize and inform policy and practice dates to the early 20th century³, there is growing interest in refining, improving, and expanding these kinds of engagements, particularly among health and human services programs.⁴ The information compiled in this brief reflects the knowledge, experiences, and insights that individuals with lived experience have been promoting for decades. The brief aims to connect these learnings to the Federal Government's efforts to advance equity and to contribute to the set of tools available to federal staff by offering examples of common models and strategies used across a sample of agencies and program areas.

Despite general expectations and anecdotes that engaging individuals with lived experience is valuable, limited research exists documenting the impact of this engagement on outcomes of federal programs and initiatives. The U.S. Department of Health and Human Services (HHS) is interested in empirical evidence on the effectiveness of engaging and learning from individuals who have lived experience across the human services field, including experiences such as substance use, community member returning from incarceration, homelessness, domestic violence, human trafficking, poverty, disabilities, and family caregiving. This brief is a first step in synthesizing the collective knowledge. Our research highlights an opportunity to improve engagement practices so that people with lived experience and federal agencies can work together to achieve structural and systems changes that can further improve outcomes for individuals, families, and communities which federal agencies seek to serve.

Data from an environmental scan of federal engagement initiatives, key informant discussions, and consultations with lived experience experts shed light on important themes about the methods for and benefits of engaging people with lived experience. For the environmental scan, the research team systematically reviewed the literature on 27 federal initiatives across seven agencies. This research helped identify key informants, including 12 federal staff members and nine nonfederal individuals with lived experience, across 11 federal initiatives. (See exhibit 1 for a list of the initiatives.)

In addition to the environmental scan and key informant discussions, the extensive and active engagement of 11 consultants with expertise on lived experience engagement is an important aspect of the study. Representing a range of races, ethnicities, nationalities, sexual orientations, gender identities, and abilities, the experts each have lived experience in one or more human services areas and have participated in some capacity in prior federal initiatives that engaged individuals with lived experience. These experts informed the work plan; identified programs and initiatives for the environmental scan; suggested content for this brief; and, most importantly, ensured the methods of engagement identified were grounded in lessons learned from past experiences to effectively, meaningfully, and respectfully engage individuals with lived experience.

³Duke, E. (1912). *Infant mortality: Results of a field study in Johnstown, PA, based on births in one calendar year*. U.S. Department of Health and Human Services, Administration for Children and Families, Children's Bureau. <https://archive.org/details/infantmortalityr00duke>

⁴Ellis, C., & Flaherty, M. (1992). *Investigating subjectivity: Research on lived experience*. SAGE Publications.

Exhibit 1. Federal Initiatives Involving Individuals with Lived Experience Included in This Study

Agency	Initiative
HHS/Administration for Children and Families (ACF), Children’s Bureau	Capacity Building Center for States
	National Youth in Transition Database Reviewers
HHS/ACF/Office of Head Start	Office of Head Start (general approach to partnering with families, rather than a specific initiative)
HHS/Administration for Community Living	Americans With Disabilities Act Participatory Action Research Consortium
	RAISE Family Caregiving Advisory Council
HHS/Office of the Assistant Secretary for Planning and Evaluation	Interagency Working Group on Youth Programs
HHS/Substance Abuse and Mental Health Services Administration	National Center for Trauma-Informed Care and Suicide Attempt Survivors Task Force (currently known as the Interagency Task Force on Trauma-Informed Care)
U.S. Department of Housing and Urban Development	Youth Homelessness Demonstration Program
U.S. Department of the Interior and U.S. Department of Justice (DOJ)	Presidential Task Force on Missing and Murdered American Indians and Alaska Natives (Operation Lady Justice)
DOJ/Office of Justice Programs	National Reentry Resource Center’s Face to Face Initiative
U.S. Department of State/Office to Monitor and Combat Trafficking in Persons	Human Trafficking Expert Consultant Network

Why Engage People with Lived Experience?

Data suggest that engaging people with lived experience yields benefits or impacts at multiple levels: individual, program/initiative, and agency. Importantly, the impact referenced here is the “perceived impact” noted in the available literature and by our project’s key informants—federal staff and/or people with lived experience who were engaged by federal initiatives—rather than the impact uncovered using experimental or quasi-experimental studies.

“For me I think it opens your eyes that when you’re reading...and having a much clearer, better, richer understanding of what people in reentry [to the community from incarceration] need and what it takes to create services that meet their needs...you write a better product that’s more accessible, more responsive. You’re crafting performance measures that your grantees have a better sense of collecting. You understand what success looks like. You’re designing training and TA that is more responsive to help federal grantees that are out in the field actually engage with people.”

— FEDERAL STAFF

The following represent benefits at three different levels noted by our project’s key informants and in the literature: the individual (both for federal staff and people with lived experience), program and initiative, and agency levels.

- **Benefits for individuals.** *Federal staff* noted they gained an improved awareness and knowledge about the strengths, needs, challenges, and systemic barriers experienced by the prioritized communities they served, and they further developed professional skills to reach and engage individuals in these communities. *Individuals with lived experience* who engaged with federal initiatives noted benefits such as increased self-efficacy and empowerment, strengthened community connectedness and social and emotional support, and a better understanding of federal programs and agencies.
- **Benefits for programs and initiatives.** Some initiatives, especially those involving legislatively mandated advisory groups or research commissions, reported benefits such as an improved ability to deliver responsive services, programming, training, and technical assistance. Informants noted that making advisory groups more representative of the priority populations strengthened products, tools, and resources by making them more accessible, responsive, and tailored to the specific needs of the priority populations. Finally, the environmental scan showed that lived experience engagements within initiatives reviewed had resulted in improved representation in and increased priority communities’ influence on decision-making processes and practices.
- **Benefits for agencies.** By informing federal agencywide strategies and decisions, engagement of people with lived experience has contributed to new or improved federal policies and practices. These improvements included directing funding and resources toward the concerns and needs of the priority communities and enhancing service and delivery infrastructure, including mechanisms for ongoing and sustained engagement of lived experience experts. Engagement also created informed and empowered groups of advocates who have extensive networks and who have the skills to speak directly to agencies and decision-makers about the needs of the priority populations they represent.

Initiative Highlight:
Face to Face Initiative



Achieving Federal Practice Changes Through Lived Experience Staffing

The Face to Face Initiative focuses on prison and sentencing reform by disseminating stories about the impacts of incarceration on individuals and families. It has helped inform and educate federal staff and executive-level state, local, and tribal leadership about these impacts. This information has helped shape the ways these leaders interpret legislation and design and administer federally funded programs. For example, one jurisdiction, in response to the engagement, conceived of and executed new state-level grants, formed a reentry council, and developed a reentry plan to coordinate and enhance services. As a result of being better informed about the human toll of incarceration on inmates and their families, federal staff feel they have strengthened the products they developed by improving their accessibility and responsiveness to the priority population and tailoring them to the population’s specific needs. The initiative also led to development of a fellowship for a person with a criminal record to guide and inform the implementation reentry and reintegration programs.

Though these are all important impacts, our research did not identify substantive impacts at the system level, though this may be due to a lack of data rather than a lack of impact on systems. This highlights an opportunity to collaboratively expand and improve the ways federal agencies engage people with lived experience in order to co-design structural changes that can further improve outcomes for individuals, families, and communities that federal agencies seek to serve.

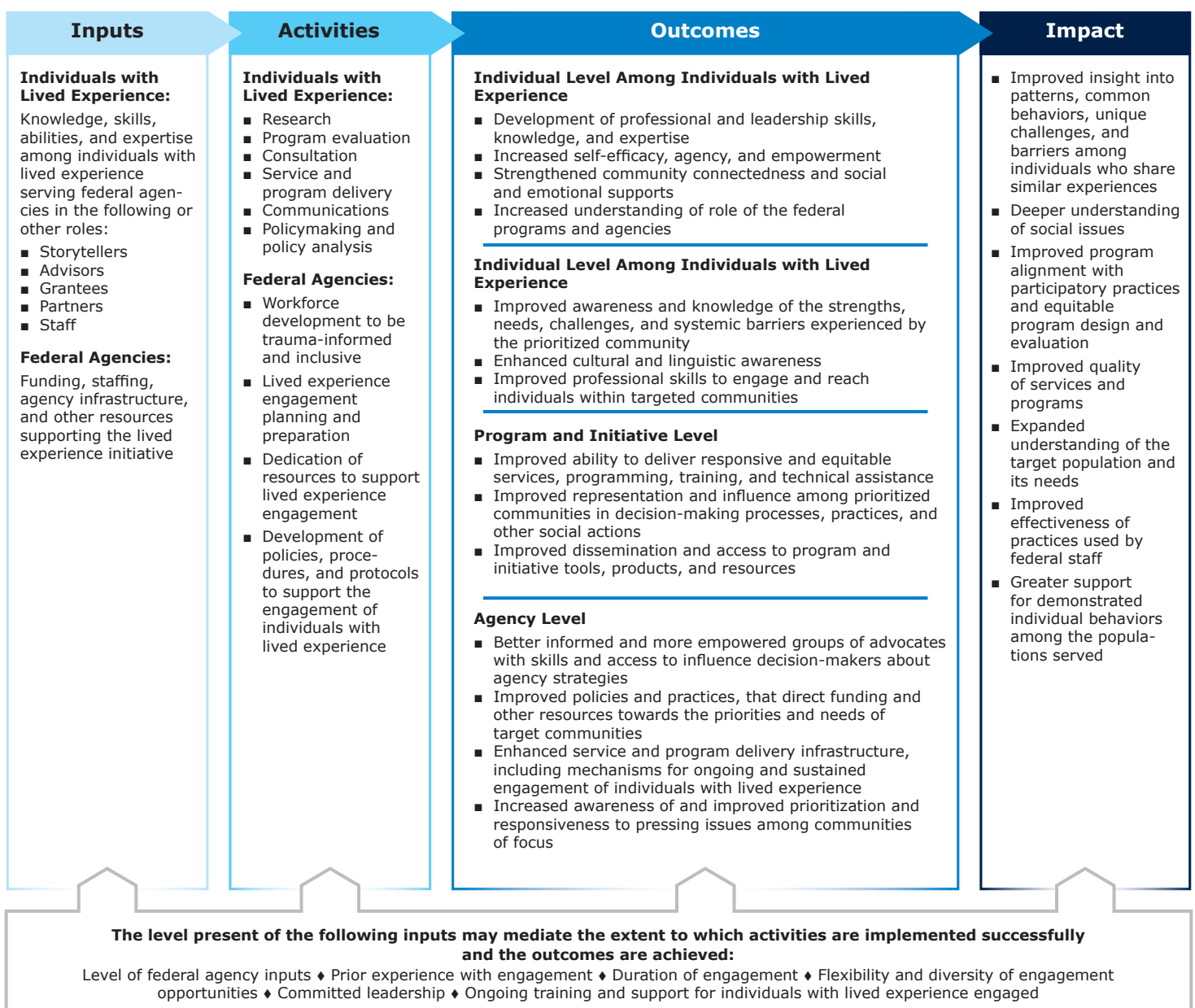
How Agencies Engage People with Lived Experience

Federal agencies have employed various models to engage individuals with lived experience. Lived experience models varied by the following characteristics:

- **Roles:** The functions performed by individuals with lived experience
- **Activities:** The actions individuals and agencies performed as part of live experience engagements
- **Emerging Strategies:** The approaches agencies took that could be adjusted and tailored for the specific implementation setting and context, and that seemed to ensure the greatest likelihood of success
- **Facilitators:** The conditions that existed within agencies that were often outside of staff control but which seemed to contribute to engagements' success

The logic model in exhibit 2 depicts the integral inputs, activities, outcomes, and impacts found across various lived experience engagement initiatives, as well as the mediating factors.

Exhibit 2. Logic Model of Lived Experience Engagement Initiatives



Roles That Individuals with Lived Experience Play

Lived experience perspectives were leveraged and incorporated into federal research, policymaking, and practice in multiple ways, including through the engagement of individuals with lived experience as (1) storytellers, (2) advisors, (3) grantees, (4) partners, and (5) staff (exhibit 3). These roles are roughly ordered by ascending level of engagement involved. Storytellers had the most limited involvement, making it an optimal role for use by newer programs to begin to engage people with lived experience. This was the most common role used among agencies to engage those with lived experience. However, many agencies moved beyond storytelling on its own. Agencies that had a deeper and more sustained investment in incorporating individuals with lived experience as a key practice to improving their services and outcomes combined storytelling with other roles to inform their work. The role of being on staff often had the most involvement and required higher levels of agency support. The appendix includes more details about these roles, including descriptions, benefits, situations where they are appropriate in future work, limitations, and other considerations.

Exhibit 3. Roles for Individuals with Lived Expertise in Federal Initiatives

Storytellers

Initiatives engaged individuals with lived experience by creating opportunities for storytelling, including listening sessions, public testimony, interviews, focus groups, and digital formats (e.g., videos). Storytelling may hold important cultural significance for some priority populations and highlight the differences that some groups experience with different government systems.

Advisors

Lived experience experts commonly served as advisors, often through groups, committees, and boards, for initiatives that develop national strategies, congressional reports, policy recommendations, and capacity-building efforts.

Grantees

Grantees used federal agency funding to engage or represent individuals with lived experience to inform the design and implementation of their work as a primary means to make policy and practice improvements in states and local communities.

Partners

Partners were engaged to provide training, technical assistance, and consultation and to develop materials to support initiatives, such as guidance, model policies, position papers, and white papers. While they made similar contributions to staff, partners were external to the federal agencies. Unlike advisors, who were typically individuals who worked with agencies, partners were typically organizations comprised of individuals with lived experience that collaborated with federal agencies and connected them to communities.

Staff

Many federal agencies' staff included people with lived experience who brought valuable expertise and perspective to their work. Some of these staff were purposefully hired because of their relevant background, and others brought relevant lived experience although this was not a requirement or consideration for the job. These staff were involved in all aspects of federal work, according to their role/position, including training, grant monitoring, ongoing consultation, coordination of discrete projects, and mentoring and coaching other staff on working with and collaborating with individuals with lived experience.

Exhibit 4 shows that all roles used by initiatives we examined featured varying degrees of shared power, authority, and responsibility among the individuals with lived experience and the federal agencies engaging them, as well as varying timeframes, levels of participation, and types of engagement activities. People with lived experience may have played multiple roles, particularly in agencies where their work was more embedded and routinized as a regular practice.

Activities Undertaken by Individuals with Lived Experience

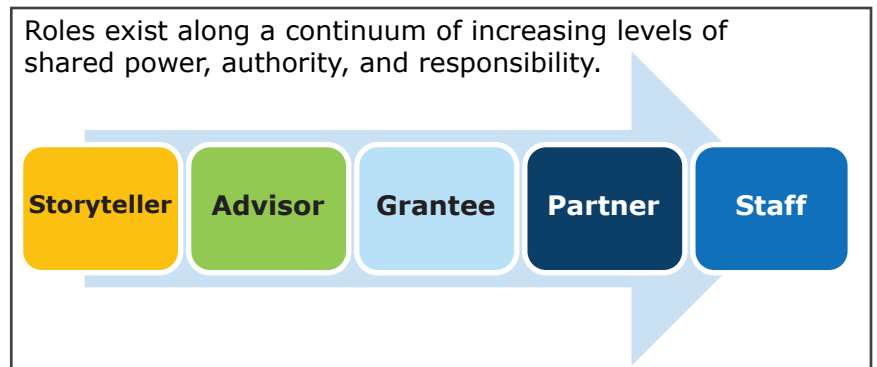
Agencies that prioritized meaningful engagement and the integration of lived experience in their work created opportunities for experts to exercise and share decision-making power.

Individuals contributed their lived experience through the following general activity areas—as well as specific tasks that occurred to achieve those activities—in the initiatives we reviewed:

- **Research and program evaluation.** Individuals with lived experience helped agencies conduct, contextualize, translate, disseminate, and foster the adoption of research and program evaluation findings to inform policy and practice. This work has extended beyond only serving as subjects of research or participating in listening session to more complex activities, such as conducting peer or grant reviews, recruiting participants, or actively designing and leading research.
- **Consultation.** Individuals with lived experience made recommendations to policymakers, planning agencies, and executive-level government officials at the federal, state, and local levels. Recommendations may have been related to funding allocation, developing strategic partnerships, program planning and implementation, service delivery, training, future evaluation, and research. In some cases, people with lived experience may have directly impacted decision-making and policy development.
- **Service and program delivery.** Individuals with lived experience provided direct services and delivered strength-based, trauma-informed support, services, and programs grounded in shared and common experiences as outreach workers, case managers, paraprofessionals, recovery specialists and coaches, and peer support specialists through consumer- and peer-operated programs and services. People with lived experience also provided technical assistance about service and program delivery.
- **Strategic communications.** Individuals with lived experience helped directly communicate with and create strategic communications tailored to federal staff, priority populations, and other program constituents about the practices, goals, and requirements for effective service and program delivery for prioritized populations.

Typical engagements involved two or more tasks, which could be associated with any of the activities. Tasks related to policy development, listening sessions or public testimony or comment, advisory, and advocacy were the most mentioned.

Exhibit 4. Roles for Individuals with Lived Experience in Federal Initiatives



Generally, the study found that programs that used fewer methods and involved fewer tasks increased the potential of exposing individuals with lived experience—including federal staff—to unintended adversity and/or secondary trauma. For example, these engagements tended to rely more heavily on sharing stories and testimonials from personal lived experience. While storytelling can be important, when not navigated carefully can have little impact on decision making or cause individuals to relive traumatic experiences or trigger the negative effects of adverse events. However, storytelling can still be a bridge to increased inclusiveness and diversity of people with cultural, ethnic, intersectional, and cross sectional identities that are unique and underrepresented in the federal government structure.

The activities and tasks people with lived experience conducted tended to differ depending on the initiative's focus:

- Initiatives that focused on improving professional practices for both federal staff and individuals with lived experience—including grant making, training, technical assistance, strategic communications, evaluation, research, and continuous program improvement tasks—often used multicomponent initiatives (i.e., involving several roles and activities for engaging individuals with lived experience). These initiatives often featured the sustained engagement of lived experience experts who provided feedback and recommendations to improve agency effectiveness and priority population outcomes.
- Initiatives that involve policymaking activities and tasks (e.g., developing sample policy language, white papers, or briefs) or limited-term research projects ranged from one-time engagements to more lengthy engagements where the specific roles and activities (typically with people with lived experience engaged as advisors, partners, and/or staff) were more defined and tied to specific timelines and deliverables.
- Research initiatives engaging people with lived experience as advisors, grantees, partners, and staff often required more experience and effort among agencies to identify, recruit, and train individuals with lived experience who possess specific and professionalized skills needed to design, implement, and conduct research activities and tasks. Similarly, policymaking initiatives required more interagency coordination, particularly if the governing policy was executed outside of the lead agency.

What is meaningful engagement?

There are many ways to integrate perspectives from people with lived experience in federal research, programming, and policymaking. While methods such as surveying program participants or asking people with lived experience to speak at events can be important, meaningful engagement is intentional and ideally provides opportunities for people with lived experience to substantively impact decision-making and outcomes. Extensive strategies to ensure meaningful engagement are discussed below, and while there is no one single approach, meaningful engagement often features the following conditions:

- Programs involve people with lived experience from the beginning of the engagement (e.g., formulating research questions, identifying programmatic or policy goals) and provide opportunities to partner with federal staff, rather than only soliciting minor input after work is nearly complete.
- Federal staff and leadership are genuinely open to perspectives and insight that people with lived experience offer, instead of simply trying to “check the box.” Although agencies may face limitations in acting on all input, those agencies seeking to meaningfully engage people strive to act on recommendations shared and provide transparency when that is not possible. People with lived experience also feel confident that their perspectives are not only respected and valued, but also that agencies do their best to act on their input.
- Agencies compensate people with lived experience for their contributions at a level that is at least commensurate with compensation provided to other experts.

Emerging Strategies Agencies Used to Ensure Meaningful Engagement

Federal agencies employed multiple strategies to integrate the input of individuals with lived experience and to support and sustain their engagement:

- **Preparing and planning for engagement.** Federal agencies and staff who prepared and planned for engaging individuals with lived experience were able to ensure they could offer the coaching, mentorship, and training needed to help them engage lived experience experts successfully. These tasks also may have better equipped federal staff and partners with the skills to offer mutually beneficial engagement and sustain inclusion of lived experience as a routine aspect of federal programs. Identifying and recruiting a range of individuals with diverse lived experience represents an important part of planning. Seeking varied perspectives and types of expertise helps prevent relying repeatedly on the same individual(s). Additionally, during the planning and preparation phases of the work, agencies could consult with other federal and state agency staff and partners with experience working with individuals with lived experience to gain insight about successfully designing and executing an engagement.
- **Considering the duration of engagement.** Some agencies engaged lived experience experts in a single activity at a single point in time (e.g., listening sessions, public testimonies, grant reviews), and others more deeply immersed experts in several activities sustained over an extended period (e.g., technical assistance provision, training, advising, consulting). Both approaches had benefits. Single point-in-time approaches seemed to allow agencies more flexibility to engage larger numbers of people with lived experience and to gather more rapid and timely feedback, but it limited the number of areas and ways that the individuals could provide input. More immersive approaches seemed to require a more dedicated and sustained investment of time and resources to engage a small, discrete number of individuals with lived experience, but they allowed for individuals with lived experience to contribute more holistically to solutions around more complex issues.
- **Dedicating sufficient resources, including compensation.** Agencies needed dedicated time, information, and financial and human resources to make engagement feasible and effective. These resources were critical to supporting proactive outreach and recruitment, the coordination of engagement opportunities, and ongoing follow-up needed to support sustained lived experience engagement. In addition, these resources helped ensure lived experience experts received equitable financial compensation for their role and level of expertise. Providing them with compensation commensurate with the rates that other experts—i.e., experts engaged based on their expertise as practitioners or researchers, rather than lived experience—receive helped recognize the valuable and unique expertise that people with lived experience lend, which promoted meaningful engagement. In addition to financial compensation via direct hourly payment, stipends, or honoraria, agencies also considered providing other benefits and resources to lived experience experts to facilitate their engagement, including incentives; grants; child care; mental health services; and funding for travel, conference participation, and continuing education. Lived experience expert informants noted several critical benefits to receiving direct compensation, including increased opportunities for professional development and skill attainment, networking access, and financial support.

Initiative Highlight: Interagency Working Group on Youth Programs

Enhancing Communications by Engaging Youth and Young Adults

The Interagency Working Group on Youth Programs (IWGYP) is composed of representatives from 22 federal departments and agencies that support programs and services focused on youth (ages 10 to 24). Created through an Executive order, the IWGYP facilitates coordination and collaboration, disseminates evidence-based information, and manages a cross-cutting federal website on youth issues (<https://youth.gov>) that has web content targeted to adults who work with youth, and youth themselves (Youth Engaged 4 Change; <https://engage.youth.gov>). It also maintains a presence on social media (Instagram, Facebook, and Twitter). The IWGYP also models youth-adult partnership by engaging youth in the planning and facilitation of federal meetings, which has resulted in video vignettes, tip sheets, and other digital content for youth and adults.

In addition, they discussed the unintended consequences that can occur when lived experience engagements have scarce resources and experts are undercompensated, which can undermine, disregard, and/or marginalize people with lived experience.

- **Ensuring flexibility and accommodation.** Lived experience engagements—particularly those that were long-term, ongoing efforts—seemed to be most successful when agencies were flexible and accommodating when working with the lived experience experts to ensure equitable access to engagement opportunities. For example, some agencies required background checks when hiring lived experience experts, which may have prohibited engaging individuals with certain lived experiences who traditionally lack access to opportunities to have their voice heard by federal agencies. Key informants noted that agencies should determine whether the background checks are truly necessary for the successful completion of the activity. In addition, language, disabilities, travel costs, business attire, technology requirements, scheduling conflicts, and child care needs were barriers or challenges to engagement for some individuals with lived experience, and agencies should consider how to proactively eliminate or reduce such barriers.
- **Providing ongoing training and support.** Providing ongoing assistance to individuals with lived experience and federal staff helped them better understand how to implement a successful engagement initiative. Training and other forms of assistance helped show individuals how to ensure engagement was strengths-based; minimize trauma and adversity; incorporate cultural humility; and ensure the engagement did not perpetuate inequities, exploitation, or disparities. For example, one initiative hosted a peer support group for its lived experience experts and federal staff with lived experience to provide support to one another in the workplace. In addition, agencies partnered with individuals with lived experience to provide ongoing technical support to agency staff, thereby guiding the direction and steps agencies took to plan lived experience engagement frameworks. Types of training and support included peer supports for engaged people with lived experience; forums for open, honest exchange; and training for federal staff to enhance critical skills, such as active listening.
- **Creating supportive policies, procedures, and protocols.** Internal policies that mandated the engagement of individuals with lived experience—as well as relevant federal laws—helped reinforce and normalize this practice and provide strong justification for agencies to devote resources to supporting lived experience engagements. Formal written policies also helped establish lived expertise as a professional experience, create requirements for lived experience in job descriptions, and ensure individuals were compensated for sharing their expertise. Written procedures may have helped standardize practices to ensure these engagements of people with lived experience were meaningful, authentic, and intentional.

Conditions for Greatest Effectiveness

Individuals with lived experience reported that initiatives with the following characteristics were the most effective:

- Had the funding, staff, infrastructure, and other resources to support engagement activities and use lived experience perspectives and input
- Offered ongoing, diverse, and meaningful opportunities for authentic and intentional engagement throughout the program lifecycle, from conceptualization through implementation and evaluation
- Possessed some prior experience with lived experience engagement that allowed for the ongoing refinement of engagement approaches and activities and the development of robust infrastructure to support lived experience engagement
- Provided equitable compensation and other incentives and resources to individuals with lived experience
- Used written policies or procedures to reinforce and sustain engagement
- Demonstrated sensitivity to culture, adverse experiences, and trauma histories and actively worked to mitigate secondary trauma exposure and make space for healing (when needed and appropriate)
- Supported collaboration and bidirectional learning between and among lived experience experts and federal staff

- **Conducting continuous quality improvement.** This was critical to sustaining lived experience engagement efforts. By creating feedback loops to inform practice, including seeking input from people with lived experience who were engaged with an initiative, agencies learned and evolved strategies over time to support the engagements, allowing them to be more effective and mutually beneficial over time.
- **Integrating people with lived experience into the agency workforce.** Employing federal staff with lived experience can help embed lived experience perspectives into federal work. Agencies have institutionalized the practice of engaging individuals with lived experience in part by recruiting, hiring, and retaining diverse groups of individuals with lived experience. Hiring individuals with diverse lived experience can help ensure that agencies do not exclude perspectives of people who have historically been underserved by federal programs and policies. This work also included providing support through supervision, coaching, and mentoring. These agencies also sought to directly engage these individuals in other capacities, including as grantees, interns, consultants, contractors, and partners. These agencies often sought to create a workforce that included people with lived experience and to train all federal staff to engage people with lived experience as partners in their work. Some agencies did this by making lived experience a requirement for employment where possible, acknowledging the importance of lived experience in job postings, or encouraging grantees to hire people with lived experience. In doing so, federal agencies created a more inclusive and diverse workforce with broader capabilities to dismantle structural inequities.

Facilitators That Contributed to Engagement Success

While federal staff had control over many of the activities and strategies previously discussed, there were some features that federal staff had less control over, including the level of maturation of the initiative, its history of incorporating lived experience in its efforts, and leadership directing such engagement methods and making decisions. Nonetheless, the following conditions facilitated equitable and effective partnerships across initiatives:

- **Prior engagement experience.** Our research shows that new initiatives tended to offer more limited types of engagement opportunities than those that had a longer history of successfully engaging individuals with lived experience. Initiatives with a longer history of engaging individuals with lived experience tended to have had the benefit of more time to refine and enhance their strategies, activities, and methods for engaging individuals with lived experience. However, this does not mean that lack of prior experience is a reason not to engage people with lived experience; it reinforces the importance of continually striving to improve engagement processes. Agencies may wish to begin engaging people with lived experience where possible, with the expectation of improving engagement practices over time by regularly seeking feedback from those engaged. Our research highlights that initiatives learned to adapt and make improvements to how they engaged individual with lived experience over time. Agencies that are just starting out can also partner with federal offices or other organizations that have a longer history of engaging people with lived experience.
- **Committed leadership.** Key informants noted that visible and tangible leadership support was critical to initiatives' success. Leadership support demonstrated to constituents that engaging those with lived experience was an expected organizational norm, could help institutionalize the use of engagement models, and could ensure lived experience informs organizational decisions. Leaders helped garner federal staff and partner buy-in and support for these efforts by participating in lived experience engagements, actively communicating the importance of the work, and articulating agency aims and goals about engaging individuals with lived experience.

Lessons Learned and Implications

Key lessons emerged from the field and through this study about how to improve federal research, policymaking, and practice by engaging individuals with lived experience. Key informants and experts with lived experience highlighted lessons related to infrastructure and resource needs, equity and access, engagement practices, and policies and protocols used to support agencies in their collaboration with individuals with lived experience. Although some agencies and federal staff may not have full control or discretion over applying some of these lessons, they can consider to what degree they can implement them to better understand the needs and desired outcomes of the priority populations and communities they serve.

“First of all, [we should] ask people if they're willing to talk about their experience. No one should presume that someone wants to share their lived experiences. We should be explicit in saying, 'Here's why I am asking, here's why I am asking you, and would you be willing to?' I think this is critical. And then asking open-ended questions about their experience and being more in discovery mode and listening, rather than trying to guide the conversation to get the answers that you want is really important.

— FEDERAL STAFF

Provide Appropriate Infrastructure and Resources

- Prioritize dollars in federal budgets and/or appropriations to support the engagement of people with lived experience.
- Ensure equitable compensation and logistical support, as well as a dedicated staff or oversight or advisory committees, that can support lived experience engagements.
- Ensure the compensation reflects the valuable expertise of individuals with lived experience and is commensurate with rates paid to other types of experts. In addition, offer a range of benefits to foster engagement, including nonmonetary benefits such as professional development and relationship-building opportunities.
- Train and prepare federal staff to meaningfully engage people with lived experience. This support includes training federal staff to provide engagement opportunities that are person and healing centered, strengths based, trauma and survivor informed, and transformational rather than transactional.

Prioritize Equity and Access

- Start with equity as an end goal when shaping all elements of engagement opportunities by proactively ensuring historically excluded populations are able to participate meaningfully. Strategize about ways to ensure equitable access to participating in opportunities to lend lived experience expertise.
- Examine where disparities exist (e.g., routine equity audits) and intentionally recruit lived experience experts who understand these disparities in order to better prioritize underrepresented, underserved, and/or under-resourced populations.
- Create culturally tailored and inclusive opportunities that allow diverse individuals with lived experience to contribute in varying ways, including opportunities for them to serve in roles ranging from entry-level to leadership positions.
- Provide engagement opportunities for many different individuals with lived experience to ensure that agencies do not rely repeatedly on the same individuals with lived experience. There is value in developing deep relationships, but overly relying on the same individuals may prevent agencies from engaging diverse perspectives.
- Create a community and foster an environment of supportive cultural diversity and inclusion that offers support and mutual respect for and among individuals with a diversity of lived experiences.
- Be cognizant of disparities in power among federal staff, their partners, and individuals with lived experience. Work to equalize that power by ensuring individuals with lived experience not only have a seat at the table but can also meaningfully contribute to decision-making throughout the full program or project lifecycle.
- Use a multitude of tools to identify and recruit individuals with lived experience so that

opportunities for engagement are not limited to the same individuals, who may be easier or more convenient for the agency to work with. Inclusive recruitment may include soliciting referrals from other individuals with lived experience, strategically marketing competitive positions and engagements, and offering proactive skill development and professional development opportunities to prepare candidates for future engagement opportunities.

- Consider using hiring, procurement, and spending practices that are flexible to broaden eligibility for consultants, contractors, and employees with lived experience from underserved communities.

“Based on my work in policy and other things, we came up with this framework for a recommendation related to the three domains of policies, programs, and practice. And then our goal was to get a broad group from around the country of people representing different types of personal experience, diversity of localities, racial and ethnic perspectives, etc. — **INDIVIDUAL WITH LIVED EXPERIENCE**”

Use Thoughtful Engagement Practices

- Use inclusive, plain language that is easily accessible and understandable for the general public when communicating about engagement opportunities to ensure broad, equitable outreach to diverse individuals with lived experience. When drafting communications or other resources, think explicitly about the intended audience.
- Build in enough time to allow people with lived experience to engage meaningfully (e.g., include lived experience individuals in the scheduling and planning processes, meet when they can attend or be flexible in participation options).
- Develop feedback mechanisms for people with lived experience to contribute to continuous quality improvement efforts related to engagement experiences.
- Collaborate to identify mutually agreed upon terms of engagement to increase the chances that the lived experience expert can complete or sustain their engagement. This includes providing individuals with a voice and choice in what they share and how they share their lived experience, as well as giving people the opportunity to choose how they identify. For example, while this brief uses the term “lived experience,” people may not identify with the term.
- To the greatest extent possible, involve people with lived experience throughout the entire decision-making process, including the conceptualization, implementation, and evaluation processes.
- Be mindful of secondary trauma, triggers, stigma, and cultural sensitivities that could be experienced by individuals with lived experience when contributing to engagement efforts, particularly when engaged as experts working as federal agency staff. Agencies can mitigate secondary trauma, triggers, and stigma by incorporating strengths-based, culturally sensitive practices and, when feasible, providing appropriate supports and resources (e.g., access to mental health professionals, time off) to lived experience experts.
- Review agency and staff engagement practices to ensure they do not exploit or tokenize lived experience. For example, these efforts may include ensuring engagements provide opportunities to substantively impact goals and questions that an initiative addresses, instead of limiting people with lived experience to only share their stories with no way to impact decisions.

Enact Policies and Protocols

- Clearly define expectations, roles, and limitations through policies and operating procedures. Do not overpromise on how or to what extent feedback from people with lived experience will be integrated.
- Carefully consider any limitations or constraints that existing legislation or agency policy may impose regarding the parameters and scope of the lived experience engagement.
- Where possible, ensure new and existing policies or legislation include actionable and tailored requirements regarding the engagement of people with lived experience.
- Examine whether there are structural and systemic barriers—or whether there is an

absence of supportive policies and practices—that may hinder appropriate levels of resource allocation, staffing, or cultural humility efforts to effectively address equitable access, diversity, and representation within lived experience engagements.






Conclusion






This study identified valuable practices and lessons learned about engaging people with lived experience. Developments in recent years have heightened the need to improve the quality and equity of human services, but people with lived experience have appealed for changes, including those discussed in this report, for decades. It is critical for federal agencies to listen to and actively engage individuals with lived experience and leverage their program and policy implementation authority to aggressively address their needs and to dismantle destructive, oppressive, and divisive practices within their systems and at the agency itself.

To achieve meaningful engagement and improve both engagement outcomes and potentially program outcomes, it is important for federal agencies to consider the intersections of equity and lived experience. Our research highlights that federal agencies may return to the same experts with lived experience, which may exclude diverse voices of individuals who have historically been underserved by federal programs and policies. Initiatives to engage people with lived experience can combat this by ensuring that lived experience engagements are equitable in terms of access and availability to individuals from diverse backgrounds, cultures, experiences, and walks of life; offer compensation for the expertise individuals with lived experience provide; and share power and decision-making with the individuals with lived experience they have engaged across all phases of the program life cycle. Many federal agencies have engaged individuals with lived experience for years, but there is significant room to create new engagement efforts, expand existing efforts, and improve practices so that federal agencies meaningfully and equitably share power with individuals with lived experience. By continuing to expand and improve engagement methods in ways that share power, federal agencies can work collaboratively with those with lived experience to achieve structural and systems changes that can further improve outcomes for individuals, families, and communities that federal agencies seek to serve.

Appendix: Matrix of Lived Experience Roles

Lived experience is the “representation and understanding of an individual’s human experiences, choices, and options and how those factors influence one’s perception of knowledge”¹ based on one’s own life. Lived experience provides insight into patterns, common behaviors, challenges, and barriers among individuals who share similar experiences. While individual federal leaders and staff have varying degrees of control over important engagement considerations, they and their partners may wish to consider different strategies to engage individuals with lived experience in shaping more effective federal policies, practices, and research. This table summarizes the potential roles for individuals with lived experience in their work with federal agencies. It describes the appropriate uses of each role, typical cross-cutting tasks and general activities for engagement, their frequency and duration, and potential limitations and solutions. Use this table to gauge the potential roles for people with lived experience that may be best suited for your agency and its initiative.

	 Storyteller	 Advisor	 Grantee	 Partner	 Staff
Appropriate Roles	<ul style="list-style-type: none"> ■ Sharing insights and context about a problem or issue ■ Educating outsiders about community or specific cultural experiences and perspectives ■ Creating space to honor, celebrate, and prioritize personal and group experiences and culture within federal systems 	<ul style="list-style-type: none"> ■ Providing information, feedback, and ideas related to a program, policy, or research area ■ Providing ongoing consultation as part of a group convened regularly or as an independent consultant who may be vetted by a formalized process 	<ul style="list-style-type: none"> ■ Infusing lived experience insights into the program and facilitating policy, practice, and research improvements ■ Informing services and program delivery at the state and community levels through grantee-level work ■ Adopting recommendations and practices to engage individuals with lived experience into grant program and services 	<ul style="list-style-type: none"> ■ Collaborating on the creation of products, programs, policies, practices, and services ■ Creating opportunity for community collaboration 	<ul style="list-style-type: none"> ■ Being fully integrated into the agency, primarily as an employee but also as a contractor or fellow
Cross Cutting Tasks	<ul style="list-style-type: none"> ■ Listening sessions ■ Public testimony ■ Interviews ■ Focus groups ■ Other forums for representation (e.g., digital stories, videos) 	<ul style="list-style-type: none"> ■ Committees ■ Workgroups ■ Advisory boards ■ Individual consultations ■ Review and feedback of work products ■ Training and technical assistance 	<ul style="list-style-type: none"> ■ Delivery of grantee-level programs and services ■ Engagement of people with lived experience as part of a grant requirement ■ Use of federal funding that requires or encourages lived experience to improve state and local programs and services. 	<ul style="list-style-type: none"> ■ Training and technical assistance ■ Consultation ■ Materials development ■ Professional development ■ Research and evaluation 	<ul style="list-style-type: none"> ■ Training and technical assistance ■ Consultation ■ Grant monitoring ■ Research and evaluation ■ Project management and coordination ■ Mentoring and coaching other staff

	 Storyteller	 Advisor	 Grantee	 Partner	 Staff
Appropriate Roles	<p>These engagements are often time-limited, ranging from a one-time engagement requiring minimal preparation to a series of focus groups requiring more information, guidance, and support.</p>	<p>These engagements often occur during a fixed and time-limited period set by legislation or agency policy. The duration of individual consultations may be similar to storytelling roles.</p>	<p>Depending on the goal, these engagements can be time-limited, occur at key junctures of the grant, or continue for the duration of the grant life cycle. Key junctures for engagement may include conceptualization, development, implementation, and evaluation of the grant.</p>	<p>The duration may be fluid depending on the scope of work, activities, and intended goal. The duration of this engagement can be fixed and time-limited or extend throughout the life of the initiative.</p>	<p>The duration will last as long as the initiative exists, for the duration of the staff member's tenure, or as long as resources are available to support the engagement of the person with lived experience as a paid professional.</p>
Cross Cutting Tasks	<p>People with lived experience may feel some level of tokenization, especially in instances in which they have little or no choice about how they participate.</p> <p>This type of engagement is limited to information sharing, which typically does not provide an opportunity for individuals with lived experience to provide direct input into the agency's work, programs, or services.</p> <p>To mitigate these issues, agencies can provide individuals with spaces and opportunities to use and share their voice and provide input to agencies about their programs and services.</p>	<p>The extent to which agencies engage people with lived experience— including the diversity and number of people engaged— and their ability to act on the input may be limited.</p> <p>To mitigate this issue, agencies may need to allocate additional infrastructure and resources to gather perspectives and insights from a wider group of individuals and to ensure their ability to act on the input.</p>	<p>A grantee may not have sufficient technical knowledge, skills, infrastructure, or resources to share lived experience or to successfully engage with people with lived experience in instances when grantees are asked to do so.</p> <p>To mitigate this issue, agencies should devote sufficient planning time and resources and facilitate collaborative peer learning across grantees.</p>	<p>The time, infrastructure, and resources required to effectively facilitate the activities can vary from simple to complex.</p> <p>To mitigate this issue, agencies should engage in thoughtful planning, establish clear expectations, and implement continuous quality improvement structures developed with people with lived experience.</p>	<p>In addition to the issues identified in the other roles, staff with lived experience may be at higher risk of experiencing secondary trauma, retraumatization, and tokenization through their work engaging others with lived experience or other tasks.</p> <p>To mitigate this issue, agencies should establish a trauma-informed and supportive agency culture and infrastructure.</p>

¹Given, L. M. (Ed.). (2008). *The SAGE encyclopedia of qualitative research methods* (Vol. 2). SAGE Publications. <https://dx.doi.org/10.4135/9781412963909>