

# How can people with lived experience be most effectively involved in systems change?

SKELTON-WILSON, S., SANDOVAL-LUNN, M., ZHANG, X., STERN, F., & KENDALL, J. (2021). *METHODS AND EMERGING STRATEGIES TO ENGAGE PEOPLE WITH LIVED EXPERIENCE: IMPROVING FEDERAL RESEARCH, POLICY, AND PRACTICE*. WASHINGTON, DC: OFFICE OF THE SECRETARY FOR PLANNING AND EVALUATION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES.

## What can we learn from this study?

This study identifies lessons learned from a literature review, discussions, and consultations with experts to more effectively and appropriately engage individuals with lived experience in efforts to improve research, policy, and practice. Although the study regards engagement in federal initiatives, the lessons learned are relevant in helping the child welfare field more effectively involve individuals with lived experience.

### Study details:

- **Population:** Expert consultants, federal staff, and nonfederal individuals with lived experience (N=32)
- **Data source:** Literature review on 27 federal initiatives, conversations with individuals with lived experience
- **Methodology:** Environmental scan, key informant discussions and consultations

## What are the critical findings?

People with lived experience have insights and expertise that can inform positive changes in practice and policy, benefiting agencies, programs, and the people they serve.

- **Individuals with lived experience play a variety of roles**, with engagement ranging from storyteller (limited engagement), to advisor, grantee, partner, and staff (high engagement).
- **Individuals may need specific supports.** Storytellers who share personal histories may relive trauma and may need access to mental health services. Covering costs of child care, travel, conference registration, and continuing education may also be important.
- **Policies and procedures should support meaningful involvement.** Background checks, scheduling conflicts, and access to child care are potential barriers.
- **Effective engagement does not “tokenize.”** Individuals should be included from the very start of project planning so their perspectives are meaningfully incorporated.
- **Equity and access should be prioritized.** Staff should be aware of disparities in power and create an environment of support and mutual respect, including using inclusive, plain language, and recruiting individuals from underrepresented populations.
- **Successful engagement starts with planning.** Extra time may need to be built into project timelines, and budgets should include compensation at rates similar to other experts.

## Why is this important for our work?

As the child welfare field transforms into a [21st century child and family well-being system](#), incorporating the insights of people with lived experience is paramount. They know the system from the inside-out and are well positioned to provide meaningful perspectives and ideas.

To learn more, see [How can we prioritize constituent voice and choice to transform foster care?](#) and additional resources on [lived expertise](#).

For more information about this study, [access it online](#) or email [KMResources@casey.org](mailto:KMResources@casey.org).