



# Advancing Primary Prevention in Human Services: Opportunities for People with Lived Experience

In August 2022, the U.S. Department of Health and Human Services held a virtual convening on how to increase primary prevention in human services systems. Through panel discussions and interactive sessions, participants discussed how human services can shift from *responding* to families in crisis to *preventing* the crisis before it occurs. Participants told us that primary prevention services—which help reduce risk and promote protective factors—can help people avoid negative experiences and outcomes. This brief highlights ways for people with lived experience to co-create with policymakers and program practitioners a new way of delivering primary prevention services.

Convening participants told us that we need a new way of delivering primary prevention services\* that promotes equity by relying on the guidance and leadership of people with lived experience. The policymakers, researchers, and program administrators behind prevention services should have lived experience and/or co-create these services with people who do. This brief shares ideas on ways policymakers, practitioners, and researchers can reach out to people with lived experience and the roles they can play.

## Lived Experience: An Essential Way of Knowing

A person can have different types of expertise about an issue, alone or in combination. People who create policies and programs have academic or practice expertise but often lack lived experience. People with lived experience, many of whom also have professional training, have unique insight into how to make policies and programs most helpful and prevent them from being harmful. Lived experience is 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 the strategies that aim to address those issues.†

### Ways to engage people with lived experience to build a primary prevention system<sup>§</sup>



† Adapted from Forde J, Alves S, Amos L, et al. Recruiting Individuals with Lived Experience. ASPE (Washington, DC) 2022. <https://aspe.hhs.gov/reports/recruiting-individuals-lived-experience>.

\* Primary prevention services include programs, policies, or other strategies that aim to prevent adverse outcomes from occurring by promoting protective factors and reducing risk factors.

§ Adapted from Skelton-Wilson S, Sandoval-Lunn M, et al. Methods and Emerging Strategies to Engage People with Lived Experience. ASPE (Washington, DC) 2021. <https://aspe.hhs.gov/reports/lived-experience-brief>.

## OPPORTUNITIES FOR PEOPLE WITH LIVED EXPERIENCE

This chart lists opportunities for people with lived experience to co-create primary prevention services. Convening participants suggested these ideas. More detail on these ideas is available in the convening summary: <https://aspe.hhs.gov/reports/primary-prevention-convening-brief>. Across these roles, it is essential to acknowledge the many types of skills and knowledge a person with lived experience may have, including academic and practice expertise. It is also critical to compensate people for sharing their lived experience and to engage them in clear roles.

**Storyteller** *Note: Those with lived experience should not be asked to share their personal stories unless they have agreed to play this role.*



### Improve service accessibility and effectiveness

Providers should learn about people's experiences accessing and receiving services. When people share their stories in a way that feels safe, providers can understand what's working, what's not, and how to make things better. Providers can reflect on and draw from people's stories to design new services, improve existing ones, and to increase equitable access to services.



### Participate in research that can build support for prevention services

To get support for policy and funding changes, program administrators need to show policymakers that primary prevention services are effective. To create that evidence, researchers often conduct studies to learn about people's experiences with prevention services. People with lived experience can be recruited to participate in interviews, focus groups, and listening sessions.

**Advisor**



### Help design research that can build support for prevention services

Researchers need to involve people with lived experience from the beginning of the research process and throughout. People with lived experience can guide research studies by helping researchers figure out the right questions to ask, the right people to ask, and the right ways to ask them. They also can help researchers interpret what they are seeing after the information is gathered.



### Co-create prevention services

To best meet people's needs, primary prevention services should be designed and implemented by the community. This will require system builders to spend time and resources to engage people thoroughly and authentically (including compensating people for their time). System builders need to recruit people with lived experience to join formal advisory groups, committees, and boards to allow for many forms of knowledge and skill to create the most effective prevention services.

**Grantee**



### Shape—and use—funding for primary prevention services

As they make grants more accessible, funders will need organizations run by people with lived experience to apply for and use that funding in ways that best meet their community's needs. In the meantime, funders need to reach out to learn about how to reduce barriers these community-run organizations may face in getting and using grant funding for primary prevention services.

**Partner**



### Rally community support for prevention services

Primary prevention services can only be effective if policymakers are willing to fund them, if organizations are willing to offer them, and if people are willing to use them. For that to happen, policymakers, program administrators, and service providers should engage community organizations and people with lived experience to help spread the word about the value of primary prevention by communicating to elected representatives, community service providers, and social networks.

**Staff**



### Join the primary prevention workforce

Ideally, the primary prevention workforce will include people with lived experience who receive the resources, supports, and training they need. To make that a reality, program administrators need to create an inclusive work environment, such as by eliminating certain educational or legal barriers to employment. Program administrators need to provide necessary resources and supports, including fair compensation and reasonable workloads. People with lived experience also need mental health and trauma support if the work is re-traumatizing for them. Finally, program administrators should provide the training workers need, including training in risk and protective factors, as well as person-first and trauma-informed approaches to service delivery.

## NEXT STEPS

We will hold roundtable discussions to move forward with ideas from the convening. The roundtables will guide efforts to build a new framework for delivering primary prevention services.

## WANT TO KNOW MORE?

This is one in a series of briefs highlighting key considerations from the convening. For other briefs in this series, see <https://aspe.hhs.gov/primary-prevention-human-services>.

## U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

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### Lived Experience Advisors

Convening participants and panelists who shared their lived experience included representatives from the following organizations:

CAMBA

Capacity Building Center for States

Family Resource Information, Education, and Network Development Service (FRIENDS)

Family Run Executive Director Leadership Association (FREDLA)

Georgia Campaign for Adolescent Power (GCAPP)

HopeWorks (New Mexico)

National Network for Youth (NN4Y)

True Colors United

Youth Collaboratory

Youth Move National