




What is Lived Experience?

Purpose This tool describes key elements of lived experience, its features in the context of health and human services, and why engaging people with lived experience is essential to ensuring our services reach all people.^{1,2}



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 systems, research, policies, practices, and programs.³ When we say **lived experience**, we mean knowledge based on someone’s perspective, personal identities, and history, beyond their professional or educational experience.



Health and human services programs, policies, strategies, and research can have wide-ranging effects on individuals and communities.



Those effects can increase or undermine opportunities for optimal health and well-being, particularly for those who have been underserved, penalized, or excluded.



Staff can partner with and learn from people with lived experience and the communities we aim to serve before enacting policies, conducting research, and developing and implementing programs.

Key elements to consider

Perspectives on the same issue vary with a person’s unique lived experience, but all perspectives are valuable.



All people have several intersecting identities, such as age, ability, and parenting status. Intersections of different identities lead to varied experiences.



Even though individuals have personal agency and choice, they do not have control over the barriers or constraints that they may face in their daily lives.



¹ Suggested Citation: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. “What is Lived Experience?” by Grace Guerrero Ramirez, Kate Bradley, Lauren Amos, Dana Jean-Baptiste, Ryan Ruggiero, Yvonne Marki, Jeremiah Donier, Helena Girouard, and Danny Murillo. Washington, District of Columbia: 2022.

² For more information on how to equitably engage people with lived experience, see <https://aspe.hhs.gov/lived-experience>.

³ Adapted based on input from HHS staff and from [Methods and Emerging Strategies to Engage People with Lived Experience](#). It is important to ask people if the term lived experience is one they prefer to use in relationship to their expertise and experiences with health and human services or issues.

Who are people with lived experience in the context of health and human services work?



People impacted by health and human services programs and systems

Staff can benefit from **learning from people who participate in or are eligible to participate in** health and human services programs, policies, and research. This includes people who are:

- ▶ Currently **using programs** that are culturally, physically, financially, and geographically attainable and responsive to their needs
- ▶ **Participating in programs but do not benefit at the same rate** as others
- ▶ **Eligible for but do not or cannot participate in** programs
- ▶ **Not currently eligible for but could benefit** from programs
- ▶ **Family members** of those involved in or eligible for programs



Health and human services staff with lived experience

Staff have different lived experiences and therefore bring **varied perspectives to health and human services work**. These perspectives are an asset and can be leveraged during their work. These lived experiences may also affect how staff interact with grantees, communities, and other partners.

People with lived experience can endure **unfair assumptions and trauma** in various contexts, including in the workplace. Whether or not staff are hired for expertise related to their lived experience, it is important to **hold internal conversations on how to respectfully engage staff with lived experience**.

How does engaging people with lived experience improve outcomes?

It is important for health and human services programs to value the perspectives of people they aim to support or who could benefit from the programs and services by learning from and acting on their perspectives, histories, priorities, and aspirations.



Strive for true partnerships:

Engage people meaningfully which can help **build or rebuild trust** between programs and people with lived experience in the communities we serve.



Meaningfully inform decisions:

Make decisions about programs, research, approaches, and policies **collaboratively** with individuals and communities that are most affected by those efforts.



Improve outcomes:

Develop programs, research, approaches, and policies that **meet people's needs** and help them reach their optimal potential.