

What is Lived Experience?

What is equity? The consistent and systematic, fair, just, and impartial treatment of all individuals, including individuals who belong to underserved communities that have been denied such treatment, such as Black, Latino, and Indigenous and Native American persons, Asian Americans and Pacific Islanders and other persons of colors; members of religious minorities; lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI+) persons; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality. Definition adapted from Executive Order 13985.

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 advancing equity. 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 denied equal access to resources and have been harmed by institutions and systems.



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 valid.



All people have several intersecting identities, such as gender identity, ability, and race. Intersections of different identities lead to advantageous and disadvantageous experiences.



People live their daily lives in the context of larger societal structures and systems. Even though they have personal agency and choice, they do not have control over the barriers or constraints that these structures and systems often impose.



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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 accessing 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 access 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 diverse perspectives to health and human services work. These perspectives are an asset and can be leveraged during their work. These lived experiences may also reflect biases that affect how staff interact with grantees, communities, and other partners.

People with lived experience can endure stigma 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 and foster safe spaces.

How does engaging people with lived experience advance equity?

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 break down power dynamics and 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 equitable outcomes:

Develop programs, research, approaches, and policies that meet people's needs and improve their access to services and programs that they need to reach their optimal potential.

This content was initially created to inform federal staff at the U.S. Department of Health and Human Services. In an effort to increase collaboration and share promising practices, the Office of the Assistant Secretary for Planning and Evaluation has made this tool available for both public and private partners. Potential audiences that may be interested in these materials include, but are not limited to, state and local governments, tribal governments, and other private or non-profit organizations focused on programs and policies relating to health and human services.