

Lived Expertise Is a Journey, Not a Project

Introduction

Peer support services empower and support parents, caregivers, and children and youth (from birth to age 24) who are experiencing social, emotional, developmental, substance use or behavioral challenges. They are a rapidly growing form of service and an essential component of the mental health system. Peers' firsthand experience and knowledge of child- and family-serving systems allow them to provide emotional, social and practical help to youth and families navigating challenges within these systems. Peer support can change how mental health professionals and social service systems approach and engage with people about their mental health and well-being.

The concept of "lived expertise" has been introduced in settings such as the child welfare system, but not until now in the mental health system. A peer with lived expertise is someone who has experience navigating a child- or family-serving system and who has deepened their learning about service systems and the peer workforce, such as by following new developments in peer advocacy or gaining knowledge of policy or systemic issues. Peers typically accomplish this while actively working toward positive changes in the mental health or another service system.

This report refers to the concept of lived expertise as a means of defining and recognizing the value of these qualifications, which peers gain as they advance in their careers. To utilize lived expertise, we must support the participation of peers and welcome their influence and leadership in the mental health system, including in service design and delivery, monitoring, reporting, research, and evaluation and improvement planning. This can lead to positive outcomes for youth and families experiencing mental health challenges, organizations that employ peers and the peers themselves.

In this report, we describe a framework for lived expertise. The framework has several goals:

1. To provide guidelines for peer advocates to learn and improve their practice
2. To help organizations recognize the value of peers with lived expertise in the mental health system, and to improve and expand opportunities for peers to collaborate with service providers as equal partners
3. To center the mental health and social service systems around people who have gained knowledge about these systems through direct and firsthand experience

We encourage mental health organizations and professionals in New York State to implement this framework so people with lived expertise can successfully participate in, influence and obtain leadership roles in the mental health and social service systems

What is lived experience?

People with lived experience have firsthand experience gained through a child- or family-serving system that they can use to help guide youth and families through similar systems and make sure all their needs are met. They can provide workshops and trainings to community members, including youth and families, to educate them on different mental health challenges and teach them skills that will help them advocate for their own needs. People with lived experience may be parents or caregivers of a child with mental health challenges or even children or youths themselves. Lived experience gives people insight into systemic patterns, common behaviors and challenges faced by those with similar experiences.

What is lived expertise?

People with lived expertise have applied their lived experience to their work and built upon it by increasing their knowledge of child- or family-serving systems and systematic barriers that prevent youth and families from accessing services. They use this knowledge to advocate to decision-makers for improvements to these systems. They are knowledgeable about the peer workforce and how to support its development, having years of direct involvement in it creating and building relationships with stakeholders and expanding their expertise to the peers around them. People with lived expertise have deep knowledge and advanced skills and should be viewed as leaders and experts in their fields.

Framework

In 2018, youth peer advocates (YPAs) completed a survey on the professional lives and roles of YPAs at New York City Department of Health and Mental Hygiene (NYC Health Department) and New York State Office of Mental Health-funded programs in NYC. The survey provided important insights into the role of YPAs, job satisfaction and job supports.

The survey results showed that many YPAs:

- Had little to no opportunities for job advancement
- Often left their jobs due to concerns about low salaries and limited opportunities for advancement
- Are interested in taking on higher-level responsibilities if available to them, such as advancing into a senior YPA position
- Want more structure and clarity in their jobs, which would prevent confusion and burnout

For more information on the survey and to view the results, visit nyc.gov/assets/doh/downloads/pdf/peer/youth-peer-advocacy-report.pdf.

Across the U.S., peers have identified challenges they face, including role confusion, lack of supervision, low wages and lack of respect for their role. Additionally, peers are often not treated equally to staff working in nonpeer roles, which makes it difficult for them to create meaningful and respectful working relationships with other mental health professionals and administrative staff. To address these challenges locally, the NYC Youth Peer Advocate Coalition (YPAC) was launched in 2020. The YPAC is a youth-guided group made up of representatives from organizations that help support and develop the YPA workforce. In support of the youth and family peer workforce, we hope this framework will:

- Help organizations address these disparities
- Increase recognition of the important contributions of peer support to the mental health system
- Lead to upward mobility for YPAs
- Create a shared vision among organizations that employ youth advocates in order to support the mental health and social services systems in NYC by fully involving people with lived expertise in how services are designed, delivered, monitored, reported, evaluated, researched and improved

Recovery, Self-Accountability, Supervision and Shadowing

Phase 1: Gaining Foundational Knowledge and Sharing Lived Experience

People in Phase 1 demonstrate lived experience through their consultation and contributions, providing feedback within established service boundaries. Examples of this include:

- Engaging with child-serving systems (such as the mental health, foster care, juvenile justice or special education system)
- Advocating within systems (including for case workers facing challenges, medication management, aging-out rights, Individualized Education Program statements, correcting misdiagnoses, and legal aid)
- Self-educating and educating peers (such as reading pamphlets, attending support groups and work groups, having one-on-one conversations, asking questions or talking to lawyers)
- Attending trainings and conferences (such as volunteering to speak about lived experience and gaining additional knowledge)
- Aging out (this applies to the foster care, juvenile justice and special education systems)

Phase 2: Deepening Knowledge and Applying Lived Experience

People who are entering the transitional Phase 2 might partner and work together with organizational staff to achieve program goals. Examples of this include:

- Working as a YPA, family peer advocate or peer specialist
- Receiving more advanced training and attending more conferences and forums
- Participating in more leadership opportunities (such as panels, presentations, peer input processes or gatherings of community members)

Phase 3: Decision-Making and Leading

People in Phase 3 demonstrate lived expertise through decision-making and leading, working as partners and contributing to decision-making or leading projects and making independent peer-informed decisions. Examples of this include:

- Advocating for and changing policies within child- or family-serving systems to reduce barriers for families and youth trying to access services
- Changing agency and program policies to advance peers in the workplace (acting as the voice for peers within an agency to create change)
- Presenting their own content at conferences
- Attending paid speaking engagements (experts may negotiate prices for sharing their lived experience and expertise)
- Receiving acknowledgment for their work in the field (such as awards or certificates)

What are the differences between lived experience and lived expertise?

The differences between lived experience and lived expertise are in a person's individual traits and attitudes, their functional and systems-level skills and competencies, the tasks they can successfully complete, and the organizational and service delivery outcomes they can achieve. People with lived experience can influence how people view peer advocacy and the concept of lived experience, while people with lived expertise can not only influence people's views but also create change on functional and systems levels through direct participation and leadership.

Attributes and Approaches

A successful peer with lived experience might have:

- A focus on recovery and results
- Authenticity based in personal experience
- An equity-focused approach
- A focus on relationships and people
- Experience with trauma
- Empathy
- An understanding of inclusivity

A successful peer with lived expertise will ideally have gained the following additional attributes from their experiences working in the mental or behavioral health field:

- Self-awareness
- Eagerness
- Persistence
- Confidence
- Self-motivation
- A focus on relationships and people
- The ability to inspire others
- Independence
- Flexibility
- The ability to welcome change
- An ongoing approach to learning
- An interest in collaboration
- Patience
- A willingness to compromise

Skills and Competencies

The skills and competencies of a successful peer with lived experience might include:

- Interpreting information
- Prioritizing tasks
- Conducting peer interviews
- Thinking analytically and solving problems
- Giving and receiving feedback

- Identifying potential in the people they serve and peers they work with
- Accessing treatment and services and navigating systems of care
- Having up-to-date knowledge of community resources and services
- Having knowledge about families, youth and other people who need support
- Having knowledge about recovery and recovery supports

A successful peer with lived expertise ideally will have gained most of the following additional functional skills, competencies and systems-level understandings from their years of experience working in the mental or behavioral health field:

- Policymaking and policy analysis
- Public speaking
- Strategic planning
- Executive decision-making
- Negotiation
- Project management
- Supervision and training of peers within organizations
- Identification of credible information and options from various resources
- Understanding and application of recovery and evidence-based practice models
- Up-to-date knowledge of child-serving systems (such as the mental health, foster care, juvenile justice and special education systems)
- Research and evaluation, including engagement in community-based participatory research (CBPR) programs
- Recognition and examination of, and response to, disparities in peer policies and systems
- Effective written communication (such as letters, emails, reports, presentations and proposals)
- Working to eliminate prejudice and discrimination against peers, youth, and families with lived experience and lived expertise
- Knowledge of legal resources and advocacy organizations for building effective advocacy plans

Advanced Systemic Advocacy

Peers can use their lived expertise to seek positive changes to existing attitudes, policies and structures in the mental and behavioral health systems, which can impact service design and delivery. They can also use their skills, experience, confidence and passion to lead initiatives that expand and contribute to the peer workforce and to mental health work nationally and locally.

How can supervisors develop peer advocates' lived expertise?

Agencies and programs can develop their staff's lived expertise through shadowing, supervision and training, and by increasing opportunities for peers to gain knowledge of different child- or family-serving systems, policies and practices and to develop advocacy skills to promote systems change.

Examples of this include:

- Encouraging the peer advocate to shadow other peer advocates who are using their lived expertise in the workplace
- Offering reflective supervision
- Developing a strengths, weaknesses, opportunities and threats (SWOT)

analysis to assess skills and knowledge level

- Encouraging the peer advocate to join the NYC Community Service Board (CSB) to stay up to date with systems policies and changes that can affect youth and families holistically
 - CSB:
nyc.gov/site/doh/health/health-topics/mh-community-services-board.page
 - Community and Citywide Education Councils:
temp.schools.nyc.gov/get-involved/families/Community-and-citywide-education-councils-cecs
- Asking peers to join decision-making meetings with program staff to ensure peer input
- Introducing peer advocates' lived expertise and their role on your team via an email or letter to stakeholders

and existing committees in order to initiate opportunities

- Providing consistent training in areas that need improvement
- Focusing on goals and not just tasks
- Delegating authority
- Demonstrating the importance of listening skills
- Encouraging peer advocates to build relationships with stakeholders within the workforce
- Ensuring peer advocates have strong knowledge of the peer workforce as well as expertise in child- or family-serving systems and policies
- Encouraging peer advocates to join peer coalitions
- Supporting and creating opportunities for peer advocates to build knowledge and promote awareness of the strengths, needs, challenges and systemic barriers experienced by youth and families

How can supervisors measure peer advocates' lived expertise?

Measuring success and growth can stimulate the learning of peer advocates and promote acceptance of them as active and respected members of the team. Examples of this include:

- Regularly updating the SWOT analysis with the peer advocate
- Monitoring peers' attendance at professional development trainings and opportunities
- Holding regular and productive performance evaluations
- Expecting staff to be credentialed and to keep their credentials in good standing (such as through renewal or continuing education units)
- Ensuring that peers are keeping up with child- or family-serving systems over time
- Ensuring that peers remain experts in youth and family peer support
- Ensuring that peers are maintaining their own recovery and are able to share that recovery journey in their work
- Assessing that peers are sharing the history of their advocacy and how far they came in their journey through lived experience, and that they are drawing on knowledge and skills that both include and go beyond their lived experience

What are the expected outcomes for peers, organizations, programs and systems who employ a peer advocate with lived expertise?

In addition to the previously discussed outcomes, the person with lived expertise may see these outcomes:

- Individual level:
 - Increased knowledge and leadership skills
 - Amplified research skills and expertise within the mental health system
 - Improved professional skills for engaging and reaching people in prioritized communities
 - Increased understanding of the role of peer programs and agencies
 - Strengthened community connectedness and social and emotional supports
 - Leadership experience or participation in peer-led research
 - Experience independently developing and delivering training
 - Validated personal opinions and viewpoints
- Agency and program level:
 - Lived experience and lived expertise valued and respected throughout the agency and program
 - Improved ability to deliver responsive and equitable services, programming, training and technical assistance
 - A better-informed and more empowered group of advocates to influence decision-makers about agency strategies
 - Improved program alignment with participatory practices and equitable program design and evaluation
 - Improved effectiveness of practices used by program staff
 - Development and knowledge of community and research policies that benefit peers in programs and the mental health system
 - Painful experiences transformed into positive solutions for communities
 - Peers leading and participating in a coalition steering committee or working group
 - Advisory groups developed and led to gather community feedback on peer-related initiatives
 - Resources developed or executive reports written and reviewing to improve quality and accessibility
 - Nonpeer programs and organizations educated on the benefits of lived experience, and peers embedded within the organization
- Systems level:
 - Improved awareness and knowledge of the strengths, needs, challenges and systemic barriers experienced by the prioritized community
 - Improved insight into common patterns and behaviors and the special challenges and barriers faced by people who share similar experiences
 - Improved practices and policies to direct funding and other resources toward the priorities of communities most in need
 - A deeper understanding of social issues
 - Amplified research and expertise throughout the mental health system

- Changes to policies and procedures in the mental health system to improve practice and service efficiency
- Decision-makers influenced to develop legislation that provides high-quality person-centered, recovery-oriented services
- Prejudice, discrimination and assumptions in systems challenged
- Actively engaged stakeholders across systems keeping up to date on systems policies
- Improved representation and increased influence of prioritized communities in decision-making processes and practices and other social actions

Summary

This framework offers an opportunity to create a shared vision for youth peer advocates, family peer advocates, agency staff, leadership and the systems in which they work. In the last decade, the power of peer support has begun to be nationally recognized for its ability to engage people in a way traditional services have not always been able to. Lived expertise is a powerful tool in the mental health toolbox that can help us design, deliver and evaluate services in new and more effective ways.

This framework on lived expertise was developed by the NYC Health Department with the New York Foundling.