



LIVED EXPERIENCE FRAMEWORK FOR NSW

Participation • Influence • Leadership

Why we need this Lived Experience Framework

People across NSW have called for our mental health and social services to be truly centred on the people who use them and supportive of their individual journeys of recovery. To achieve this, we must embrace the participation, influence and leadership of people with lived experience of mental health issues and caring, families and kinship groups in service design, delivery, monitoring, reporting, research, evaluation and improvement activities. This will lead to better outcomes for people experiencing mental health issues and those who offer them hope and support, as well as improving the working environment of those who give professional help.

This *Lived Experience Framework* (Framework) is the response to the call for embedding lived experience across the sector and system processes, comprises a language guide, vision, guiding principles, actions and implementation approach to embed lived experience across mental health and social services systems.

In co-designing this Framework, participants endeavoured to live out this vision by bringing together people with lived experience of mental health issues and caring, families and kinship groups as well as stakeholders from within the mental health and social services systems. Together, their challenge was to listen, acknowledge their differences and find a common ground that extended respect to the needs and hopes of all. This document reflects their wisdom, compassion and commitment.

This Framework provides a guide to encourage efforts to be brave, generous and curious in spirit, to seek out opportunities to learn and improve, and for people with lived experience of mental health issues and caring, families and kinship groups to work together with service providers as equal partners. This Framework is to be implemented by mental health and social services in NSW so that people with lived experience of mental health issues and caring, families and kinship groups participate in, influence and have leadership in mental health and social services in NSW.

Who this Framework is for?

This Framework puts forward a shared vision for substantive change in the culture, leadership and structures that underpin our mental health and social services systems in NSW to embed the voice of lived experience in the way they design, deliver, monitor, report on, evaluate and improve services and conduct research.

Mental health and social services systems include:

- government health services including local health districts, specialty health networks, drug and alcohol services, and all NSW Health structures
- government social services providers including, but not limited to, the NSW Department of Family and Community Services, Department of Justice, Department of Education, Aboriginal Affairs and Department of Finance, Services and Innovation
- primary health networks
- private health and social service providers
- non-government organisations, including Aboriginal Community Controlled Health Services
- education providers (primary, tertiary and vocational)
- policy, advocacy and research organisations
- community groups and other service providers.

Guiding language

Language has a profound impact on people and the use of inclusive and contemporary language empowers people, minimises stigma and changes culture over time. The co-design process used to develop this Framework included extensive work on the development of the most respectful, inclusive language that represents the lived experience of people with mental health issues and caring, families and kinship groups. The language used is explained below.

People who have experienced a mental health issue and have recovered, or who currently have a personal lived experience of mental health issues and are on their recovery journey, are referred to as **'people with lived experience of mental health issues'** in this Framework.

The Framework also uses language which acknowledges the lived experience of carers, families, kinship groups and friends supporting people with lived experience of mental health issues.

When speaking collectively, the Framework refers to the **'lived experience of people with mental health issues and caring, families and kinship groups'**.

What is the purpose of this Framework?

To improve the mental health and wellbeing of people living in NSW, it is essential that people with a lived experience of mental health issues and caring, families and kinship groups can participate in, influence and lead service design, delivery, monitoring, reporting, research, evaluation and improvement activities. This will achieve stronger services and better outcomes for all people in NSW.

This Framework:

- Provides strategic direction and vision for embedding lived experience of mental health issues and caring, families and kinship groups
- Provides guidelines for actions for individuals, services, agencies and organisations
- Clearly articulates the culture shift that is required
- Communicates the values and principles that will enable systems change
- Encourages and supports continual collaborative engagement



How this Framework was developed

Living Well: A Strategic Plan for Mental Health in NSW 2014-2024, provided actions to guide mental health reform including the participation of people with lived experience of mental health issues and caring, families and kinship groups in service design and improvements.

The NSW Mental Health Commission implemented these actions by supporting the development of this Framework through a two-staged co-design approach. Stage one included a Consumer-led Lived Experience Project and a Carer-led Lived Experience Project. Stage two involved establishing an Advisory Group, including Deputy Commissioner Fay Jackson, three members of each of the previous projects' steering groups and three additional stakeholders.

The Advisory Group met to design processes and inform a co-design workshop. The co-design workshop brought together members of the previous projects' steering groups and stakeholders from a mix of mental health services, peak bodies, government and non-government health, education/vocation, justice, disability and social service providers and policy makers.

Getting started

All mental health and social services need to be proactive, move quickly, invest energy and show commitment to embedding this Framework. This will require collaboration between people with lived experience of mental health issues and caring, families and kinship groups, government agencies and non-government organisations to build the conditions for necessary capability building.

The following approach will help support agencies, service providers and other stakeholders to develop their own action plans to embed this Framework:

- trust the expertise and lived experience of people with mental health issues and caring, families and kinship groups
- respectfully apply and embed lived experience skills, information and insights
- develop a 'safe' space for dialogue and respectful inclusion of people with lived experience and caring, families and kinship groups and continued learning
- allow for ongoing capacity building of all participants (awareness and skills to change culture)
- work to challenge the status quo regarding mindsets, values, culture and current work practices
- develop a response with a structured and phased implementation (embedding) process
- create or adopt existing practical tools for change and provide support and training
- commit to ongoing collaborative engagement through co-leadership, co-design, co-creation, co-production, evaluation and shared accountability across the system.

The vision

- Every aspect of mental health and social service design, delivery, monitoring, reporting, research, evaluation and improvement activities are informed by the insights of people with lived experience of mental health issues and caring, families and kinship groups.
- Every aspect of mental health and social service design, delivery, monitoring, reporting, research, evaluation and improvement activities are done in respectful and equitable partnership with people with lived experience of mental health issues and caring, families and kinship groups.
- Mental health and wellbeing is seen, responded to and prioritised equally with physical health.
- Mental health and social services across NSW recognise, respect and support the leadership and participation of people with lived experience of mental health issues and caring, families and kinship groups.
- Mental health and social services provide access to work opportunities in supportive and inclusive workplaces for people with lived experience of mental health issues to support their recovery.

Guiding principles

The following principles guide action.

Principle	What this means
Informed by Lived Experience	Expertise, experience, wisdom, knowledge, compassion, and resilience of people with lived experience of mental health issues and caring, families and kinship groups is part of the structure, service design, delivery, monitoring, reporting, research, evaluation and improvement activities of all aspects of mental health and social services. This will require collaboration and true partnerships.
Flexible and agile	Mental health and social services demonstrate flexibility and agility through being willing to embrace risks, innovate and respond in a timely way. This includes being open to learning by exploring and challenging the stigmatising beliefs, assumptions, practices and culture behind what has been done before.
Transparent and accountable	Mental health and social services share, communicate, celebrate great outcomes and allow themselves to be scrutinised for the purposes of continual learning, adaptation and improvement.
Sustainable	Mental health and social services and the community build a focus on sustainability through knowing what is currently working well and exploring ways to enable more humane, healing, efficient and effective practice using available resources.
Continually learning	Mental health and social services are committed to continual dialogue and learning across services and systems. This includes being open and willing to work with new ideas as they emerge regardless of who or where they come from.

How can change be achieved?

The Framework provides an overarching set of objectives, immediate actions and future priority actions, under three focus areas: services, leadership and systems.

To support the change required a range of possible outcomes, or measures of success, are proposed. Given the variety of settings, range and focus of services, services or individuals should use this Framework to develop and plan their own actions and measure the related outcomes tailored to their circumstances.

The table over the page outlines the actions to achieve change and nine key outcomes from implementing the Framework.

Lived Experience Framework for NSW

Actions to achieve change

Focus areas	Service action <i>Shifting the usual way of doing things, the cultures we foster, the assumptions we make and the stories we tell.</i>	Leadership action <i>Demonstrating leadership commitment and action and building leadership capacity in teams.</i>	Systems level action <i>Refocusing policies, resources, education and employment opportunities and structures.</i>
Objectives	<p>Culture and approach</p> <ul style="list-style-type: none"> • The value of lived experience of people with mental health issues and caring, families and kinship groups is recognised across services and communities. • Holistic, person centered and trauma-informed approaches to care are focused on solutions and leverage people's strengths. <p>Quality improvement</p> <ul style="list-style-type: none"> • Organisations are safe, empathic, inclusive, curious and continually learning and improving. 	<p>Agile leadership</p> <ul style="list-style-type: none"> • Leaders are publicly committed to implementing this Framework and influence current and emerging leaders to do the same. • Leaders are committed to collaboration, transparency, shared power in leadership and shared responsibility. <p>Capacity building</p> <ul style="list-style-type: none"> • Leaders sponsor formal change management processes to embed this Framework. • Leaders support staff to attend training opportunities to assist with embedding lived experience. • Leaders ensure their services are employing people with lived experience of mental health issues and/or families and carers and provide them with development opportunities in leadership. 	<p>Policy</p> <ul style="list-style-type: none"> • All policy, planning, service design, evaluation, research, monitoring, improvement activities and reporting is done collaboratively and transparently through co-design and co-production. These efforts explicitly state they are co-designed. <p>Organisational structures</p> <ul style="list-style-type: none"> • Organisations are structured in a way that is relevant to people with lived experience of mental health issues and caring, families and kinship groups and are supportive of their participation, influence and leadership. <p>Resources</p> <ul style="list-style-type: none"> • Resources are allocated fairly for equity and greatest impact. <p>Education</p> <ul style="list-style-type: none"> • People with lived experience of mental health issues and caring, families and kinship groups are partners in education and training design (including resources), delivery, assessment, evaluation and improvement. • Education, training and supervision is available for people with lived experience of mental health issues and caring, families and kinship groups. <p>Employment opportunities</p> <ul style="list-style-type: none"> • Employment opportunities and support is available for people with lived experience of mental health issues and caring, families and kinship groups across the mental health and social support system.

Service action	Leadership action	Systems level action
<p>Language</p> <ul style="list-style-type: none"> Assertively apply a recovery oriented and trauma informed language guide such as the <i>Mental Health Coordinating Council Recovery Oriented Language Guide</i> or the <i>National Communications Charter</i>. <p>Culture and approach</p> <ul style="list-style-type: none"> Mental health services implement recovery-oriented guidance such as the <i>National Framework for Recovery Oriented Mental Health Services</i>. Services implement guidance in delivering trauma-informed care such as the <i>'The Last Frontier' Practice Guidelines for Treatment of Complex Trauma and Trauma Informed Care and Service Delivery</i> (Blue Knot Foundation). Embrace and support "dignity of risk" for people receiving support. This will involve balancing service risks with opportunities to embrace innovation. <p>Co-design and co-production</p> <ul style="list-style-type: none"> Co-design mental health service environments (including emergency departments, inpatient and forensic units, community mental health and other specialist facilities) with people with lived experience of mental health issues and caring, families and kinship groups to provide care in the most respectful environment possible. <p>Quality improvement</p> <ul style="list-style-type: none"> Use recovery-oriented service assessment tools and outcome measures such as the <i>World Health Organization Disability Assessment Schedule</i> and <i>Recovery Oriented Service Self-Assessment Toolkit</i>. 	<p>Agile leadership</p> <ul style="list-style-type: none"> Advocate for commitment to this Framework from leaders across mental health and social services. Identify champions across all levels of mental health and social services and incentivise them to lead changes described in this Framework. Establish consumer peer worker and carer peer worker roles across all levels in mental health and social services. Advocate for roles for people with lived experience of mental health issues and lived experience of caring roles across all levels of mental health and social services. <p>Capacity building</p> <ul style="list-style-type: none"> Create and support opportunities for people with lived experience of mental health issues and caring, families and kinship groups to develop leadership capabilities. Apply and monitor formal change management processes to embed this Framework. Sponsor the development and use of available tools to implement this Framework across mental health and social services. 	<p>Policy and organisational change</p> <ul style="list-style-type: none"> Develop an approach to deliver this Framework and ensure its application in all mental health and social services. Co-design mental health and social policies, procedures and guidelines with people with lived experience of mental health issues and caring, families and kinship groups. Review, develop and implement paid participation policies for people with lived experience of mental health issues and caring, families and kinship groups in all mental health and social services. <p>Resources</p> <ul style="list-style-type: none"> Audit existing policies, procedures, guidelines and resources in mental health and social services to better understand what are in existence, how they are being used, what is needed to implement this Framework and identify resources to undertake this change. Ensure the participation, influence and leadership of people with lived experience of mental health issues and caring, families and kinship groups is considered in all new funding arrangements, including research. <p>Education</p> <ul style="list-style-type: none"> Develop and deliver training focused on challenging assumptions, beliefs and behaviours around the value of the lived experience of people with mental health issues and caring, families and kinship groups in mental health and social services. <p>Employment opportunities</p> <ul style="list-style-type: none"> Co-design a system of paid opportunities for a variety of people with lived experience, including carers, families and kinship groups to participate, influence and lead mental health and social services. Annually increase the number of consumer peer worker and carer peer worker roles in all government and non-government mental health and social services. Formalise supervision structures for consumer peer workers and carer peer workers in all government and non-government mental health and social services.

	Service action	Leadership action	Systems level action
Future priority actions	<p>Culture and approach</p> <ul style="list-style-type: none"> Undertake and document mandatory staff training in the value of holistic, person-centered, recovery-oriented and trauma-informed care in all mental health and social services. <p>Co-design and co-production</p> <ul style="list-style-type: none"> Include people with lived experience of mental health issues and caring, families and kinship groups in accreditation or other review processes to reflect and record changing attitudes to risk and compare performance. Capture feedback from people with lived experience of mental health issues and caring, families and kinship groups on their experience of mental health and social service experiences regularly. Include measures of social inclusion and citizenship. <p>Quality improvement</p> <ul style="list-style-type: none"> Compare performance of mental health and social services in implementing and embedding this Framework. Contribute to the evidence base. 	<p>Agile leadership</p> <ul style="list-style-type: none"> Establish leadership roles for people with lived experience of mental health issues, and caring, families and kinship groups in mental health and social services. Adopt shared evaluation systems and commit to continual improvement across the mental health and social services system. <p>Capacity building</p> <ul style="list-style-type: none"> Develop peer-to-peer networks across the mental health and social services system for those leading change. 	<p>Policy and organisational change</p> <ul style="list-style-type: none"> Develop new structures that favour collaboration, inclusion and active citizenship over competition and unbalanced power. Foster new mentoring and development pathways and career progression for people with lived experience of mental health issues and caring, families and kinship groups. Ensure zero tolerance of stigma and discrimination and adopt recovery-based practice in all system wide policies. Design workplaces that are flexible and provide support to all. Increase current and open new services that are led by people with lived experience of mental health issues and caring, families and kinship groups. These are often called peer operated services. Build networks at all system levels that encourage positive interactions. Develop shared measurement processes for transparent monitoring and reporting of progress. <p>Education</p> <ul style="list-style-type: none"> Work with education, training and accreditation providers to incorporate lived experience of people with mental health issues and caring, families and kinship groups into their curriculum and frameworks. <p>Resources - Explore creative ways to generate income and share resources.</p> <p>Employment opportunities</p> <ul style="list-style-type: none"> Increase designated and non-designated roles for people with lived experience of mental health issues and caring, families and kinship groups and include this in service funding agreements. Ensure that people with lived experience of mental health issues and caring, families and kinship groups are involved in the design, delivery, research and evaluation of all services.
Outcomes	<ol style="list-style-type: none"> The number of full time equivalent paid positions for people with lived experience of mental health issues and caring, families and kinship groups increase in each mental health and social service annually to optimal levels. Designated roles of people with lived experience of mental health issues and caring, families and kinship groups are identified across all levels in mental health and social services. Service accreditation processes demonstrate that they meet or exceed standards for lived experience participation and leadership. NSW Government reports and publicly releases data to demonstrate increases in and impacts of projects co-designed with people with lived experience of mental health issues and caring, families and kinship groups. Paid participation policies have been developed and implemented in all mental health and social services. Lived experience participation is formalised in policy of all government and non-government mental health and social services. All public mental health services meet <i>National Safety and Quality Health Service Standard 2: Partnering with Consumers</i>. All mental health programs and services demonstrate they are implementing <i>A National Framework for Recovery Oriented Mental Health Services</i>. Non-government organisations adopt suitable recovery-oriented tools to reflect the recovery-focus of their service. 		