



Engaging with Lived Experience

A strategic framework for guiding our work impacting mental health
State Insurance Regulatory Authority

FOREWORD



MESSAGE FROM CARMEL DONNELLY, CHIEF EXECUTIVE, STATE INSURANCE REGULATORY AUTHORITY

At SIRA we work with many individuals, community groups and businesses to support people to recover from injury and illness and to participate in work and community. Inclusion and participation are key to recovery and holistic well-being for those who have acquired disability, including invisible disability like mental health issues.

We now know that we all have mental health, and that from time to time, due to life events, or other factors, any one of us could experience mental health challenges that mean we need to adjust parts of our life while we recover. This strategic framework provides an opportunity to support more collaborative and rigorous ways to engage with people who have had a real-life experience (often referred to as people with lived experience) relevant to the policy, program, or resource under development.

Work on this framework began in September 2019, with the aim of supporting and improving the State Insurance Regulatory Authority's (SIRA) work on mental health, by setting out a blueprint for how to leverage the voice of lived experience. This framework will enable more customer-centric design and delivery of services.

The framework was developed in consultation with SIRA's recovery @ work reference group, which includes people with a range of experiences, with 50% of the group identifying as having a lived experience of mental health recovery in the workplace. The reference group members added their wisdom and experiences to strengthen the language and content of the framework. I would like to express my deep gratitude to the reference group members for the energy, openness, trust, time and dedication they brought to this initiative.

SIRA implements this strategic framework with a commitment to continue building genuine and innovative engagement with customers, leading to more inclusive and cost-effective services and better health and wellbeing outcomes for NSW citizens.

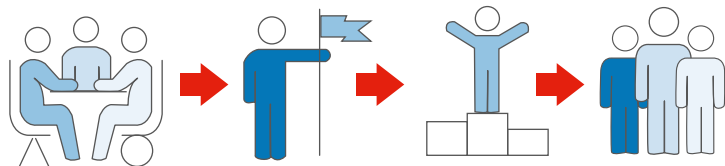
ENGAGING WITH LIVED EXPERIENCE

A strategic framework for guiding our work impacting mental health

WHAT IS ENGAGING WITH LIVED EXPERIENCE?

Listening to, involving and partnering

with people with lived experience of mental health recovery is critical to creating person-centred initiatives.



Participation & engagement

Person-centred initiatives

Better outcomes

Greater impact

It is the most effective way for us to understand how to best meet people's needs, and to deliver policies and programs that do this.

HOW DO WE DO IT BEST?

Partnership

Respect

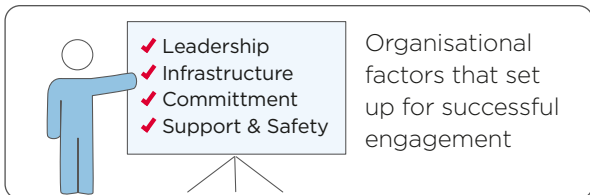
Inclusion

Guiding principles to ensure engagement is meaningful

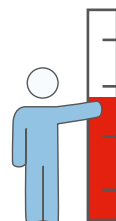
Authenticity

Transparency

Improvement



FIT-FOR-PURPOSE ENGAGEMENT METHODS



Measuring success

- a variety of people are involved
- more people are involved
- we put our principles into practice
- people understand the purpose
- there is a clear feedback loop



Guidance & Resources

NSW Lived Experience Framework
Guidelines & Toolkits

CONTENTS

A strategic framework for guiding our work impacting mental health	3
SECTION 1: RATIONALE	5
1.1 The strategic imperative	5
1.2 Why does engaging lived experience matter for our work?.....	6
1.3 Who will we engage with?.....	7
1.4 Why does language matter?.....	8
SECTION 2: PURPOSE	9
2.1 How does this Framework help improve our work?.....	9
2.2 Who needs to use this Framework?.....	9
2.3 What are the guiding principles for engaging lived experience?.....	10
SECTION 3: PRACTICE	11
3.1 How do we set up for success?.....	11
3.2 What does good practice in engaging the voice of lived experience look like? What is not?.....	12
3.3 What methods are fit for purpose?.....	14
3.4 How will we know engagement is succeeding	15
3.5 Further guidance and resources	15
3.6 Document Approval	16
3.7 Document Version Control	16
3.8 Review Date	16

SECTION 1: RATIONALE

THIS IS MUCH MORE THAN A PLEASANT, INCLUSIVE IDEA. A SUBSTANTIAL AND GROWING BODY OF EVIDENCE SHOWS THAT SERVICES DESIGNED IN COLLABORATION WITH THOSE WHO USE THEM ARE MORE EFFICIENT AND LESS EXPENSIVE.

NSW Government's Living Well: A Strategic Plan for Mental Health in NSW 2014-2024



1.1 THE STRATEGIC IMPERATIVE

Premier's Priorities: World class public service

The NSW Premier's priorities are a commitment to making a significant difference to enhance the quality of life of the people of NSW - including putting the customer at the centre of everything we do.

NSW Government core values

Everything the NSW Government does is guided by its four core values:

INTEGRITY | TRUST | SERVICE | ACCOUNTABILITY

NSW Government strategic directions

The NSW Mentally Healthy Workplaces Strategy 2018-2022 aims to get organisations, leaders and managers to 'walk the talk' and commits to engaging a broad range of stakeholders, starting with people with lived experience of mental health recovery at work and also including at-risk workers, employers, unions, industry-specific peak bodies and other employer representatives, service providers, insurers and regulators.

The Lived Experience Framework for NSW calls on social service systems to embed the voice of lived experience in design, delivery and improvement.

1.2 WHY DOES ENGAGING LIVED EXPERIENCE MATTER FOR OUR WORK?



Better outcomes

Centring mental health programs on the people who use them leads to better outcomes for communities and for individuals. It is an essential step to breaking down stigma and discrimination. Our work directly impacts the lives of people with mental health issues, and we are well-placed to help establish best practice.



Person-centred

Listening to, involving and partnering with people with lived experience of mental health issues is critical to creating person-centred initiatives. It is the most effective way for us to understand how to best meet people's needs, and to deliver programs that do this.



Greater impact

Collaboratively developed and delivered programs are:

- more responsive and relevant to people's diverse needs
- safer
- higher quality
- more accessible
- more accountable
- more cost-effective
- achieve better mental health and wellbeing outcomes.

Sources: Fifth National Mental Health Plan, Living Well: A Strategic Plan for Mental Health in NSW 2014-2024, National Mental Health Commission's Effective Participation, OECD Health Ministerial Statement 2017

1.3 WHO WILL WE ENGAGE WITH?



MANY DIFFERENT PEOPLE ARE AFFECTED BY OUR WORK.

We listen to, involve and partner with people with lived experience of mental health issues who:

- use our services
- are impacted by our programs
- work at SIRA or provide services to SIRA
- may be struggling, coping or flourishing.

Priority groups are targeted, including:

- vulnerable people including casual employees and those in the gig economy, young and older people, people with disability or brain injury, Indigenous people and those from minority cultural groups, and people who are homeless, veterans or leaving custody
- people who care for or represent those with mental health issues, to reach those they care for - including service providers, carers and advocates.

1.4 WHY DOES LANGUAGE MATTER?

WE USE PERSON-CENTRED LANGUAGE, RATHER THAN LABELS. PEOPLE SHOULD NEVER BE REFERRED TO BY A DIAGNOSIS. WHEREVER POSSIBLE, WE ASK PEOPLE HOW THEY WOULD LIKE TO BE ADDRESSED.

Respectful language includes the terms:

mental health issues to refer to a range of conditions and experiences impacting people's mental health and wellbeing

people with lived experience to refer to 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

families and other support people to refer to carers, families, kinship groups and friends supporting people with lived experience

Language has a profound impact on people and the use of inclusive and contemporary language empowers people, minimises stigma and changes culture over time.

NSW LIVED EXPERIENCE FRAMEWORK: NSW Mental Health Commission



SECTION 2: PURPOSE

2.1 HOW DOES THIS FRAMEWORK HELP IMPROVE OUR WORK?

It **explains why** bringing the voice of lived experience into our work is important.

It **shows how** leaders, managers and teams can promote engaging the voice of lived experience in any work that impacts people with mental health issues.

It **sets out the methods** we can use to bring the voice of lived experience into our work.



2.2 WHO NEEDS TO USE THIS FRAMEWORK?

Policy and Program

WHO: Teams developing or evaluating policies, programs or funding specifically impacting people with mental health issues.

HOW: Consult with and involve people with lived experience from project initiation to deployment and evaluation, using methods including surveys, focus groups, or consumer-led research.

Regulation

WHO: Teams involved in the regulation of insurance or other industries directly impacting people with mental health issues.

HOW: Bring the voices of people with lived experience into business-critical processes using digital tools such as online surveys and interactive forums.

Developing Resources

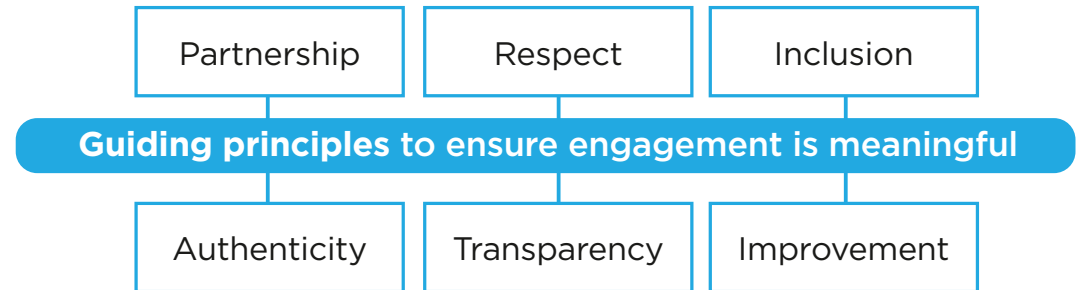
WHO: Teams developing guides, toolkits and resources aimed at assisting or supporting people with mental health issues.

HOW: Initiate collaborations such as working groups or co-design to involve people with lived experience in all aspects of resource development.

2.3 WHAT ARE THE GUIDING PRINCIPLES FOR ENGAGING LIVED EXPERIENCE?

WHAT MAKES THE ENGAGEMENT OF PEOPLE WITH LIVED EXPERIENCE OF MENTAL HEALTH ISSUES MEANINGFUL?

Fulfilling these principles ensures engagement is meaningful.



GUIDING PRINCIPLES

PARTNERSHIP

We proactively involve people with lived experience in our work. Lived experience is recognised as important and all contributions are valued.

RESPECT

Everyone recognises and respects each other's perspectives, knowledge and beliefs. Engagement methods actively support the safety and participation of people with lived experience.

INCLUSION

Engagement processes are accessible and relevant to a diverse range of people, especially those not usually heard. We provide plenty of time, resources and support. Direct participation is paid.

AUTHENTICITY

People work together in an open, honest and trustworthy way. There is no pretence and everyone is prepared to hear views they may not agree with. No one promotes unrealistic expectations.

TRANSPARENCY

The right people are in the room at the right time. Engagement starts in the early stages of decision-making. Everyone is told how their contributions were taken into account with a feedback loop.

IMPROVEMENT

Engagement is evaluated and the findings are used to improve future engagement activities. Both staff and external stakeholders are given support and training to build their participation capacity.

SECTION 3: PRACTICE

3.1 HOW DO WE SET UP FOR SUCCESS?

CREATING AN ENVIRONMENT THAT FOSTERS MEANINGFUL ENGAGEMENT OF LIVED EXPERIENCE INVOLVES PEOPLE THROUGHOUT OUR ORGANISATION.

Making engagement of lived experience a fundamental part of the way we do business depends on these four organisational factors:



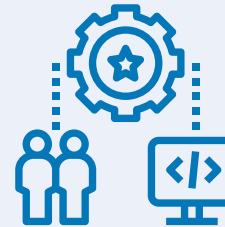
LEADERSHIP

Executives, steering committees and project leaders champion engagement and ensure it is done well and shapes programs.



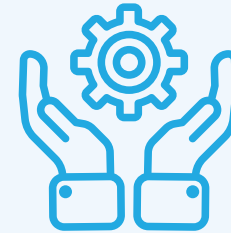
COMMITMENT

Everyone involved is genuinely guided by the principles of meaningful engagement in this framework, and ensures they are front of mind for everyone throughout engagement activities.



INFRASTRUCTURE

There are clear processes and procedures for recruiting people to and running engagement activities, and feeding the results into program design and development.



SUPPORT & SAFETY

Staff and external stakeholders receive training to build their capacity to engage. People with lived experience are supported by peer networks. Clear processes are in place for responding to discomfort and distress.

3.2 GOOD PRACTICE IN ENGAGING THE VOICE OF LIVED EXPERIENCE

WHAT DOES GOOD PRACTICE IN ENGAGING THE VOICE OF LIVED EXPERIENCE LOOK LIKE?



LEADERS CREATING CULTURE ENSURE:

- various experience is recognised and all contributions are valued
- people work together respectfully
- engagement is an important part of routine practice
- the status quo is open to constructive challenge
- people do what they say they will, or explain why not
- engagement is evaluated and improved.



MANAGERS ALLOCATING RESOURCES ENSURE:

- sufficient resources are dedicated to address barriers to participation and so that new and diverse voices are heard
- independent facilitators are used in sensitive contexts
- people with lived experience have easy access to the support they need to make participation safe and meaningful, in particular networks of peers and paid participation.



PROJECT TEAMS ENSURE:

- engagement is trauma-informed
- engagement includes a clear explanation of the issue and its broader social or regulatory context
- research and background knowledge is shared
- plain English, open-ended questions and methods suited to people's needs
- information is openly shared, feedback is given and decision-making is transparent.

3.2 NOT GOOD PRACTICE IN ENGAGING THE VOICE OF LIVED EXPERIENCE

WHAT IS NOT GOOD PRACTICE?



A CULTURE WHERE:

- engagement is tokenistic or seen to be an added requirement, rather than business-critical
- assumptions aren't open to question
- grey areas and gaps are not acknowledged
- people make commitments they can't fulfill
- there is no feedback loop.



PROCESSES ALLOW:

- people to be engaged too late to create change
- insufficient differentiation between groups such as consumers and carers
- group discussions to be diverted or narrowly controlled to suit a pre-determined agenda or desired outcomes.



PEOPLE EXPERIENCE:

- their lived expertise going unrecognized
- being interrupted or cut off, or not being listened to
- the use of jargon or technical terms without explanation
- their perspectives or views being dismissed
- being treated as a diagnosis, not a person.

3.3 WHAT METHODS ARE FIT FOR PURPOSE?

We use engagement methods that:

- are suitable for our customers, staff and other stakeholders
- are dynamic and efficient
- harness digital innovations
- leverage existing knowledge and networks.



METHODS OF ENGAGEMENT

CONSULTATIONS

We leverage our relationships with organisations which gather and represent the views of people with lived experience, such as peak bodies, community groups and forums and Indigenous organisations, and we plan and run consultations in partnership with these bodies.

DIGITAL INNOVATIONS

We use social media platforms, online surveys and digital feedback tools to exchange information with stakeholders using two-way processes. When developing or improving initiatives, relevant discussion boards and interactive forums are explored.

WORKING GROUPS

We will include two or more people with lived experience, their representatives or advocates on relevant working groups designing, developing, progressing or evaluating mental health initiatives. Terms of reference and processes to ensure safety will be clear.

FOCUS GROUPS

We use focus groups to generate fresh ideas and perspectives to inform mental health initiatives. These employ creative and inclusive tactics such as brainstorming, world cafe and small group activities.

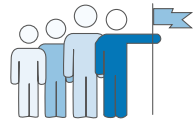
CONSUMER-LED RESEARCH

We encourage the use of consumer researchers wherever relevant. Through working with consumer researchers, we help build the capacity and reach of this sector.

CO-DESIGN

We consider and support co-design approaches to elements of our service provision for people with mental health problems. Co-design mechanisms will be established in consultation with consumer peak bodies.

3.4 HOW WILL WE KNOW ENGAGEMENT IS SUCCEEDING



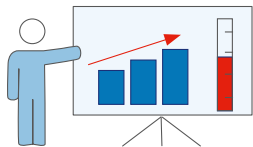
More people are involved

We track those participating in our engagement activities - both the numbers of participants and who they represent. Success includes involving more people overall, and more people from priority, vulnerable and hard-to-reach groups.



Principles in practice

We ask the people we engage if our approaches uphold the guiding principles set out in this Framework. Success means our approaches are partnerships, respectful, inclusive, authentic and transparent, and open to improvement.



Purposeful

We check that everyone involved understands how their input was taken into consideration and how it contributed to the outcome. Success includes a clear feedback loop.

3.5 FURTHER GUIDANCE AND RESOURCES

PRACTICAL GUIDELINES & RESOURCES

National Mental Health Commission's Consumer and Carer Engagement:
mentalhealthcommission.gov.au/Mental-health-Reform/Consumer-and-carer-engagement

Recovery-Oriented Language Guide: mhcc.org.au/wp-content/uploads/2019/08/Recovery-Oriented-Language-Guide_2019ed_v1_20190809-Web.pdf

LIVED EXPERIENCE FRAMEWORK

Co-designed framework for implementation by mental health and social service agencies in NSW:
nswmentalhealthcommission.com.au/resources/lived-experience-framework

CO-DESIGN GUIDELINES & TOOLKIT

WA Council of Social Service: wacoss.org.au/wp-content/uploads/2017/07/co-design-toolkit-combined-2-1.pdf

NSW Agency for Clinical Innovation: aci.health.nsw.gov.au/__data/assets/pdf_file/0013/502240/Guide-Build-Codesign-Capability.pdf

ENGAGEMENT GUIDES & TOOLS

Health Consumers Queensland: hcq.org.au

APPROVAL AND REVIEW

3.6 DOCUMENT APPROVAL

Name	Position (eg. General Manager, Deputy Secretary, Secretary)	Signature	Date (DD/MM/YYYY)

3.7 DOCUMENT VERSION CONTROL

Show examples related to your specific policy.

Version	Status	Date	Prepared By	Comments
eg. 1.0, 2.0, 3.0	eg. Draft, Final, Approved	DD/MM/YYYY	Name	eg. V1.0 approved, V2.0 revised incorporating comments from Business Units, V3.0 revised

3.8 REVIEW DATE

This policy will be reviewed in

Date (MM/YYYY)

It may be reviewed earlier in response to post-implementation feedback from Business Units.

