

The National Mental Health Commission

# Sit beside me, not above me

Supporting safe and effective engagement and  
participation of people with lived experience

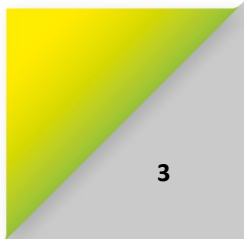


**Australian Government**  
**National Mental Health Commission**



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# Preface

The National Mental Health Commission (NMHC) is strongly committed to improving engagement and participation with people with lived experience, their families and other support people.

Engagement and participation with people with lived experience in mental health and suicide prevention that actively supports co-design, co-production, and co-delivery of systems and services leads to better health and wellbeing outcomes, aids recovery, and achieves better experiences for service users and service providers. This requires strong policy commitment to partnering with people with lived experience in monitoring and reviewing system and service performance, and decision-making about what is deemed to be a desired outcome.

Further to the NMHC's 2017 Consumer and Carer Engagement and Participation Project, this report was commissioned to examine ways to support people with lived experience to effectively and safely participate with services, organisations and systems. In 2018, we worked with David Butt & Associates to consult with key leaders to understand how to support people with lived experience to fulfil appointed or assigned roles, regardless of whether they are a CEO, a peer worker, a committee member or a board member.

This report describes essential ingredients and considerations for effective and safe engagement and participation, and demonstrates positive changes. But it also confirms that more still needs to be done. It highlights that supporting better, safer and more effective engagement and participation with people with lived experience, their families and other support people requires shared or mutual development for all people engaged in mental health and suicide prevention, and not just those with lived experience.

The NMHC's forward work program focuses on strengthening partnerships with consumers, carers, families and support people, as well as service providers, peak bodies, primary health networks and governments, to enhance opportunities for genuine and meaningful engagement and participation. Building on our previous work, we are developing a national guide to assist policy makers, service providers, professionals and people with lived experience achieve best practice in engagement and participation. We are also committed to undertaking an annual consultation with people with lived experience so we can hear and better understand their experience and impact of mental health reforms. And we are working with the Safety and Quality Partnership Standing Committee and the National Mental Health Consumer and Carer Forum to develop a consumer and carer guide that addresses how consumers and carers can participate in all aspects of what is undertaken within a mental health service so their role in ongoing safety and quality initiatives is strengthened.

***"I need someone to sit with me, not save me."***

***Jackie Crowe***

# Acknowledgements

We thank all those who shared their experiences to inform this report. This included leaders from within the system who have lived experience, and their families and other support people. It included clinical and non-clinical leaders working on service, organisation and system change that involves the engagement and participation with people with lived experience. And it included people expressing opinions on behalf of their service, organisation or system.

Our deepest thanks go to Jackie Crowe's family, Gary Jaensch and children, Zak and Cassie, who supported Jackie in her numerous roles across the mental health and suicide prevention systems. Jackie was an inaugural National Mental Health Commissioner who fiercely championed better outcomes for people with lived experience over the course of her life and was an inspirational and driving force behind the Commission's work in this space.

As a Commissioner, Jackie's impact was profound in ensuring the NMHC always took a person-centred approach – that people with lived experience, their families and other support people were at the centre of all the NMHC did. She was a fearless champion against stigma and discrimination and for the rights of the millions of people impacted by mental ill health and suicide. She was a powerful advocate for ending seclusion and restraint and wanted to see all mental health units have multidisciplinary teams with the skills to deliver a therapeutic program and environment on an extended-hours basis. She was fearless and in awe of no one. She was always willing to ask the hard questions, to push for changes that would benefit people. Jackie was always asking "Why?" or, perhaps more importantly, "Why not?" She had an exceptional capacity to combine her own lived experience as a consumer and carer, to walk with people and families affected by mental health conditions and suicide, and then to add that knowledge to her continuously growing expertise in being able to communicate and passionately advocate strategically and nationally.

Jackie always had time for everyone – and that must have been incredibly demanding because everyone wanted to talk with Jackie. She was warm and compassionate, full of ideas, and she was always willing to contribute. And she was fun – and funny. She was absolutely passionate about the value of families, their relationships and support, epitomised by her love for her own family. Jackie is sadly missed by us all. She passed away on 21 October 2017 from natural causes due to physical health complications.



***"The values of Kindness, Respect and Understanding cost so little yet have such powerful impacts that last for a very long time."***  
***Jackie Crowe blog, 10 October 2017***

## About the project

The NMHC initiated the project to provide advice on ways to support people with lived experience to safely and effectively participate in consumer and carer engagement.

The intent of the project was to identify what good practices exist and what can be improved.

The project involved reviewing current practices in policies, frameworks and practice guidelines, and face-to-face or phone interviews with 55 key stakeholders including many people with lived experience and others who operate as leaders and managers within mental health and suicide prevention services, organisations and systems. Some information was also provided by email. The NMHC and the consultant determined the stakeholders. The findings in this report come from the information, experiences, priorities and opinions expressed by these various people, reviews from current literature, and draws on the consultant's experience working in mental health and suicide prevention.

## A note on language

Words and language were identified in this project as being extremely important.

Consistent with the language of recovery, the terms 'person' and 'people', 'person in recovery', 'person with lived experience' and 'people with lived experience', 'lived expertise' and 'expert by experience/training' are used wherever possible rather than the terms 'clients', 'service users' or 'patients', which focus on deficits or relationships to services.

For similar reasons, this report uses the term 'families and other support people,' which includes family members, partners, friends or anyone whose primary relationship with the person concerned is a personal, supportive and caring one.

It is acknowledged that many people prefer the words 'consumers' and 'carers' or 'people with lived experience'. In this report, 'lived experience' refers to people who have experience of mental ill-health either as a consumer or a carer/family member/support person. Where quotes are used from people with lived experience, even though they largely are de-identified, the title they have used for themselves has been used – for example, Senior Consumer or Carer Leader.

References to 'safe' relate to everyone who works in mental health and suicide prevention – not just to those people who declare a lived experience and includes practices and environments that support the safety of all involved.

Participation is described as:

*participation by consumers and carers in formal or informal planning, delivery, implementation, and evaluation of all activities associated with mental health services (voluntary or paid), as well as in all processes which effect[sic] the lives of consumers and carers, through sharing of information, opinions, and decision making power.<sup>1</sup>*

The terms engagement and participation are used together in this report to include the methods of engagement and the practice of participation. This can occur along a continuum, through no or low engagement, tokenism and minimum consultation, representation, co-design, and to lived experience-led models. In co-design and lived experience-led models, other stakeholders are also engaged in the process, but the process, and the achievement of results, cannot proceed unless a majority led group of people with lived experience support it.

# 1. The role of lived experience

*People with lived experience, families and other support people need to be recognised as active partners with the same rights and responsibilities as people without lived experience.*

People with lived experience can and do operate at all levels of the system – individual, service, organisational or strategic systems levels. They may be advocates, advisors and supporters, and may have roles in governance, policy development, planning, service design, delivery, or monitoring and evaluation:

- for individuals (potentially themselves, a family member or friend)
- for services and programs
- within and across entire organisations (small, medium and large)
- at a strategic systems level, with potential impact on regional, state/territory or national policy, planning and implementation.

A number of people spoke of the different cultures between the mental health and suicide prevention sectors; there are areas of commonality and differences that need to be recognised and respected. Mental health focuses on functional capacity (or functional impairment) with a diagnostic basis. Suicide on the other hand may not have any obvious clinical diagnosis. It is important that boards, CEOs, managers, policy makers, and clinical leaders develop processes and approaches that support the different perspectives and cultures of people with lived experience, their families and other support people in relation to mental health and suicide prevention.

*“With mental illness, there is often a lot of anger associated with the way a person – or their family or carer – has been treated. With suicide, it tends to be more about grief and an inability to understand.”*

*Person with lived experience of suicide within the family*

Discussions about engagement and participation must include all people who are impacted, whether they are primary users of the system, or families and other support people. There is extensive recognition that everyone needs to be in this together – that a ‘them and us’ approach is not the pathway to success. Despite the overwhelming evidence of the value that people with lived experience can bring to improving the safety, quality, efficiency and effectiveness of services and systems, too often there is a lack of respect and recognition of the value of these perspectives. People with lived experience should be treated, remunerated and reimbursed appropriately and in a manner that recognises them as genuine partners with other stakeholders at the decision making table.

Lived experience is only one skill or attribute which a person may need to perform a particular role or function, and the full range of skills required will change according to the role. There is a difference between experience and expertise and it is recognised that as the roles of people with lived experience move ‘higher’ or expand in scope, so does the need for different levels of expertise. For example, a person may have skills as a peer worker engaged in supporting individuals in their recovery journey but this in itself does not equip them to participate on national, state or territory mental health commissions, boards or broader policy advisory committees. Similarly, people working at systemic levels may not have worked on the frontline and may not necessarily have the skills to provide effective and meaningful peer support at an individual or group level. Each role has different objectives and requires a different range of skills.



## 2. Safe engagement and participation

*The system in which people live and work needs to be safe for all, regardless of whether or not people have a declared lived experience.*

Ensuring safe practices and environments is a requirement of all workplaces, all roles, and all communities – not just within mental health or suicide prevention.

Work Health and Safety practices and legislation apply to all Australian workplaces and focus on the environment a person works within, rather than on the individual person. However, when a person shows signs of psychological or physical distress, there is a requirement for leaders and organisations to focus on the supports that an individual person needs. Some stakeholders identified an increased adoption of voluntary self-care and/or wellbeing plans available to all staff, such as Flourish Australia's Personal Situation Plan,<sup>2</sup> that address individual safety.

A safe environment is subjective and can vary from individual to individual. Sharing personal stories and exposing vulnerability requires courage in oneself and trust in others. Safe engagement and participation means that people with lived experience feel comfortable being involved and speaking about their experience because the behaviours and actions of others demonstrate respect and a willingness to listen and learn. This can also be supported by training on safely sharing personal stories.

Support also needs to come from peers. A number of those consulted noted that lateral, or horizontal, violence (i.e. displaced violence or aggression directed against one's peers, often in the context of feeling powerless with authorities or systems) impacts safety and security of all involved. When this occurs, it was felt this behaviour should be identified and responded to with processes and systems that emphasise the importance of respect and kindness.

People with a lived experience may have unique needs and require specific supports but they are not necessarily the most vulnerable. Some people may have a lived experience, but may not have declared this experience and others may discover they are vulnerable when exposed to complex and emotionally challenging circumstances. For example, a person with a lived experience may have developed resilience and coping mechanisms to deal with vicarious trauma when they are exposed to it. Others who have not had that experience may find such circumstances highly traumatising.

Stakeholders support embedding safe and effective engagement and participation in mental health and suicide prevention as key requirements within the National Safety and Quality Health Service Standards and the National Standards for Mental Health Services.

## 3. Effective engagement and participation

*If people with lived experience are to engage effectively at all levels of the system, they need to be supported.*

People with lived experience engage and participate at individual, service, organisational and systems levels within mental health and suicide prevention. However, implementation of engagement and participation is not uniform and too often there is a lack of respect and recognition of the value of the perspective people with lived experience bring. It is important that discussions and arrangements about engagement and participation include all those impacted, whether they are primary users of the system, or families and other support people.

Much has been said and written about ‘enabling’ people with lived experience, their families and other support people, to engage and participate in co-design of policies, services and actions that impact on their ability to live contributing lives within thriving communities. Yet ‘enabling engagement’ is likened to doing ‘to’ people, rather than doing ‘with’ or doing ‘for’ people. Ideally, the relationship should be seen as two-way, with co-design principles helping to overcome power imbalances and to deliver activities and results that are acceptable to all.

To break down power inequities that often exist in decision making between consumers and carers and health professionals, effective engagement and participation needs to be seen through a different lens, or in fact through two lenses:

- people with lived experience, their families and other support people need to support (‘enable’) services, organisations and systems to learn and benefit from their experiences (including from using their services, organisations and systems) and their knowledge and skills
- services, organisations and systems need to engage with people with lived experience in mental health and suicide prevention in the design, production, delivery and performance monitoring of systems and services so they can learn from their experiences, improve their services, and achieve better health and wellbeing outcomes.

Very importantly, there was strong feedback that any steps taken to improve, strengthen or introduce engagement and participation should avoid creating new behavioural or risk management approaches that single out people who declare they have a lived experience. That would be discriminatory and would take the engagement and participation process backwards. Risk management should apply equally to everyone, not only those who identify as having a lived experience. Identification of the potential risks for all stakeholders involved in projects, actions and committees should be considered.

There needs to be more collaborative practice, where people with lived experience, their families and other support people work alongside clinicians, other staff, managers, CEOs, board directors, funders, researchers, and policy makers in a range of areas, including identifying problems, co-design and implementation of proposed solutions, and learning which promotes continuous improvement.

## 4. Essential ingredients for safe and effective engagement and participation

*Maximising potential for safe and effective engagement should involve reciprocal responsibilities that sit with people with lived experience, their families and other support people, services, organisations and system leaders.*

There is a range of supports and tools that should be used so all people across individual, service, organisational and systems levels can engage and participate effectively and safely. These apply to all people working within or with services, organisations and systems, as well as to people with lived experience, their families and other support people – they are all in this together. This means a powerful culture of effective and safe engagement and participation with people with lived experience, their families and other support people can be embedded as the norm for how policies, programs, services, strategies and systems are designed, delivered and experienced throughout Australia.

Safe and effective engagement and participation is enhanced by the following key ingredients:

- strong leadership
- a culture that recognises engagement and participation is everyone's responsibility
- values of kindness, respect and understanding
- freedom from stigma and discrimination
- enhanced health literacy
- continuous quality improvement
- training and skills development for all involved
- ongoing research and evaluation.

These ingredients have been identified as being not only important to safe and effective engagement, but essential in demonstrating respect and recognition of people with lived experience as equals in processes and activities. Stakeholders identified operational (e.g. secretariat support) and strategic (e.g. training and development in corporate and clinical governance) support is required to fulfil lived experience roles.

A major deterrent to safe and effective engagement and participation is the stigma and discrimination which occurs from within the health workforce. Building awareness and knowledge about the impact of stigma and discrimination in mental health and suicide prevention fosters mutual respect and understanding across the workforce and with people with lived experience, their families and other support people.

Notably, the promotion of the importance of safe and effective engagement and participation of people with lived experience should not be borne solely by peer workers or positions such as senior consumer and carer advisors, but recognised and promoted by leaders and managers. Safe and effective engagement and participation is the responsibility of everyone within the system. Responsibility for effective engagement and participation does not rest with, nor should be substituted by, the peer workforce. Boards, CEOs, managers, policy makers and clinical leaders must take responsibility for leadership in effective and safe engagement and participation with people with lived experience, their families and other support people.

***“You need to come with a positive outlook and that means you need to have processed your stuff – you can't do it once you get appointed. You need to listen and treat people with respect... As they say, you catch more flies with honey than with vinegar.”***

Senior consumer leader and advocate

People with lived experience wanting to maximise the benefits of their engagement and participation should be supported and encouraged to:

- be clear with themselves and with others as to why they want to engage, what the decision making process is and what they are aiming to achieve
- determine where they want to focus: individual engagement, advocacy and support, service and organisational change, and/or strategic systems and policy levels
- ensure they have (or develop) the skills and capacities to engage and contribute at that level (which often will extend beyond their own lived experience)
- be prepared to demonstrate those skills through formal selection, appointment and performance review processes
- practice self-care and awareness
- ensure they are linked into networks and other supports, including the ability to be informed by the experiences and knowledge of others
- treat others with respect and understanding – just as they would expect to be treated
- engage and participate in respectful, civil debate, recognising the potential different views and experiences of other people.

Services, organisations and systems leaders wanting to maximise the benefits of safe and effective engagement with people with lived experience have a duty to:

- take responsibility for initiating and leading service engagement activities
- be clear up front – with themselves and with people they engage with – as to why they are engaging, what they are aiming to achieve and what the decision making process is
- document what they are seeking and how they are going to go about it
- begin early: plan and engage people at the start of the process
- take the time to build relationships
- be transparent with individuals, and organisations representing or identifying those individuals, about what their engagement will involve in terms of skills requirements, time commitments, remuneration and expense arrangements, what supports are available (e.g. printing, travel, technical advice), and in particular about decision making processes
- be transparent about the types of issues people with lived experience are likely to confront in the role or process e.g. experiences of other people’s lived experience including potentially trauma
- communicate frequently and regularly, ‘close the loop’ and provide feedback on decisions and actions
- engage and participate with people representing diverse community groups e.g. Aboriginal and Torres Strait Islander peoples; people from Culturally and Linguistically Diverse (CALD) communities; people with intellectual and physical disabilities, people with lived experience of dual diagnosis; people who identify as Lesbian, Gay, Bisexual, Transgender, or Intersex (LGBTI); and children, adolescents and young people
- make processes and supports transparent and equitable
- ensure adequate and formal processes, matching the requirements of the task at hand, rather than informal and ad hoc (this could include documented task specifications, position descriptions, selection processes, feedback and review)
- recognise where their duty of care lies from the perspective of work health and safety policy to individuals they engage
- ensure people are treated with respect, and are not subjected to stigma and discrimination - provide people with details of complaints handling processes, and have available methods of escalating or supporting individuals where evidence emerges that this is required
- ensure cultural competence, particularly for Aboriginal and Torres Strait Islander peoples
- ensure people can access time out when they need it e.g. safe spaces, breakout rooms
- identify risks and use agreed mitigation strategies
- offer individual self-care and/or wellbeing plans for anyone who requests one
- use review processes to promote learning and opportunities for continuous improvement
- continuously build a culture which recognises the value of lived experience and actively seeks safe and effective engagement and participation with people with lived experience in all activities they undertake
- continuously build the leadership capacities of the workforce to ensure people at all levels work respectfully and effectively with each other and with external stakeholders, including people with lived experience, and that they recognise the specific value that lived experience can add

## 5. Supporting safe and effective engagement and participation

This section summarises key factors that support better, safe and more effective engagement and participation. Many of these factors are universal, applicable beyond mental health and suicide prevention. They apply to anyone wanting to engage and participate with individuals, families or communities in co-design, production, and delivery of systems and services, across a range of sectors including health, education, disability, and employment.

### Connections

*Relationships, communication, connectedness, shared experience, understanding, growth, empowerment, respect and kindness should be employed as pathways to recovery, supporting engagement and participation.*

A clear and frequent message from consultations in the development of this report was the importance of people with lived experience, their families and other support people being provided with strong support networks tailored to their individual needs and not operating in isolation.

Peer support was identified as an extremely important tool to provide this support. The principle of peer support is based on 'being there', for and with others. The purpose is to support engagement and participation through providing advice, debriefing and escalation mechanisms when necessary. Peer support can be provided formally or informally to people with lived experience, their families and other support people to be linked into networks.

Peer support can be provided in a range of ways:<sup>3</sup>

- one-on-one or in a group
- by volunteers or paid employees
- peer-led or facilitated
- in person, on the phone or via the internet
- through workshops or social activities
- in ad hoc or ongoing formats.

Communities of Practice are another mechanism that can support connections. It involves collective learning and identifying problems, co-design and implementing proposed solutions to those problems, to collectively benefit from the learnings of those processes, and to look for continuous improvement opportunities. Communities of Practice involve people with lived experience, their families and other support people, clinicians, other staff, managers, CEOs, board directors, funders, researchers, and policy makers.

*"...my peers across the world mostly just ask for one thing when it comes to how they would like to be treated in the workplace – the one thing they ask for is kindness. And I understand how they feel and why they value kindness so highly."*

Jackie Crowe

### Digital innovation

*The digital age is driving systems, services, and greater opportunities for engagement and participation which should be explored.*

New digital solutions have generated entirely new ways to engage and participate with people with lived experience. Social media provides more opportunities to link with others in peer support chat rooms or through blogs, Facebook, Snapchat, and Instagram. Views, advice and feedback on issues and improvements needed in mental health and suicide prevention can be sought 'en masse' and quickly. Real-time feedback on people's experience of service is achievable, as demonstrated in retail services and suppliers. To support safe and effective

engagement and participation, policy makers, funders and service providers need to be ready to respond to real-time feedback and manage online discussion in their respective mental health and suicide prevention space.

We live in a digital age, where people communicate and receive information online rather than face-to-face and receive, process, and generate information and data at an incredible speed. This is particularly the case for young people who are likely to have a different experience and expectations of mental health and suicide prevention services to that of their parents or grandparents. It is likely that their engagement and participation preferences may also be quite different. Services, organisations and system managers should utilise a broad range of digital strategies to enhance engagement and participation opportunities. This will involve many of the same duties as are listed on page 11. Very importantly, digital engagement and participation needs to be safe and should consider safeguards against cyber bullying, body image pressures, suicide and suicide attempts.

### **Generational differences**

*There are vast variations in people's lived experiences across generations – all of which are valid and need to be represented.*

There are vast differences in people's experiences of the system. Contributing to this is generational change, relative improvements in mental health and suicide prevention treatments and supports, increased diversity of populations, and the range of functional impairment.

Many of those who originally took up the voice of lived experience in the 1980s and 1990s lived through what could be called the 'institutionalisation era'. They may have been subjected to what now is recognised as dehumanising and highly traumatic treatment (to the individual, their families, carers and other support people), including high rates of seclusion and restraint. It has taken incredible courage, commitment and tenacity for them to be able to challenge and advocate for change – for themselves but also for those who come after them – over what for many has been a sustained (and often frustrating) period of many, many years.

The next generation experienced the 'deinstitutionalisation era', where large institutions were progressively downsized or closed, and increasingly services were mainstreamed into general hospitals or into community settings (albeit in stops and starts and with serious concern about the lack of adequate support within the community, including psychosocial supports).

Now another generation is emerging, with young people having different experiences to previous generations. Many young people would not identify themselves as a 'consumer' or user of mental health services. They live in a different era – a digital age where they do much of their transacting and receipt of knowledge online rather than face to face and they are likely to have a different experience of stigma and discrimination

These different experiences are all relevant and all matter. Current senior consultants with lived experience need to be involved in supporting succession planning for current and future consumer and carer leaders. Experiences and learnings from different generations need to be understood, valued and built upon.

*"I'm a firm believer in a post-modernist view of truth – truth is relative to one's own experience so you cannot discount the views of those who have come before, of those now, and of those who are coming through. They have all had their challenges, some things are common – for example, the disrespect – and some things are different. One thing we can all see as a common platform is the need for mutual respect: Respect for the cause, for the people you share the cause with, and respect for those who work in services and systems and who are being asked to go through the change. We are all here to work together to change and make that difference. Understanding is an important means of acknowledging where they've all come from."*

Young leader with lived experience

## Skills based approach

*Lived experience is only one skill or attribute that a person may need to perform a particular role or function; the full range of skills required will change according to the role.*

Of itself, having a lived experience does not make an individual an expert in systems, strategy, governance, policy or service delivery. In the same way that training as a clinician – such as a psychiatrist, psychologist or mental health nurse – does not of itself equip a person with the expertise to sit on boards and national advisory structures.

Feedback from consultations for this project confirmed the importance of supporting people to contribute at the levels they would like to contribute, and the need to support people from diverse backgrounds so they can effectively and safely engage and participate at all levels of the system. Recognising and valuing people with lived experience as partners in health and health service provision is necessary for safe and high-quality care. This means everyone involved needs to be able to give and receive, listen and understand, and interpret and act on data, information and knowledge. It requires the use of appropriate communication methods and content so that information is understood, discussed and debated and sound decisions can be made. Training and development in health literacy is one way to support people to be involved as equals when they are engaging and participating with other experts who have health professional backgrounds.<sup>4</sup>

The development of clearly defined specifications for positions and roles where lived experience is a requirement and a skills-based approach to training and development will further support co-design and production in mental health and suicide prevention systems. Building capacity in a broad range of areas – such as leadership, clinical and corporate governance, financial management, strategy, policy development, advocacy, conflict management, co-design, co-production, monitoring and reporting – is required to fill the increasing number of roles needed for a contemporary and future-focused system. Processes of co-design, co-production and co-commissioning take time, and may require new skills. It is recognised that capability development applies to all people working in the mental health and suicide prevention sector, including people with lived experience.

There is an increasing range of organisations providing opportunities for skills development – peak bodies, mental health commissions, non-government organisations (NGOs), service providers, government agencies, and educational institutes. There are also many organisations that have set up lived experience registers and networks. Some sit within the existing mental health and suicide prevention systems but those found in other sectors like disability and employment may still be applicable and highly relevant.

### Example:

Roses in the Ocean was formed by people with lived experience of suicide and aims to build the capacity of people with lived experience to be involved in all different aspects of suicide prevention. People are trained to fulfil the skills required for various roles – on reference groups for Primary Health Networks, research and other committees, public speaking and events management – whatever it is that suits their skills set and appetite for involvement. It includes a national mentoring program, which wraps supports around them, working to gauge the impact on them as individuals and the impact on the organisations which engage them.

At present there is no systematic approach within the mental health and suicide prevention systems to create a pipeline of trained and skilled people who have lived experience and want to contribute. Participants suggested a systematic approach was needed and considered that this function could be led by a newly developed peak organisation, or facilitated through an existing organisation such as the National Mental Health Consumers and Carers Forum if resourced appropriately, or the NMHC. It was considered NMHC could achieve this by partnerships with the State Commissions, peak bodies such as Mental Health Australia and Suicide Prevention Australia, and other peak bodies for people with lived experience, their families and other support people.



Another suggestion was to engage senior people with lived experience operating at senior levels within society – in health, business, executive and other leadership roles, who for various reasons have not declared their lived experience – to contribute to governance and other roles in mental health and suicide prevention. This requires an ongoing focus on reducing stigma and discrimination in the workplace and broader community so that they are willing to declare their lived experience and become engaged and involved in reform. Training and support for these people also is needed to build capacity to share their lived experience and apply it in a meaningful and purposeful way.

It was suggested a National Framework on Skills and Competencies could be developed to describe the skills and requirements of safe and effective engagement and participation of people with lived experience, at different levels within the system. This may range from core competencies such as the ability of people to speak about their own lived experience to higher level skills required for good corporate and clinical governance.

## Workforce Culture

*There is a well-known saying “culture beats strategy”, so it is essential to build and maintain a culture that supports engagement and participation.*

Safe and effective engagement and participation needs to be supported by strong community and workplace culture underpinned by shared values. There also needs to be a willingness to engage and connect in a meaningful way with people with lived experience, their families and other support people. There was agreement that behavioural and culture change in the workforce occurs when there is understanding and recognition that mental health and suicide impacts everyone, and that safe and effective engagement and participation is relevant to all people. Embracing this increases the use of the skills and knowledge of people with lived experience. A major factor in building, measuring and demonstrating strong, high performing culture is the alignment of experience and satisfaction between staff and people, their families and other support people who use systems and services.

Workforce factors impacting safe and effective engagement and participation evident from this project include:

- workforce shortages, poor distribution and composition
- poor culture, at individual, service, organisation and systems levels
- varying degrees of recognition, commitment and action demonstrated by executives and senior management of the value of lived experience
- limited awareness of responsibilities and duty of care in engaging people with lived experience, their families and other support people
- limited capacity and capability in understanding and knowing how to effectively engage and participate at different levels of decision making
- limited collaborative leadership
- pressure to perform, often across a range of competing or even conflicting priorities, among policy makers, funders and service providers
- time and funding pressures
- stigma and discrimination which occurs from within the health workforce
- limited prioritisation or recognition of the importance of engagement and participation in service commissioning, contracting, funding and performance reporting arrangements
- limited engagement with diverse populations
- absence of compelling incentives to make effective engagement and participation a program, organisational or systems priority.

**Example:**

The challenge of engaging leadership is outlined and highlighted well in *The Review of seclusion, restraint and observation of consumers with a mental illness in NSW Health facilities*,<sup>i</sup> chaired by NSW Chief Psychiatrist Dr Murray Wright and with Jackie Crowe as a review team member.

Recommendation 1 of that Review reads:

“There is clear international evidence that high-performing health services require clinical and collaborative leadership and a patient safety culture. Collaborative leadership was not evident to the review team. NSW Health must establish and adopt an integrated leadership development framework applicable to all staff at all stages of their career.”

All recommendations of the Review have now been accepted by the NSW Government.

<sup>i</sup> NSW Ministry of Health. Review of seclusion, restraint and observation of consumers with a mental illness in NSW Health facilities. Sydney: NSW Ministry of Health; 2017. Available from:

<http://www.health.nsw.gov.au/patients/mentalhealth/Documents/report-seclusion-restraint-observation.pdf>

There is a need for training and continuous development for those who engage with people with lived experience, their families and other support people both in the mental health sector and in other areas such as education, disability, employment, police and justice. This is not easy: processes of co-design, co-production and co-commissioning take time, and often new skills. Investment in integrated leadership development applicable to all staff at all stages of their career is important. It was felt the mechanisms, structures and strategies needed to implement safe and effective engagement and participation need to be complemented by comprehensive, sustainable and widespread cultural change.

What gets measured, gets done. People working in services, organisations and systems tend to do what they are rewarded for, and what their performance is assessed against – particularly where there is benchmarking and public reporting. The incentive to ensure effective and safe engagement and participation with people with lived experience would be significantly strengthened if commissioning and funding of services and organisations included performance reporting requirements and evidence of that engagement in co-design, monitoring and service improvement.

There also is support for the implementation of mechanisms which can assess and demonstrate safe and effective engagement and participation; for example, as key requirements within the National Safety and Quality Health Service Standards and the National Standards for Mental Health Services.

***“Accreditation could be strengthened to require organisations to demonstrate they are engaging effectively in co-design with people with lived experience – if organisations want to operate in this space there are certain expectations or requirements they have to meet.”***

Mental health service CEO

## Research

*Lived experience-led research in areas identified as important by those with lived experience, their families and other support people is fundamental to future change and better outcomes.*

For safe and effective engagement and participation in research, monitoring and evaluation, people need to know and experience that their views are listened to and respected, and that a focus on the users of services will be at the centre of the approach. Fundamental to this is the development and application of research into practice. Research and evaluation should demonstrate a strong focus on lived experience including:

- co-design of research proposals
- measures of person and family experience of service
- lived experience self-rated measures
- measures of staff attitudes, beliefs, behaviours, and overall wellbeing

The need for a more strategic approach is confirmed in the Fifth Plan:

*A strategic approach to research is necessary to ensure better treatment options are available in the future and the best outcomes are achieved from care. Involving consumers and carers in the prioritisation of research objectives, targeting research funding to high priority areas and improving data collection tools are potential improvements that could translate to better services.<sup>5</sup>*

## Self-determination

*It is an individual's choice – their right to determine – what roles and responsibilities they wish to take on and to put themselves forward to participate and engage.*

A fundamental right of all Australian people – regardless of whether or not they have a lived experience – is the right to self-determination – in line with Australia's obligations contained in:

- International Covenant on Civil and Political Rights
- International Covenant on Economic, Social and Cultural Rights
- Convention on the Rights of Persons with Disabilities
- Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
- Convention on the Rights of the Child
- Convention on the Elimination of All Forms of Discrimination Against Women
- International Convention on the Elimination of All Forms of Racial Discrimination
- United Nations Declaration on the Rights of Indigenous Peoples

There is support for rigorous and transparent screening and selection processes for lived experience roles, supported by clear information on capabilities and commitments. These are normal processes for job positions, boards, councils and advisory committees and means people with lived experience are not treated differently from those who do not have a lived experience. Organisations need to be very clear upfront about the role or roles they are seeking to fill, their expectations of the work and workload involved, levels of reward or remuneration, and what supports will be provided to individuals. This assists people with lived experience to choose which roles or responsibilities they wish to pursue. Consultations to develop this report confirmed that some organisations already do this well.

**Example:**

The headspace Youth National Reference Group (hY NRG) is made up of a diverse group of young people of varying ages, genders and cultural backgrounds. People on hY NRG represent each state and territory and work with headspace to ensure young people's voices and opinions remain front and centre. They have support networks through their local headspace, each of which has a Youth Reference Group.

In 2017, 150 young people from these local networks applied for membership of hY NRG. After a rigorous shortlisting process, 50 of them were interviewed and 20 of them were selected (including four Indigenous young people). They then underwent an induction process as well as developing their own Wellbeing Plans where they advised of anything they currently were dealing with that they wanted headspace National (hN) to know about. They also rated how difficult they were finding life at the moment, nominated someone as a support person and advised how they would like to be supported if they experienced difficulties. Before each meeting, they filled in a new Wellbeing Plan.

hY NRG participants are not required to appear in the media but where that is requested and they choose to do so hN takes them through media readiness training, including a Media Plan and a Media Readiness Checklist.

Where there are requests for representation from young people, these requests come through hN and they must be documented so there is clarity about what is required. These opportunities are shared around the group and the intent is to always have two people in attendance, never just one – they work as a team. This is so that young people are able to support each other, share the workload, and ensure that a diversity of voices and experiences are included in each project. They consult on a variety of hN programs and initiatives, have the opportunity to design and lead their own projects, sit on interview panels for staff, and hN works with them to identify skills and experiences from their time on hY NRG which can add value to their CVs – for example, as public speakers, conference organisers, project managers and media representation.

***“It’s not easy to be a leader in this space. There’s a lot of aloneness no matter how many people are around you. You’ve got everyone’s hopes hanging on your back and your own crap to deal with at the same time. No-one external to you can help you manage that if you can’t manage yourself. You have to find your own philosophy. It’s how much of your own life you can keep stable while you maintain the message. If your key role is clear then it’s easier to manage. We’ve chosen this role. We all could have done different roles but we didn’t and we therefore have an obligation to people to do this well.”***

Senior consumer leader and advocate

## Supporting diversity

*Support needs to be provided so that people from diverse backgrounds can effectively and safely engage and participate at all levels of the system.*

Services, organisations and systems need to recognise and support the particular requirements to ensure people from diverse backgrounds are able to effectively engage and participate at all levels.

This includes:

- Aboriginal and Torres Strait Islander people
- culturally and linguistically diverse groups, as well as refugees and survivors of torture and trauma
- Lesbian, Gay, Bi-sexual, Transgender, Intersex, Queer people
- people experiencing economic disadvantage
- people in rural and remote communities
- socially isolated people
- older people
- people in justice and forensic systems
- people with disability
- people who are homeless or at risk of homelessness.

At times, various governments, Commissions and NGOs have developed and implemented leadership training programs for people with lived experience that are responsive to gender, age, culture, spirituality and other diversity. These programs have been delivered at no or low cost for the people involved helping to support people with lived experience regardless of income or financial position.

### Example:

An excellent place to start in identifying the approach which should be taken in engaging and participating with Aboriginal and Torres Strait Islander communities is through recognition and application of the [Gayaa Dhuwi \(Proud Spirit\) Declaration](#).

The *Gayaa Dhuwi Declaration* was developed in recognition that the mental health of Aboriginal and Torres Strait Islander peoples is significantly worse than that of other Australians across many indicators, and that in particular, suicide rates are twice as high. The National Aboriginal and Torres Strait Islander Leadership in Mental Health (NATSILMH) notes:<sup>i</sup>

*The reasons for the gap are many but include the lack of culturally competent and safe services within the mental health system, that balance clinical responses with culturally-informed responses including access to cultural healing. To rectify this, Aboriginal and Torres Strait Islander leadership is needed in those parts of the mental health system that work with Aboriginal and Torres Strait Islander populations.*

The NMHC and State Mental Health Commissions have pledged their support for the Gayaa Dhuwi (Proud Spirit) Declaration; its five elements are central to the development and implementation of actions in the Fifth National Mental Health and Suicide Prevention Plan (Fifth Plan).

<sup>i</sup> National Aboriginal and Torres Strait Islander Leadership in Mental Health. *Gayaa Dhuwi (Proud Spirit) Declaration: a companion declaration to the Wharerātā Declaration for use by Aboriginal and Torres Strait Islander peoples*. National Aboriginal and Torres Strait Islander Leadership in Mental Health; 2010. Available from: [http://natsilmh.org.au/sites/default/files/gayaa\\_dhuwi\\_declaration\\_A4.pdf](http://natsilmh.org.au/sites/default/files/gayaa_dhuwi_declaration_A4.pdf).

## 6. Conclusion

The engagement and participation of people with lived experience in mental health and suicide prevention has achieved much over the years and continues to bring about positive change. People are working together with good intent; they want to develop policies and plan and provide services that result in better health and wellbeing outcomes. There are supports, frameworks and tools for people to safely and effectively engage and participate so that people with lived experience sit at the table as equals. These range from operational to high level strategic support and include environmental factors. But more is needed. A paradigm shift is required to align a whole new set of beliefs, behaviours, systems, and data.

Supporting safe and effective engagement and participation requires shared or mutual development between all people engaged in mental health and suicide prevention, and not just those with lived experience. Responsibility sits with people with lived experience, their families and other support people, as well as with leaders, service providers, organisations and systems which engage with people.

Based on the views, experiences and evidence collected for this project, the NMHC considers the following actions particularly relevant to drive cultural change and achieve safer and more effective engagement and participation:

1. Develop a National Framework on Skills and Competencies to support people with lived experience to operate at different levels within the mental health and suicide prevention systems - this may range from core competencies such as the ability of people to speak about their own lived experience (or desire to contribute to mental health and suicide prevention) to higher level skills required for good corporate and clinical governance
2. Establish agreed objective and comparable performance reporting requirements and indicators for services and organisations on safe and effective engagement and participation
3. Further investigate whether the lived experience workforce supply will meet increasing requirements across different levels in the system for people with lived experience to engage and participate
4. Include safe and effective engagement and participation in mental health and suicide prevention as key requirements within the National Safety and Quality Health Service Standards and the National Standards for Mental Health Services
5. Increase awareness of and access to evidence-based education, training and development to support and develop skills required for lived experience roles to operate at different levels of the mental health and suicide prevention systems – these programs could be in areas such as health literacy, leadership, clinical and corporate governance, financial management, strategy, policy development, advocacy, conflict management, co-design, co-production, monitoring and reporting
6. Promote and develop the capabilities, principles and practices of recovery-oriented practice for providers, practitioners, managers and support staff and others working in mental health and suicide prevention who work with people with lived experience, their families and other support people.

Many elements of these actions will be supported by work the NMHC is currently undertaking. For example, under the Fifth National Mental Health and Suicide Prevention Plan, the NMHC has been tasked with the development of a guide for consumers and carers to engage in all aspects of mental health services to strengthen their role in safety and quality initiatives, as well as the development of Peer Workforce Development Guidelines. The NMHC is also supporting emerging leaders both within and outside the mental health sector through its Australian Mental Health Leaders Fellowship. The NMHC will also seek to progress the above actions through other processes, such as the Workforce Development Program to be developed under the Fifth Plan, and through engagement with

other agencies, such as the Australian Commission on Safety and Quality in Health Care and jurisdictional mental health commissions.

This project, together with other work where the NMHC examined policies and frameworks for consumer and carer engagement and participation, demonstrates there are countless policies, procedures, strategies, plans, reports, standards and indeed laws about what needs to and should happen. There are excellent examples of good practice. Things have improved and continue to improve. But like many issues in mental health and suicide prevention, systems are patchy, siloed, highly dependent on individual endeavour and commitment, and lack uniform application. Work must continue to support better, more safe and effective engagement and participation with people with lived experience, their families and other support people. The NMHC will continue to promote safe and effective consumer and carer engagement and participation as it has done since its establishment, as a focus area and an important and ongoing part of the NMHC's core business.

## References

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