

10th Annual

SERVICE USERS ACADEMIA SYMPOSIUM

20TH - 21ST NOV 2025
VIRTUAL, HOSTED BY AUT

CO-HOSTS



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SUAS 2025 HOSTS

The Faculty of Health and Environmental Science is the largest educator of health professionals in Aotearoa, New Zealand.

The Faculty has been involved in SUAS since its inception and its present involvement is centred around the Faculty's Advisory Group on Lived Experience of Mental Health and Addictions, which was established in 2018. This Advisory Group consists of lived experience experts external to the Faculty working with allies working as academics within the Faculty. The aim of the group is to assist the Faculty to create a vision of having lived experience expertise involvement in teaching, research and within the dynamic culture of the Faculty. It has also been instrumental in developing a bespoke academic pathway in the Faculty for those with lived experience.

ORGANISING COMMITTEE

The organising committee are members of Auckland University of Technology's (AUT) Lived Experience Advisory Group which consists of lived experience leaders and academics alongside their ally counterparts.

It is our honour and privilege to be hosting this year's Symposium and we are looking forward to spending time with like-minded individuals.

We have several goals for this year's symposium:



Goal # 1

SUAS 2025 attendees have a memorable experience where they feel cared for, valued and can contribute to meaningful discussions and learn from others



Goal # 2

Transforming SUAS as a space that empowers, uplifts and elevates the indigenous lived experience voice in academia and research.



Goal # 3

Looking back to look ahead - reflecting on where we have been and planning for the future of SUAS

SERVICE USERS ACADEMIA SYMPOSIUM 2025

20th – 21st Nov 2025 | Virtual Online

Reflect. Share. Build on our learnings

Auckland University of Technology (AUT) is proud to present the Service Users Academia Symposium 2025, a transformative two-day event bringing together the Peer, Lived Experience workforce, alongside Peer, Lived Experience academics, researchers and our partners, supporters and allies across Aotearoa New Zealand, Australia and Europe.

Location: Virtual Online

Dates: November 20-21, 2025

Times - All times mentioned in this programme are NZDT (UTC +13)

Day 1: 9.30am - 4.30pm

Day 2: 9.30am - 4:00pm

What to Expect:

- Inspiring keynote speakers
- 3 concurrent streams of content
- Showcase of innovate projects
- Access to self-care and wellness content
- Opportunity to connect with like - minded people via our chat function
- Access to the Resource Library which includes past presentations (PowerPoint slides and references)
- Access to the EventsAir App
- Access to our exhibitors' page which includes poster presentations from other attendees, and information about key sector services and organisations
- Chances to win great prizes



Nau mai Haere mai

Welcome

Reflect. Share. Build on our learnings

'Kua tawhiti kē tō haerenga mai, kia kore e haere tonu. He nui rawa ō mahi kia kore e mahi tonu'

'We have come too far not to go further. We have done too much not to do more'.



TE WĀ TAKA – PROGRAMME

Nāu te rourou, nāku te rourou - ka ora ai te iwi

With your basket and my basket, we will sustain everyone.

Nau mai haere mai e te whānau.

The theme of the event is taken from the whakataukāki by Sir Hemi Henare

*'Kua tawhiti kē tō haerenga mai, kia kore e haere tonu. He nui rawa ō mahi kia kore e mahi tonu'
'We have come too far not to go further. We have done too much not to do more'.*

This whakataukāki speaks to perseverance, endurance, and dedication in pursuit of our goals and aspirations. It encourages us to never give up on the future we want to see. Now more than ever this whakataukāki is a reminder to us all that, no matter what, the work must go on.

These are the sub-themes we hope to explore together over the next couple of days -

Looking back and looking forward

A stocktake of where we are at and how we got there? Where we will be in 10 years' time. Mapping fault lines and building foundations for lived experience in academia, untangling knots and weaving new threads for lived experience in academia.

Lived experience expertise and research methodology and outcomes

Lived experience data sovereignty, LE research priorities, methodological considerations & approaches to LE research.

Bridging the gaps: Equity, diversity and inclusion.

What can academia offer service users today?

What does lived experience have to do with academia?

Making academia a more welcoming place for lived experience. Bringing the wisdom of lived experience into academia, Moving beyond tokenism, Tensions and alliances between academia and lived experience and the place of allyship.

RA TUATAHI - DAY ONE

09:30 AM:	WELCOME, OPENING KARAKIA (PRAYER) AND ADDRESS		
9:50 am:	Keynote Address - Mary O’Hagan Currently the Director Lived Experience at Wellways Australia, Mary has been involved in mental health for over 30 years initially as a user of mental health services – then in various advocacy, advisory, provision, entrepreneurial, funding, consultancy, board and commissioner roles – at the local, national and international levels.		
10:40 AM: MORNING TEA BREAK			
11AM: Breakout session 1			
Stream 1: Looking back and looking foward	Stream 2: Bridging the gaps: Equity, diversity and inclusion.	Stream 3: Lived experience expertise and research methodology	
Bodies of knowledge: sharing space, learning and ways of knowing for a collaborative workforce	Exploring Citizen Capital as a lever to recovering our lives	Delusions: More than fixed, false beliefs	
Georgia Collins, Tristine Tilley & Katie Owen	Lyn Mahboub, Amanda Aiyana, Trish Tran, and Julie Netto	Hamilton Kennedy	
Our Safety Together Relational and Rights base approach to navigating safety/risk	Navigating the doctoral journey: The lived experience supervisor, ally supervisor, and doctoral student in collaborative practice	Maddening post-qualitative inquiry: Our attempts at Mad cartography	
Helena Roennfeldt, Katie Larsen, Deb Carlon	Julia Ryan, Sarah Gordon, Joanne E. Taylor	Aimee Sinclair & Lyn Mahboub	
12:00 PM: LUNCH			
POSTER PRESENTATIONS			
1:00 PM:	Keynote Address - Ted Johnston (Tagakala and Taepithiggi) Teddy is a proud Queer, Neurodivergent and First Nations Person. Teddy has lost many loved ones to suicide, including his brother, and is a suicide survivor himself. He brings the heart of his lived experiences and expertise into his work as a senior public servant, striving to make systems kinder and more just for marginalised communities.		

1:50 PM : Breakout session 2

Stream 1: Looking back and looking forward	Stream 2: Bridging the gaps: Equity, diversity and inclusion.	Stream 3: Lived experience expertise and research methodology
<i>Results of a Co-design Workshop: Young People Living with Psychosis</i>	<i>The role of trauma-informed lawyering in protecting community legal service clients' human rights: Preliminary enquiries</i>	<i>Are we Experiencing a Clinical Ceiling? Barriers to Lived Experience led Approaches in the Mental Health Sector</i>
El Amanni, A; Jenkins, M; Chinn, V	Puneet Sansanwal	Katie Larsen, Helena Roennfeldt, Ellie Hodges, Louise Byrne, Deb Carlon
<i>RESPECT through My Advance Preference Statements (MAPS)</i>	<i>Carer, Griever, Leader: Making Academia a Place Where Complex Lives Can Belong</i>	<i>Moving beyond Co-design: Community Lived Experience Led Coding, Interpretation and Analysis.</i>
Sarah Gordon, Katey Thom & Rachel Tester	Michael Elwan	Megan Elizabeth

2:50 PM: AFTERNOON TEA

3:15 PM : Breakout session 3

Stream 1: Looking back and looking forward	Stream 2: Bridging the gaps: Equity, diversity and inclusion.	Stream 3: Lived experience expertise and research methodology
<i>Mapping the Global Mad Movement: Lived Experience Leadership, Epistemic Justice, and the Future of Mental Health Advocacy.</i>	<i>Lived experience in higher education teaching: insights from guest editing a journal special issue</i>	<i>Expanded I poems': a participatory data analysis and co-inquiry process of Northumbria university's 'Public involvement and coproduction in research' programme led by people with lived experience of mental distress.</i>
Matthew Jackman	Dr Snita Ahir-Knight and Dr Hazel Godfrey	Dr Jacqui Lovell, Natasha Downs, Katie Romney, Fiona Cammack
<i>Questioning the role of peer supporters</i>	<i>Wairua Pūruatanga: the role of Indigenous wisdom in shaping contemporary healthcare practice</i>	<i>Abolition Perspectives in Mental Health: A service user research project</i>
Dr Karen Machin	Huia Monro	Nina Joffee-Kohn & Cath Roper

4:15 PM : Day 1 Closing Remarks and Karakia

RA TUARUA - DAY TWO

09:30 AM:	Opening Karakia (prayer) and Welcome to Day 2		
9:40 AM:	Keynote Address - Egan Bidois (<i>Ngāti Ranginui, Ngāīterangi, Te Arawa</i>) Egan brings a wealth of knowledge to this space having worked in the mental health sector for over 25 years. He was the first Director, Lived Experience at Te Aka Whaiora, Māori Health Authority - the first role of its kind. Egan is an internationally published author and a highly regarded mental health trainer, advisor, and advocate.		
10:30 AM: MORNING TEA BREAK			
10:50 AM: Panel discussion - Service Users in Academia ‘Being at university. Inspiring hope for our whanau who are currently studying and experiencing distress. Supporting our allies to understand what sorts of things they can do to support students..			
11:20 AM: Breakout session 4			
Stream 1: Looking back and looking foward	Stream 2: Bridging the gaps: Equity, diversity and inclusion.	Stream 3: Lived experience expertise and research methodology	
<i>A thriving peer workforce for the future: getting the structures and supports right for sustainable workforce expansion and impact</i>	<i>Building Belonging: A Neurodivergent-Led Model for Inclusion in Academic Spaces</i>	<i>Co design Co Production and Co Creation – Moving into Third Space Thinking from a Māori First Nations Perspective</i>	
Emily Castagnini, Tessa Zirnsak	Jess Goodman	Jason Haitana	
<i>Death in Digital Spaces: Suicide Prevention for the Modern Age</i>	<i>From outsider to insider? Moving towards epistemic justice for peer supporters within Aotearoa’s mental health system</i>	<i>Using diverse lived experience to sense make with people through crisis</i>	
Anna Ashton	Alexander Walker	Cassi Strauss, Jesse Shears, Emiko Artemis	
12:20 PM: LUNCH			
POSTER PRESENTATIONS			

1:20 PM: Breakout session 5

Stream 1: Looking back and looking forward	Stream 2: Bridging the gaps: Equity, diversity and inclusion.	Stream 3: Lived experience expertise and research methodology
<i>Reflections on a developmental evaluation adventure in a peer service</i>	<i>Dismantling and reframing the constructs of trauma and trauma informed care through autoethnography focused on harmful power</i>	<i>Epistemological anarchism as theory and method in lived experience research</i>
Laura Ashton & Magdel Hammond, Elizabeth Tingle	Jaqu Ball	Terri Warner
<i>Establishing a Lived Experience Research Group and community of practice to support capacity building and activity in lived experience research</i>	<i>Madness Hospitality and Belonging</i>	<i>"I'm afraid I'm nothing without my degree": Barriers to peer-clinician knowledge-sharing in an integrated mental health and AOD service</i>
Tula Brannelly & Gina Giordani	Jason Kumar	James A. Coutinho, Caitlin Jablonka, Priscilla Ennals

2:20 PM: AFTERNOON TEA

2:45 PM: Breakout session 6

Stream 1: Looking back and looking forward	Stream 2: Bridging the gaps: Equity, diversity and inclusion.	Stream 3: Lived experience expertise and research methodology
<i>Climbing Arnstein's Ladder of Citizen Participation in the design, delivery and evaluation of mental health curricula</i>	<i>Spinning plates on the edge of a volcano: Respecting rights, will and preferences for tāngata whaiora in an unstable health system</i>	<i>Exponential Growth of "Patient Involvement": Much Ado and Not Doing Much</i>
A/Prof. Paul Badcock, Dr. Chrissie Hughes, Hannah Blackwell, Amelia Asciutto	Johnnie Potiki	Brett Scholz

3:15 PM:

Panel discussion - Reflections on Symposium Themes

3:45 PM:

Closing remarks, karakia, awards

END OF SERVICE USERS ACADEMIA SYMPOSIUM 2025

KEY NOTE SPEAKERS



MARY O'HAGAN

Currently the Director Lived Experience at Wellways Australia, Mary has been involved in mental health issues for over 30 years.

Mary helped to initiate the 'mad' movement in New Zealand in the late 1980s and was the founding chairperson of the first worldwide network by and for people with mental distress in the early 1990s (World Network of Users and Survivors of Psychiatry).

She is a pioneer in the peer workforce and creator of a social enterprise, PeerZone, that develops resources and supports for people with mental distress and the people who support them.

Mary has written an award-winning memoir called 'Madness Made Me'. In 2015 she was made a Member of the New Zealand Order of Merit for services to mental health.



TEDDY JOHNSTON

Teddy is a proud Tagakala and Taepithiggi person—a Queer, Neurodivergent and First Nations person from the Gulf of Carpentaria, Far North Queensland. Teddy has lost many loved ones to suicide, including his brother, and is a suicide survivor himself. He brings the heart of his lived experiences and expertise into his work as a senior public servant, striving to make systems kinder and more just for marginalised communities. His career spans social policy, criminal justice, mental health, and Indigenous Affairs.

As a keen touch footballer, representing Victoria, ACT, and Southwest NSW at the National Touch Championships, Teddy believes in being authentic and unapologetic about queerness and blakness, no matter the setting.

Teddy is passionate about coaching and mentorship - particularly First Nations public servants - anything he can do to empower others.



EGAN BIDOIS (Ngāti Ranginui, Ngāiterangi, Te Arawa)

Egan brings a wealth of knowledge to this space having worked in the mental health sector for over 25 years. He has worked as a support worker, community team coordinator, policy advisor, service manager, as well as sitting upon numerous boards and advisory groups both nationally and internationally. He was the first Indigenous Lived Experience Director at Te Aka Whaiora, Māori Health Authority - the first role of its kind.

Egan is an internationally published author and a highly regarded mental health trainer, advisor, and advocate. He is deeply passionate about whai ora focused care, recovery for tāngata whaiora Māori and enhancing all people's journeys towards wellbeing.

Egan has presented at national and international conferences, speaking on various lived experience issues with a particular focus on tāngata whaiora Māori and schizophrenia/psychosis from a Te Ao Māori perspective.

POSTER PRESENTATIONS

Poster presentations will be available for symposium attendees to watch during lunch breaks and after the symposium. These will be in the format of pre-recorded videos between 5-10 minutes long where presenters will talk about their research, project or ideas.

There won't be scheduled time for viewers to discuss the poster presentation with presenters, however some presenters may choose to leave their contact details for viewers to connect with them.

Note: Further information about where to view the poster presentations will be in the final programme as we are still building out the virtual platform.

See next page for the list of poster presentations



Presentation title	Presenter/s
What value does “lived experience” have? A contemporary view	Hamilton Kennedy
Te Reo Orooro – Growing and Understanding Psychosis from a Lived Experienced Māori First Nations Perspective	Jason Haitana
Peer workers as icing on the cake or re-defining the recipe? Outcomes from exploring peer work with social work students	Aimee Sinclair, Julie Netto
The value of Lived Experience partnerships in research on complex social issues	Megan Bell, Kirsten Sykes, Trish Tran, Yosef Sokol
Reframing work – how supporting people with lived experience into self-employment can become an integral, fulfilling, and purposeful part of their recovery and sustained wellbeing.	Katie Rickson
From Tokenism to Transformation: How Allyship and Cultural Safety Helped Me Thrive in Academia	Michael Elwan
A Powerful Platform for Change: Minds Lived Experience Governance Framework	Ellie Hodges, Katie Larsen, Deb Carlon, Helena Roennfeldt
Connection and Community Transformative Lived Expertise-Led Approached	Deb Carlon, Katie Larsen, Ellie Hodges
What impact does lived experience informed education have on medical students’ understanding of addiction and recovery?	Rachel Tester
Neurodivergent tertiary students: Diverseminds@Massey working towards change and valuing lived experience	Betsy, Kat , Starzie, Candace, David, Jess, Chance, and Isobel
An innovative and evaluative method to uphold lived experience in research	Amanda Luckman
Insights & Chaos: Leading Mental Health Service-User Research	El Amanni, A; Jenkins, M; Chinn, V;
Consumer perspective contributions to freely available Safewards resources & training; a lasting impact	Dr. Bridget Hamilton and Puneet Sansanwal
Role of the lived experience workforce and consumer advocates in implementing the recommendations of Royal Commission (Victoria) in eliminating violence from mental health settings	Puneet Sansanwal
Co-creation of a support program for Lived Experience Workforce members undertaking tertiary studies: approach and methodology	Puneet Sansanwal

ABSTRACTS

DAY 1 (11 AM - 12PM)

STREAM 1: LOOKING BACK AND LOOKING FORWARD

Authors: Georgia Collins, Tristine Tilley & Katie Owen

Title: Bodies of knowledge: sharing space, learning and ways of knowing for a collaborative workforce

Affiliation: School of Health and Wellbeing, Whitireia and Weltec, Porirua, NZ

Abstract: Globally and in Aotearoa, the mental health and addiction sector is facing unprecedented workforce challenges. There is a commitment to transformation of mental health services with people with lived experience leading the way (Te Hiringa Mahara, 2019). Research demonstrates the benefits of developing the Consumer, Peer Support and Lived Experience (CPSLE) workforce, and supports the intention to diversify the Mental health and addiction workforce to include more peer workers in a mix of peer, cultural support, and clinical workforces (Government Inquiry into Mental Health and Addiction, 2019, Workforce Plan, 2024). This presentation will explore an innovative approach to developing shared understanding, interprofessional learning and collaboration in the future workforce. The aims of the approach were for undergraduate nursing ākonga (students) and ākonga working in peer support roles to have an opportunity to develop a shared understanding through a co-designed and co-delivered workshop. Specific learning outcomes included all ākonga developing a shared understanding of

- the impact of negative language, stigma, and discrimination on tangata whaiora,
- the different roles within the Consumer, Peer Support and Lived Experience workforce
- and the importance of interprofessional respect and collaboration to support the future direction of Mental health and Addiction services in Aotearoa.

The presenters will highlight the key outcomes from the workshop, some successes and challenges and conclude with suggestions for ongoing opportunities for interprofessional learning and collaboration for ākonga with the School of Health and Wellbeing.

Authors: Helena Roennfeldt, Katie Larsen, Deb Carlon, Mel Sherrin

Title: Our Safety Together Relational and Rights base approach to navigating safety/risk

Affiliation: Mind Australia

Abstract:

Explore the opportunities that evolve by holding risk relationally as we seek to support both individual and collective safety.

This presentation explores an alternative approach to navigating risk within the context of relational safety. The Our Safety Together framework outlines a relational and rights-based approach to understanding and responding to risk. It sees safety and the risk of harm in terms of the person, relationships, environment, and context rather than standardised checklists, recognising that safety is subjective and contextual and risk is fluid.

Our Safety Together disrupts the usual practice of assessing individual risk within the broader mental health sector. In doing so, it seeks to support both individual and collective safety.

This framework recognises that safety is relational and contextual, and risk is fluid. It recognises that safety is more than the risk of harm to self and others. For lived experience and peer workers, the basis of practice is relationships built on trust, mutuality, respect, and shared safety.

At their heart, the principles and practices in Our Safety Together seek to provide a lived, experience-led approach to safety and risk that are compatible with legislative requirements and operationalises the ambitions set out by human rights legislation to better uphold the human rights of people who use Mind's services and those who work in them (Katterl & Maylea, 2021).

STREAM 2: BRIDGING THE GAPS: EQUITY, DIVERSITY AND INCLUSION

Authors: Julie Netto, Lyn Mahboub, Aimee Sinclair

Title: Exploring Citizen Capital as a lever to recovering our lives

Abstract:

The Valuing Lived Experience Program (VLEP) was established in 2015 and has grown to facilitate lived experience teaching into over 17 courses in the Curtin School of Allied Health. This breadth of activity demonstrates the VLEP's capacity to impact widely and across different disciplines. The VLEP is made up of various activities that work to build the capacity of both academics, as well as Trained Lived Experience Educators (LEEs) and is grounded in national policy on consumer and family participation and involvement, working towards epistemic justice in mental health education. Citizen capital is defined as "The range of resources that everyone needs ... in their lives to enable them to live safely and well in their communities". This research evaluates the contribution of LEEs' involvement in tertiary education and how this involvement may build one's social, cultural, and economic capital, moving people from service users (possibly on disability support pensions) to LEEs, authors, and other meaningful roles. We used collaborative autoethnography, which is underpinned by principles of autoethnography, participatory research, and narrative inquiry. Writing collaboratively is a way to show difference in interpretations, even with shared experiences. Four LEEs, two LEAs, and one academic ally contributed to the research. Contribution involved engaging in collective dialogue and writing across several meetings and a workshop, guided by reflective prompts regarding citizen capital and lived experience education.

Authors: Julia Ryan, Sarah Gordon, Joanne E. Taylor, & Rachael Pond

Title: Navigating the doctoral journey: The lived experience supervisor, ally supervisor, and doctoral student in collaborative practice

Affiliation: Te Kunenga ki Purehuroa - Massey University, Te Whare Wananga o Waikato - University of Waikato

Abstract: Doctoral supervision is a complex and dynamic process that shapes the research and researcher. This presentation explores an example of the tripartite supervision approach involving a lived experience supervisor, an ally supervisor, and a doctoral student, in the context of an applied doctoral qualification in clinical psychology. The lived experience supervisor provides critical knowledge based in direct engagement with the research topic, while the ally supervisor bridges academic frameworks and expectations. The doctoral student, positioned at the intersection of these perspectives, navigates the complexities of integrating diverse epistemologies into their work, and benefits from multidimensional mentorship. We discuss the challenges and benefits of this triadic supervisory model. In our experience, the approach fosters deeper engagement with marginalised knowledge systems, enhances knowledge production, improves ethical research practices, influences reflexivity and power dynamics, and challenges dominant paradigms in academia. We highlight the value of integrating lived experience into academic research, the role of the ally supervisor and the learning required of them, and the doctoral student's evolving agency in the process. This presentation contributes to discussions on inclusive and transformative doctoral supervision.

STREAM 3: LIVED EXPERIENCE EXPERTISE AND RESEARCH METHODOLOGY

Author: Hamilton Kennedy

Title: Delusions: More than fixed, false beliefs

Affiliation: La Trobe University

Abstract: Delusions are typically regarded as fixed, false beliefs, yet for those experiencing such phenomena, they hold deep personal significance. This thesis examines the histories and origins of such beliefs, with the aim of exploring and documenting the social contexts that contribute to their formation. Through repeated interviews with 11 individuals labelled as delusional, their experiences and narratives were collected and examined as the 'truths of delusion.' Utilising Mad Studies as methodology, the research explores the systemic and broader influences on these individuals' lives, while also focusing on the personal impacts of these influences. The findings suggest that delusional experiences can be understood within three distinct categories: beliefs that could be broadly considered true by others, beliefs with significant connections to real events, and beliefs that resist simple categorisation as true or false. This thesis challenges conventional views of delusions as irrational, false, or bizarre, advocating instead for an understanding of delusions in their social context.

Authors: Aimee Sinclair & Lyn Mahboub

Title: Maddening post-qualitative inquiry: Our attempts at Mad cartography

Affiliation: Curtin University

Abstract: In this presentation we will share our attempts to do research differently, bringing together Mad theorising with post-qualitative inquiry. Both post qualitative inquiry and Mad methodologies sit on the methodological fringes, although their potential for creating new knowledges and practices are increasingly recognised. We explore the potential for bringing these two approaches together by describing and reflecting on a workshop, in which we joined together with individuals experienced with peer support work, to map affective intensities within mental health systems. Our hope is that the presentation will provoke other creative ways of thinking about, and doing research, that centre the experiences of service users/survivors, and value madness for its potential in sparking alternative practices. This presentation is based on a paper published in Qualitative Health Research: "Maddening post qualitative inquiry: An exercise in collective (Mad) theorising"

STREAM 1: LOOKING BACK AND LOOKING FORWARD

Authors: El Amanni, A; Jenkins, M; Chinn, V; Briony; Ciaran; Caroline

Title: Results of a Co-design Workshop: Young People Living with Psychosis

Affiliation: University of Otago

Abstract:

Those of us living with psychosis face poorer health outcomes and reduced life expectancy. Despite mental health services addressing our acute mental health needs, our physical, social, and cultural wellbeing is often overlooked. Co-design can benefit people with lived experience when we are treated as equal partners alongside clinicians, whānau, and researchers. Our co-design research aimed to identify meaningful activities that could support the social and cultural wellbeing of youth receiving specialist mental health care for first-episode psychosis in Wellington, Aotearoa New Zealand.

A co-facilitated co-design workshop was held with youth mental health service users. A range of creative and engaging activities were used to explore participants' preferences and draw out feedback on what types of activities they would find most useful. The ethically approved co-design methodology was grounded in the principles of an existing co-design protocol (Te Hekenga Whaiora) and principles of youth engagement development by Ara Taiohi – the peak body for youth development in Aotearoa (Mana Taiohi).

Participants preferred that the programme begin with informal, hands-on group activities that facilitate social connection with peers and offer a sense of freedom, agency, and personal choice. They expressed a desire for nature-based, food-related, and movement-focused activities, which must be realistic with the experience of living with psychosis. To complement the programme, participants valued opportunities for conversations with peers about managing diet, exercise, and medication use; expressive activities, personal storytelling, and cultural and spiritual personal reflection; and time spent in personally meaningful places as a source of comfort.

Our findings demonstrated that young people living with psychosis seem to value social connection, personal meaning, and opportunities for self-determination. They can benefit from culturally responsive activities that honour personal agency, strengthen connection to nature, and provide meaningful peer support. The co-design process generated these rich insights and empowered lived experience leadership from young people with their wellbeing.

Authors: Te Kete Rongomau project team- Sarah Gordon, Katey Thom, Rachel Tester

Title: RESPECT through My Advance Preference Statements (MAPS)

Affiliation: University of Waikato

Abstract: Stakeholders have expressed that Mental Health Advance Preference Statements (MAPS) are a useful tool that can facilitate supported decision-making – where we are supported to make decisions based on our own will and preferences. This is in contrast to substitute decision-making, often enabled through mental health legislation, where others are able to make decisions for us based on what they consider to be in our best interests. Funded by the Health Research Council, this comprehensive project involves the creation, implementation, and evaluation of MAPS in the mental health settings of Te Whatu Ora Lakes and Te Whatu Ora Waikato. We identify the research approach as a combination of being Māori-centred according to Te Ara Tika guidelines (as we have created and are conducting the project as a collective composed of Māori and non-Māori) and co-produced (as we have created and are conducting the project as a collective composed of the diverse voices of tāngata whaiora who experience mental distress alongside those who work and research mental health services). This presentation will profile the suite of resources that have been created and the initial analysis of the evaluation as to the impact they are having. This research is particularly important given that supported decision-making is the most significant feature shaping future mental health services, including the repeal and reform of the Aotearoa New Zealand mental health Act.

To understand how the Te Kete Rongomau project team envisaged and implemented equitable approaches to design and implementation of My Advanced Preference Statements (MAPS), please see the Spinning plates on the edge of a volcano presentation by the Māori implementation team.

STREAM 2: BRIDGING THE GAPS: EQUITY, DIVERSITY AND INCLUSION

Author: Puneet Sansanwal

Title: The role of trauma-informed lawyering in protecting community legal service clients' human rights: Preliminary enquiries

Affiliation: La Trobe University

Abstract: Major Community Legal Centres (CLCs) in Australia are starting to introduce 'trauma-informed' approaches to legal practice. Trauma-informed approaches include CLC lawyers and staff having greater awareness of the intersectional issues faced by their clients and thus preventing additional trauma. Trauma-informed services aim to empower clients and improve their safety, and promote trust between clients and service providers. Ideally, this approach will help deliver services that better uphold the rights of legal service clients, though there is little research on whether this is indeed the case.

This paper presents preliminary findings from PhD research examining the role of trauma-informed practices by CLCs in upholding the human rights of their clients. This research builds on previous research showing that Australian CLC clients are among the most disadvantaged populations in the country, with a very high proportion of this group have survived traumatic life experiences. The presentation will share a synthesis of literature on (including grey literature) trauma-informed services and human rights

This research forms part of an ARC funded research project titled 'Supporting Trauma-Informed Legal Services (STILS): A Stepped-Wedge Multi-Site Study' led by Professor Chris Maylea and Associate Professor Piers Gooding at La Trobe University. The project will examine the efficacy of trauma informed practices in the legal aid sector and the implications for human rights.

Author: Michael Elwan

Title: Carer, Griever, Leader: Making Academia a Place Where Complex Lives Can Belong

Affiliation: Lived Experience Solutions (LEXs)

Abstract: This presentation invites audiences to reimagine academia not as a neutral site of research, but as a space where complex lives can fully belong. My journey into academic life was shaped by profound grief, responsibility, and cultural displacement. I was a young carer to my blind father, and later supported my mother through years of mental health challenges - until she died by suicide. I carry not only these losses, but also the story of migrating to Australia and forging a path toward leadership through education, frontline service, and now, doctoral research.

Rather than seeing these experiences as barriers to academic success, I've come to understand them as the very foundation of my leadership. This session explores how lived experience - especially when shaped by grief, care, and cultural identity - can be held with dignity and purpose in academic spaces.

I introduce a framework of "grief-informed leadership" - a values-based leadership approach that centres relational ethics, emotional insight, and cultural humility. I reflect on the enabling conditions that supported me to show up not just as a student, but as a whole person: flexible structures, safety-first supervision, and mentorship that understood grief not as a liability, but a legitimate lens of knowledge.

I also name the unseen emotional labour that culturally diverse leaders carry - balancing performance with pain, and often doing the invisible work of emotional translation for institutions not built for us. These stories and insights now shape my work through Lived Experience Solutions (LEXs), where I support individuals and organisations to lead with complexity, care, and cultural depth.

This session offers a vision for belonging - not as permission granted, but as justice realised. It will resonate with leaders, educators, and allies committed to building spaces that welcome - not flatten - lived experience.

STREAM 3: LIVED EXPERIENCE EXPERTISE AND RESEARCH METHODOLOGY

Authors: Katie Larsen, Helena Roennfeldt, Ellie Hodges, Louise Byrne, Deb Carlon

Title: Are we Experiencing a Clinical Ceiling? Barriers to Lived Experience led Approaches in the Mental Health Sector

Affiliation: Mind Australia

Abstract:

This presentation considers limited opportunities for lived experience leadership and lived experience-led services revealing a 'clinical ceiling'. The clinical ceiling describes restrictions on lived experience with lived experience roles often not given authority or high-level decision-making responsibility. Under the clinical ceiling, lived experience roles are limited in how much they can influence reform as they are invalidated within the dominance of clinical practice models and medical model. Lived experience led approaches are advocated as true options for people experiencing distress. However, lived experience led approaches require courage to challenge longstanding power structures. To maximise the potential of lived experience work, we must address attitudinal and structural barriers and enable lived experience-led practices and leadership – smashing through the clinical ceiling.

Author: Megan Elizabeth

Title: Moving beyond Co-design: Community Lived Experience Led Coding, Interpretation and Analysis.

Affiliation: Changing Minds Trust

Abstract: Changing Minds are developing a Lived Experience led framework for supporting communities to be active participants in the coding and interpretation phases of qualitative analysis about them and their communities. Through this work our aim is to support the community to lead through expertise in research and insights, develop additional insights and reflection about the issues important to individuals and their whānau, and enhance data sovereignty for our community. Co-design or co-creation processes are becoming the norm within Lived Experience spaces. However, some Tāngata Mātau ā-wheako (people with Lived Experience of mental distress, addiction or substance use) still struggle to see themselves in the final research product or report. Building on our 'Positive Health System Transformation for Tāngata Mātau ā-wheako' and 'What Makes Lived Experience Engagement feel Meaningful, Valued and Respected' insights, the community has identified the translation of our voices within the analysis and interpretation phases as a key moment where our insights and expertise can be uplifted or lost. We want to hear and see our voices in work about us, and ultimately see our insights prioritised in outcomes. The development of this framework alongside our insights and engagement work programme in 2025 will also enable us to analyse how interpretations of data, codes and themes differ between community coded, Changing Minds coded, and 'third party' coded samples within a grounded theory and thematic analysis approach. We will share our findings and insights to date as part of this session and welcome discussion from the Lived Experience and academic community. When complete this framework will be a resource available to the Lived Experience community.

STREAM 1: LOOKING BACK AND LOOKING FORWARD

Author: Matthew Jackman

Title: Mapping the Global Mad Movement: Lived Experience Leadership, Epistemic Justice, and the Future of Mental Health Advocacy

Affiliation: University of Sydney

Abstract: This PhD research explores the global Mad movement through the leadership, knowledge, and resistance of Mad people, psychiatric survivors, consumers, ex-patients, and peers (c/s/x/m). Grounded in Mad studies, critical social theory, and survivor epistemologies, the study aims to understand how lived experience leaders across diverse cultural and geopolitical contexts perceive the current state and future trajectory of the international Mad movement. The research employs a qualitative design combining genealogy, textual analysis, and a global scoping review, followed by in-depth interviews with Mad movement leaders across WHO regions. It seeks to document how lived experiences, identities, and positionalities shape leadership strategies, movement priorities, and resistance to dominant biomedical and institutional paradigms. The project explores key tensions such as reform vs. abolition, co-optation vs. authenticity, and visibility vs. silencing in global mental health spaces. Through reclaiming madness as a site of knowledge, resistance, and pride, the research challenges medicalised narratives and advocates for systemic transformation rooted in justice, community, and collective care. It also interrogates epistemic injustice in mental health systems, calling for the legitimisation of Mad and survivor-led knowledge in research, policy, and service design.

Author: Dr Karen Machin

Title: Questioning the role of peer supporters

Abstract: This session presents a discussion based in my recent PhD study of peer supporters and aims to encourage reflection on their role. While entangled in debates about practicalities including whether true peer support should be paid, I became distracted by echoes of Sherry Mead's question of 'what makes peer support unique?'. Concerns in the literature about lack of clarity of their role contrast with the flexibility and person-centred adaptability required in practice. Within the literature, the metaphor of a bridge describes the liminal position between service user and service provider, with peer supporters being neither wholly one nor the other. But in the descriptions, the bridge was either the essence of the role itself, providing translation between service users and providers, or it provided the route from lived experience to becoming a provider, with the provider role being seen as most desirable. In contrast, I suggest that perhaps the unique role of peer supporters might be to curate the liminal space to offer a communitas of joy. Instead of trying to bridge the gap, peer supporters might curate a unique space of possibility thinking from which people using their service might move on. In conclusion, I question how this learning from peer support might have similarities and potential learning for lived experience researchers. Both share a concern about their position within a system. Both share a potential ambition of lived experience leadership. But whereas peer support has potential to exist in minor spaces such as user led organisations, where are the alternatives for survivor researchers?

STREAM 2: BRIDGING THE GAPS: EQUITY, DIVERSITY AND INCLUSION

Authors: Dr Snita Ahir-Knight and Dr Hazel Godfrey

Title: Lived experience in higher education teaching: insights from guest editing a journal special issue

Affiliation: World of Difference | He Ao Whakatoihara kore, University of Otago and School of Science in Society, Te Herenga Waka—Victoria University of Wellington, Aotearoa New Zealand.

Abstract: In this presentation, we will reflect on the insights gained when guest editing a special issue for the journal Higher Education Research & Development on the multifaceted role of lived experience in higher education teaching. We will focus on the interesting insights the editorial process uncovered. These insights relate to how bringing lived expertise into teaching can help achieve equity, diversity, and inclusion in academia. The broader goal of the session is to engage attendees in a discussion on how lived experience expertise can be better embedded in academic teaching practices to support diverse voices and foster inclusivity.

This abstract was written a month before the special issue submission deadline. We have already had meaningful conversations with potential authors and each other as co-guest editors that have informed this abstract.

We will present insights uncovered during the editorial journey, including:

- Lived experience in academia: A discussion on how academics not in a lived experience role were (or were not) open about sharing their lived experiences and the challenges involved.
- Context of global change: How the editorial process unfolded amidst significant global policy shifts.
- Emotional impact: Addressing the emotional impact accompanying the lived experience work as co-guest editors and authors.

The session will conclude by looking ahead to the future of integrating lived experience in higher education by building on the insights gained through this editorial journey. In the spirit of the whakataukī, the progress we have made thus far must propel us forward, inspiring continued efforts to shape a more inclusive and impactful future in higher education.

Author: Huia Monro

Title: Wairua Pūruatanga: the role of Indigenous wisdom in shaping contemporary healthcare practice

Abstract:

This presentation aims to explore the challenges of defining and integrating Wairua within the New Zealand health system without stripping this kupu of its linguistic context, and its conceptual complexity. I will introduce the Wairua Pūruatanga model as a framework for understanding Wairua through both personal and connective dimensions. I will highlight the importance of Wairua in holistic health approaches, particularly within Te Whare Tapa Whā, and examine how many modern holistic models of health mirror an indigenous understanding. Ultimately, I will advocate for the recognition and empowerment of Indigenous wisdom in shaping contemporary healthcare practices.

I will cover the following key points;

- Why we hesitate to define Wairua: Understanding the concepts of testimonial smothering and hermeneutic injustice in the case of Māori knowledge.
- Understanding Wairua within its linguistic context: The importance of creating a non-reductive definition.
- Introducing Wairua Pūruatanga as a model: Defining Wairua Matawhaiaro and Wairua Hononga (personal and connective Wairua).
- Wairua in practice: A lived experience perspective concerning the presence or lack of Wairua in service user-practitioner relationships.
- Wairua and Te Whare Tapa Whā: Understanding why we begin with Wairua when working with a holistic perspective of health.
- Wairua, science, and Indigenous knowledge: Discussing modern health models through a Māori lens.

STREAM 3: LIVED EXPERIENCE EXPERTISE AND RESEARCH METHODOLOGY

Authors: Dr Jacqui Lovell, Natasha Downs, Katie Romney, Fiona Cammack

Title: Expanded I poems': a participatory data analysis and co-inquiry process of Northumbria university's 'Public involvement and coproduction in research' programme led by people with lived experience of mental distress.

Affiliation: Survivor Researcher Network cic; Northumbria University

Abstract: Gilligan, Spencer, Weinberg and Bertsch (2003) developed 'I poems' as a data analysis process, seeking out the 'contra-puntal' voices of the women who took part in their research. Lovell (2017) explored this approach during participatory action research, focusing on its accessibility and usefulness as a participatory data analysis process. The adaptation of this approach and the subsequent development of 'Expanded I poems' (Lovell, 2017) supported reflection by people, with lived experience of mental distress, across personal, objectified, interpersonal, group and community levels of experience. **Aims:** A social realist approach to the evaluation of a 'Public involvement and coproduction in research' programme (housed within the Department of Education, Social Work and Wellbeing at Northumbria University) was undertaken in partnership with learners and facilitators, who are all people with lived experience of mental distress. Social realism is defined as the realistic depiction in art and / or research of contemporary life, as a means of social and/ or political comment. **Results:** The results of this process are presented together with I, It, You, We and They poems that illustrate the points being made across individual, objectified, interpersonal, group and community levels of experience, respectively. **Conclusions** are drawn from this participatory data analysis that build upon the lived experience of the facilitators and learners in this experiential learning process (Freire, 1985). This participatory process demonstrates that critical reflection and participative co-inquiry using co-creative arts have the power to break down the 'them and us' dichotomy that is so often in evidence within academic programmes and the research and evaluation that accompany them.

Authors: Nina Joffe-Kohn & Cath Roper

Title: Abolition Perspectives in Mental Health: A service user research project

Affiliation: Centre for Mental Health Nursing, Melbourne University

Abstract:

This presentation summarises some of the thinking connected with abolitionist perspectives in the context of psychiatry and mental health laws. The approach taken to the topic situates abolitionist perspectives within historical and current activism of consumer/survivors, First Nations activists in Australia and abolition activism from the US.

Sources explored include websites, podcasts, videos, blogs, informal 'grey' literature and 'formal' literature as well as interviews with 15 advocates and activists from different countries. This presentation will report on some of the results of this lived experience-led research.

The Abolitionist Perspectives project was commissioned by the Independent Review of Compulsory Treatment Criteria and Alignment of Decision-making Laws Panel in the context of Victoria's incoming Mental Health and Wellbeing Act 2023.

Abolition is a political vision involving the creation of lasting alternatives to punishment and incarceration as well as a broad strategy engaging in the dismantling of systems that control, oppress and maintain inequalities among people. For abolitionists, in the context of psychiatry, mental health laws are discriminatory and cause harm. Abolitionist practices offer an inspiring counter to familiar arguments claiming alternatives need to be in place before we can dismantle coercive mental health laws. Consent-based community initiatives already exist, and we do not yet know what other possibilities might emerge. We position both First Nations people's campaigns for legal change and their fight for community controlled organisations as examples of abolition leadership.

- First Nations leadership in the space of self-determination has paved the groundwork for abolition in theory and in practice, we welcome attendees to engage with diverse ways of thinking and doing.
- Attendees are encouraged to engage with the service users perspectives of abolition in a way that perceives abolition as possible and within our reach.

STREAM 1: LOOKING BACK AND LOOKING FORWARD

Authors: Emily Castagnini, Tessa Zirnsak & Priscilla Ennals, Lisa Brophy, Rebecca Spies, Miranda Frare

Title: A thriving peer workforce for the future: getting the structures and supports right for sustainable workforce expansion and impact

Affiliation: Neami National, La Trobe University

Abstract:

Neami has rapidly increased its designated Lived Experience workforce over the last few years, and we acknowledge we have not paid enough attention to getting the supports and structures right. We're taking stock of what supports are valued and available to the LE workforce, to ensure we're renewing our structures in line with the preferences of the people who matter most.

This study uses a mixed method design across three sequential phases. We began with a survey of Neami's 250+ LE workforce to understand people's use and preferences for supports. This was followed by interviews to deepen understanding of the value and impacts of supports. Our study concluded with a focus group to test findings and develop recommendations.

Our findings will describe the organisational supports and structures needed to foster a large and thriving Lived Experience workforce. We will discuss support preferences, impacts, and barriers and enablers to accessing supports. We will consider the implications for organisations and funders.

As we envision thriving, well-supported LE workforces, we pause to understand where we are now. We're testing assumptions to ensure that our future visions are grounded in the needs, preferences, and hopes of the LE workforce.

Author: Anna Ashton

Title: Death in Digital Spaces: Suicide Prevention for the Modern Age

Affiliation: Te Whatu Ora, Health New Zealand

Abstract:

Digital spaces can be deadly and yet over a decade in to their irreversible integration into daily life our services are ill-prepared to respond. But my lived experience calls to me, it reminds me of the whakataukī 'kia whakatōmuri te haere whakamua – walk backwards into the future with your eyes fixed on the past', it asks me to return to the digital landscape that almost took my life and make the invisible visible. To translate the language and the culture of the pro-harm communities and teach our system to save rangatahi from things that until now only they could see.

Therefore, the aim of this session is to take a non-blaming approach to understanding the balance of negative and positive factors in the real versus online world that drive youth into digital spaces to get their needs met, the risks they encounter there and the coping strategies and systemic changes we can impart to manage them.

STREAM 2: BRIDGING THE GAPS: EQUITY, DIVERSITY AND INCLUSION

Author: Jess Goodman

Title: Building Belonging: A Neurodivergent-Led Model for Inclusion in Academic Spaces

Affiliation: Massey University, School of Psychology

Abstract:

This presentation explores the development and impact of Diverse Minds @ Massey Manawatū, a student-led club for neurodivergent tertiary students grounded in lived experience leadership, disability justice, and mutual support. Founded by a postgraduate psychology student with lived experience of ADHD, chronic illness, and academic marginalisation, Diverse Minds offers a case study in creating culturally safe, accessible, and affirming academic spaces for students who are often underserved by traditional university systems.

The club fosters inclusion through social meetups, advocacy resources, and co-designed wellbeing initiatives—ranging from game days and fidget libraries to mental health workshops and study survival kits. The work is grounded in the understanding that neurodivergent students connect, learn, and flourish in diverse ways—and that traditional deficit models often fail to support these needs. This session will share the story of Diverse Minds' creation, challenges, and successes, and outline practical steps for building similar initiatives elsewhere.

The session invites critical reflection on the role of lived experience leadership in academic institutions: How can we meaningfully include neurodivergent voices in shaping education, research, and support systems? What tensions arise when lived experience-led efforts intersect with bureaucratic or under-resourced university structures? How do we avoid tokenism while ensuring accountability?

This presentation will be of interest to service users, educators, researchers, and students committed to inclusion, equity, and structural change. By focusing on grassroots approaches and student leadership, it opens space for dialogue about how we might go further—and do more—together.

Author: Alexander Walker

Title: From outsider to insider? Moving towards epistemic justice for peer supporters within Aotearoa's mental health system

Affiliation: Te Herenga Waka – Victoria University of Wellington

Abstract:

Aotearoa is expanding the peer support workforce within its mental health system. However, peer supporters face challenges when working within traditional mental health spaces: distrust from other mental health professionals, struggling against a dominant biomedical framing of mental distress, feeling relegated to an assistant clinician role, and ambiguities concerning role definition and scope.

I explored how peer supporters experience epistemic conditions within the mental health system and what casual mechanisms contributes to epistemic injustice in this context. I identified key factors that can protect peer support's epistemic qualities when situated within mainstream mental health services.

The main phase of the study comprised 27 interviews, with 14 peer supporters and 14 clinical professionals. I analysed interviews using a critical realist adaptation of reflexive thematic analysis. Following this, I drafted a framework for peer support epistemic justice and consulted with six peer supporters to further develop the framework.

Peer supporters operate within an epistemically precarious position in Aotearoa. They are expected to transform the mental health system and challenge clinical culture – while being paid less than other professions and lacking typical markers of legitimacy that denote epistemic authority. Peer supporters occupy the bottom of a systemic knowledge hierarchy which enshrines a medical episteme as the highest form of mental health knowledge. Peer support is at risk of losing its distinctive features and falling into a 'mini clinician' role. Continuing stigma against people with mental distress devalues how peer support knowledge is received.

Peer support can positively impact Aotearoa's mental health system. However, actualising this potential will require attending to the structural and relational conditions within the system which inhibit flourishing of peer supporter knowledge. Peer support is positioned by policy as a force for transformation but this transformative capability rests upon a move towards epistemic justice.

STREAM 3: LIVED EXPERIENCE EXPERTISE AND RESEARCH METHODOLOGY

Authors: Jason Haitana

Title: Co design Co Production and Co Creation – Moving into Third Space Thinking from a Māori First Nations Perspective

Abstract:

Background: Third space thinking is about moving into new thinking around system and service design, and how to use methodologies that are useful and valuable. These are co design, co production and co creation with a particular Māori spin (ref: J Haitana. K. Wixon and M. Brown).

Findings: That there are creative and insightful means of engagement for people, in terms of design, production and creation of safe spaces.

Conclusions: That being able to understand at least the tenets that underpin the main three methodologies of engagement that gives clinicians a better appreciate on how this work is carried out, and how useful it can be.

Authors: Cassi Strauss, Jesse Shears, Emiko Artemis

Title: Using diverse lived experience to sense make with people through crisis

Affiliation: Neami National

Abstract:

People experiencing suicidal distress and psychological crisis describe a multitude of factors that contribute to their distress. While there is strong recognition of the range of environmental and social factors potentially impacting people's lives in the context of crisis, crisis service responses don't always provide opportunities to make sense of or address these.

As Lived Experience workers we return to grounded ways of knowing – observation, reflection, connection, and dialogue – to help us make sense of this divide. We have shared stories and pooled expertise to deepen our understanding of what matters in responding to people when social determinants loom large in their distress and crisis.

This presentation will unpack, from a lived experience staff perspective, what matters in responding to people when social determinants loom large in their distress and crisis. It will cue areas of focus for future research and support provision in this area

We will reflect on the different service contexts we work in across Australia. We all have roles in a community mental health organisation and notice many similarities in factors and issues present for people experiencing distress. Our unique histories and framings help us think differently about how crisis is brought about or exacerbated by these factors, for example, homeless and housing instability, the challenges of navigating the world with autism, and other situational distress. Our framings help us make sense of ways to move through experiences of crisis - exploring what may be supportive in the short, medium and longer term. These lived knowledges offer ways forward in contexts that can feel hopeless, overwhelming or impossible.

STREAM 1: LOOKING BACK AND LOOKING FORWARD

Author: Laura Ashton

Title: Reflections on a developmental evaluation adventure in a peer service

Affiliation: Ka Puta Ka Ora Emerge Aotearoa

Abstract:

In 2024, Mind and Body, a longstanding lived experience/peer-led organisation in Aotearoa/New Zealand, established a new peer support and education service in Waihōpai/Invercargill. The organisation decided to run a two-year developmental evaluation alongside the development of the service. In this presentation, three participants in this process – the evaluator and two senior leaders (all of whom have lived experience) – will critically reflect on the experience, bringing their diverse perspectives to consider what they learned from the process. Their reflections will build a rich picture for people about the complexity of embedding evaluative thinking and practice into a new place-based initiative that is strongly values-led and committed to the principles of being peer-led. The discussion will be candid, embracing the diverse participants' perspectives on how to integrate an inclusive, participatory, people-centred approach, that meets the demands and needs of peer workers inside the service as well as those in the wider community. We will reflect on the process of co-creating a peer workforce (where none previously existed), including the impact of peer workers' personal experiences on shaping both the service and the evaluation. Furthermore, we will demonstrate how evaluation capabilities and capacity can be supported to grow in a complex and demanding policy and service delivery context and the potential implications of our learning for developing the future Consumer Peer Support and Lived Experience workforce.

Authors: Tula Brannelly & Gina Giordani

Title: Establishing a Lived Experience Research Group and community of practice to support capacity building and activity in lived experience research

Affiliation: AUT and Te Pou

Abstract:

Establishing a Lived Experience Research Group and Lived Experience Community of Practice to support capacity building and activity in lived experience research

Looking back to look forward in building lived experience research capability, this presentation outlines the development of a Lived Experience Research Group in a university, AUT, affiliated to a Lived Experience research community of practice in a non-governmental organisation, Te Pou. In 2024, members of an existing AUT Lived Experience advisory group discussed the potential for a more explicit research focus in their work which aligned well with Te Pou's aims of developing research capacity.

The aim of this session is to 1) share the progress to date in the development of the research group; and 2) to invite ideas and questions about priorities for Lived Experience research, and 3) to invite membership into the research group and community of practice.

STREAM 2: BRIDGING THE GAPS: EQUITY, DIVERSITY AND INCLUSION

Author: Jaq Ball

Title: Dismantling and reframing the constructs of trauma and trauma informed care through autoethnography focused on harmful power

Affiliation: University of Canberra

Abstract:

In Australia, our understanding of trauma draws on a flawed, Eurocentric construction. Support for people who have experienced trauma exists largely within the hierarchical biomedical based mental health system, which was designed without lived experience expertise. This system problematises trauma as a conceptually narrow individual issue without recognition of systems of oppression or unequal power relations (harmful power). That definition of trauma has been developed without lived experience input.

Similarly, there are concerns with the version of trauma informed care that has been politically endorsed and considered best practice in a number of settings. Its conceptualisation has omitted lived experience expertise across disciplines, including within mental health. This provides an explanation for existent difficulty with "implementation". The preservation of this top-down conceptualisation of trauma informed care is a concerning act of harmful power. There is an under-acknowledged problem with harmful power relating to trauma and trauma informed care that is cyclically taught and occurs in the academy and the mental health system. This problem needs to be explored from a lived experience perspective.

Autoethnography is being used to analyse the authors' two-decade journalled experiences throughout three roles or identities: service user of the mental health system, undergraduate student of psychology, and PhD candidate whose research originally aimed to improve "prevalence" of trauma informed care.

Preliminary results indicate harmful power reinforces the dominant understanding of trauma and trauma informed care, while resistance work, including peer support, aids the impact. Lived experience led constructions would prevent the need for such taxing counterwork.

We need to rebuild the bodies of academic literature on trauma and trauma informed care from a lived experience standpoint.

Author: Jason Kumar

Title: Madness Hospitality and Belonging

Affiliation: University of Auckland

Abstract:

At the age of 17, I became a prisoner and later a forensic psychiatric patient, transitioning from a prison special unit to a forensic hospital, and finally to community supervision. After years of struggling as a community patient on a benefit, I returned as a consumer advisor, working with the same systems and clinicians who had once scrutinised and contained me. This presentation explores the journey of navigating madness within forensic mental health services and asks whether we need to rethink how people with lived experience are treated - not just clinically, but socially and politically. The session aims to examine how lived experience can enter into dialogue with academic theory. Using ideas from Lévinas and Derrida, it reflects on what forensic services reveal about the politics of care, and explores how their ideas might support more just and humane approaches. Forensic services sit at the intersection of competing imperatives: society's demand for punishment, the justice system's focus on risk, and psychiatry's drive to diagnose and medicate. In this context, madness is seen as a threat to neutralise or a disorder to manage, rarely as a human experience with meaning. Drawing on Lévinas' ethics of the Other and Derrida's concept of hospitality, I argue that forensic services inevitably intertwine care with hostility. I propose that services might better serve both patients and the public by moving towards an ethics of hospitality that makes room for madness. This presentation challenges the assumption that inclusion should only be the reward for recovery. It argues that services need to be accountable not only for risk, but also for the harm that occurs in the name of treatment. Bringing Lévinas and Derrida in dialogue with lived experience can offer one way to understand these fault lines and help us consider more compassionate responses.

STREAM 3: LIVED EXPERIENCE EXPERTISE AND RESEARCH METHODOLOGY

Author: Terri Warner

Title: Epistemological anarchism as theory and method in lived experience research

Affiliation: The Australian National University

Abstract:

Service user researchers bridge the gap between academic researchers and people with direct experience, but service user led research is sometimes seen as less objective, or less 'scientific' than other types of research, especially when they use qualitative methods. This links to a broader problem of research outside of science being seen as less valuable, or less valid.

Paul Feyerabend proposed what he called 'epistemological anarchism' as a critique of, and remedy for, the position of scientific knowledge in Western society, which he argued had more to do with social authority and power than with either its method or the results it produced. Feyerabend advocated for a theoretical and epistemological pluralism that would embrace experiential knowledges as well as creative and flexible approaches to methodology.

The aim of this session is to introduce epistemological anarchism as a theory and as an approach to method that could be adopted by service user researchers. Using recent doctoral research as an example, the session will explore existing and potential links between epistemological anarchism and service user led research, and how the critique underpinning epistemological anarchism can be used to advocate for the expansion of service user leadership in health and social care.

Service user researchers often must choose to align with, or break away from, the ways of knowing developed within established academic disciplines. This can be an uncomfortable and complicated decision. Further, fixed ideas about the theoretical authority of science may perpetuate epistemic violence against members of marginalised groups. Service user researchers need, and deserve, methodological and theoretical options that are anti-oppressive and respect them as both knowers and producers of knowledge. Epistemological anarchism offers a critical way of working with different ways of knowing, without necessarily accepting or aligning with them.

Authors: James A. Coutinho, Caitlin Jablonka, Priscilla Ennals

Title: "I'm afraid I'm nothing without my degree": Barriers to peer-clinician knowledge-sharing in an integrated mental health and AOD service

Affiliation: Neami National, the University of Melbourne, La Trobe University

Abstract:

We report on a study that links research with practice development interventions at an integrated mental health and alcohol-and-other-drug (AOD) service. The service employs a mix of clinicians and peer support workers to provide care and support to people in the community. The research had three aims: i) to understand how peer support workers and clinicians were sharing knowledge with one another in order to learn from one another's practices and deliver responsive and effective care; ii) to understand the barriers to knowledge-sharing across peer and clinical roles; and iii) to promote more effective, two-way knowledge-sharing between peer and clinical roles. In the first stage of the research, we used survey-based methods and social network analysis (SNA) to map the knowledge-sharing relationships between peers and clinicians in the service. We found that peers sought out clinicians for knowledge more than vice-versa, reflecting an informal hierarchy between clinicians and peers. In the second stage of the research, we designed and delivered reflective workshops with staff, which aimed to create psychologically safe-enough spaces in which staff could identify barriers to effective knowledge-sharing and co-design solutions to promote two-way knowledge sharing. We found that while some knowledge-sharing barriers reflect wider systemic challenges, many lie at the level of peer-clinician collaborative practice. In particular, clinicians and peers used different strategies to shield themselves from the difficulties of open and vulnerable collaboration, with clinicians asserting professional status and practice and peers resorting to 'othering' of clinicians. The workshops enabled staff to own these behaviours and to consider alternative approaches to collaboration. Overall, our presentation showcases an innovative methodology which links research with practice development, so that the collective knowledges and skills of all staff are harnessed to support service users.

STREAM 1: LOOKING BACK AND LOOKING FORWARD

Authors: A/Prof. Paul Badcock, Dr. Chrissie Hughes, Hannah Blackwell, Amelia Asciutto, Dr. Caitlin McDowell

Title: Climbing Arnstein's Ladder of Citizen Participation in the design, delivery and evaluation of mental health curricula

Affiliation: Centre for Youth Mental Health, The University of Melbourne

Abstract:

Arnstein's Ladder of Citizen Participation (1969) describes citizen involvement in planning processes from exclusion to tokenism to citizen control. This framework is helpful for us to consider who has power when important decisions are being made. In recent years, mental health services and tertiary education providers have increased efforts to meaningfully incorporate consumer participation in key decisions and activities, however these efforts have been sporadic.

Within The University of Melbourne's Centre for Youth Mental Health, we have a suite of longstanding youth mental health courses. However, it has proven challenging to incorporate meaningful lived experience retrospectively. Learning from this, when developing two new microcredentials last year, we sought to co-design the curricula with young people with lived experience of mental ill-health and their carers as early as possible in the process.

Concurrently, in order to learn and compare our experiences with other mental health educators across the University, we conducted research to investigate subject coordinators' perspectives and experiences of involving service-users in the design, delivery and/or evaluation of mental health curricula across our Faculty. We found that efforts varied and while there was one consumer-led subject and some examples of collaboration in design and delivery elsewhere, most reported non-participation of mental health service-users and no involvement in the evaluation of curricula. The key themes emerging from the qualitative analysis of interview transcripts were 'meaningful vs tokenistic involvement', 'impact on student learning and experience', 'barriers' and 'enablers'.

In this session, we will briefly share our experience of incorporating lived experience in youth mental health curricula at The University of Melbourne's Centre for Youth Mental Health. The key themes from our qualitative analysis will be used to guide discussion in the workshop, and explore how we can move forward, continuing to climb the rungs of the Ladder of Citizen Participation in academia.

STREAM 2: BRIDGING THE GAPS: EQUITY, DIVERSITY AND INCLUSION

Authors: Johnnie Potiki, Armon Tamatea, Areta Ranginui Charlton, Wi Te Tau Huata, Wheeti Maipi, Cindy Shepherd.

Title: Spinning plates on the edge of a volcano: Respecting rights, will and preferences for tāngata whaiora in an unstable health system

Abstract:

The Tohu or by-line of our title – Respecting our rights, will and preferences – serves to bring together our domestic and international obligations, particularly with respect to this concept of supported decision-making, which requires all forms of support, including the most intensive, to be based on the will and preferences of the person concerned. We have used the constitution model outlined in He Puapua as an overarching structure to ensure our research is Te Tiriti o Waitangi-led, upholds UN treaties and is in step with good co-governance practices for the health sector. He Puapua provides a roadmap for Aotearoa to fully realise the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), and in doing so, also helps us to envisage mental health services that are compliant with Te Tiriti o Waitangi and the United Nations Code of Right for People with Disabilities.

He Puapua draws on Matike Mai to conceptualise Te Tiriti o Waitangi relationships in constitutional terms, outlining three spheres of influence over decision-making: Rangatiratanga, Kāwanatanga, and Relational. The Rangatiratanga sphere includes Māori governance for our people and places. The Kāwanatanga sphere represents Crown governance. An overlapping and larger Relational sphere reflects the space where Māori and the Crown join in decision-making over mutual concerns. Our overarching action research approach includes the generation of both Māori-specific resources and general resources, created through kanohi ki te kanohi hui led by Māori research team members. This session will share how we envisaged and implemented equitable approaches to design and implementation of My Advanced Preference Statements (MAPS), and the juggling of plates that occurs when implementing action research in health spaces.

To view the suite of MAPS resources that have been created as part of the Te Kete Rongomau project, please see the overview presentation by the wider research team.

STREAM 3: LIVED EXPERIENCE EXPERTISE AND RESEARCH METHODOLOGY

Author: Brett Scholz

Title: Exponential Growth of “Patient Involvement”: Much Ado and Not Doing Much

Affiliation: The Australian National University

Abstract:

Over the past decade, health research has seen an exponential rise in published studies claiming to use participatory approaches such as co-production, co-design, and patient and public involvement. Some scholars even suggest we are in a “participatory era.” However, as these initiatives multiply, so too do tokenistic practices that exclude people working from lived experience perspectives from meaningful decision-making and agenda-setting roles in health policy, services, research, and education. Ironically, the growing emphasis on patient “involvement” appears to obscure a decline in approaches that genuinely challenge power imbalances. In this presentation, I trace the history of lived experience movements in health. I share my ambivalence about some recent developments (such as The Lancet Psychiatry’s lived experience engagement statements) that both call attention to participatory approaches, but echo exclusionary and tokenistic practices if incorrectly applied. I argue that, in our rush to appear truly participatory, health research and researchers risk deepening power disparities rather than dismantling them. Despite these concerns, this presentation ends on a hopeful note. I propose concrete ways to ensure that people working from lived experience perspectives lead decision-making, shape research priorities, and author lived experience statements—rather than being relegated to roles with no real influence over epistemic or practical processes. I reflect on the way we might use existing systems to develop more lived experience leadership opportunities and to call out initiatives that limit people with lived experience perspectives to menial tasks such as advisory roles or priority-setting exercises.

MY NOTES

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MY THOUGHTS/IDEAS FOR THE FUTURE OF SUAS

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HAERE RA - FAREWELL

'Kua tawhiti kē tō haerenga mai, kia kore e haere tonu. He nui rawa ō mahi kia kore e mahi tonu'

'We have come too far not to go further. We have done too much not to do more'.

We must all do what we can to foster and grow opportunities for service user leadership and co-production in mental health and addiction. Together we will continue to advance the discipline of service user academia.

Our work will continue to drive meaningful discussions and the valuing of lived experience knowledge and expertise in academia, research and workforce development

Thank you for coming and sharing your words, your thoughts and your learnings with us all.

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