7Th SERVICE USER ACADEMIA SYMPOSIUM

MASTER OF CEREMONIES, KEY-NOTES AND PLENARIES

20TH AND 21ST NOVEMBER, 2017

UNIVERSITY OF OTAGO WELLINGTON
23A MEIN STREET NEWTOWN
WELLINGTON NEW ZEALAND

CO-HOSTS

University of Otago – Te Whare Wānanga o Otāgo – New Zealand

ACT Government Health

Synergy Nursing & Midwifery Research Centre

CPN Centre for Psychiatric Nursing – advancing mental health practice

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Tama Tū Tama Ora CONNECT – Supporting Recovery

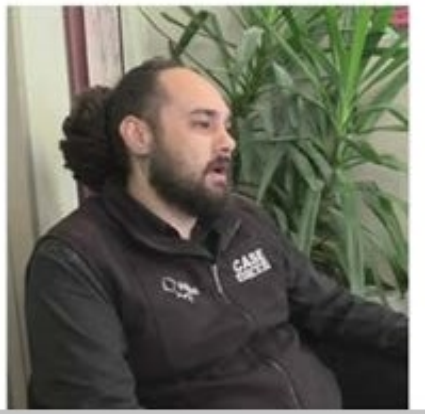
Building Bridges

mind&body

kites

Master of Ceremonies

TANE RANGIHUNA



Tikanga Māori

Taitai, Aorangi, Hikurangi maunga
Toka tu, toka ahuru e kore e nekeneke te tauranga o
Nukutaememeha waka.
Wharekia, Whanakao
Ngati Porou motuhake I runga ra te ranganui a Toi
Te hononga o aku tapuae
Ki te whai ao ki te ao marama
Haumie! Hui e!

Tane works as a project specialist and cultural advisor at Kites Trust, providing tikanga Māori support and undertaking project work. Tane was brought up on the East Coast with his maternal Grandparents and embraces his Māori matauranga.

A competent presenter and facilitator, Tane has a wealth of knowledge about te reo and Māori protocol. Tane also offers cultural training for providers to better understand the "Māori ways of doing things".

For the first time, the service user academia symposium 2017 will have a master of ceremonies and we are thrilled to have Tane as our inaugural MC.

Key-Notes

WANDA BENNETTS

Title: To be or not to be a representative – that is the question.

Affiliation: Independent Mental Health advocacy (IMHA), Australia

Abstract

Unpacking the concept and context of being a 'representative'is incredibly complex and touches on many issues. These can broadly be conceived as issues that are definitional, attitudinal, ethical and practical.It also raises many, many, many questions that need to be considered.

Asking for a representative needs to be a well considered choice based on what is really wanted and has to be weighed up against other ways of asking for a particular voice to be heard. It needs to be cognizant of what expertise looks like, who has it and how it can be best harnessed.

The way we understand, feel about and approach the concept of representation can have an impact on how we create connections or create disconnections. This then also impacts on how we can build bridges and relationships that have the potential to create new understandings and infinite possibilities for future thinking.

This presentation aims to highlight the issues as I have come to understand and experience them and to raise questions for further exploration of this topic. It also hopes to create discussion and critical thinking that will further inform, contribute to, and enhance all our understandings and practice in the future.

Biography

Wanda has a background in education and a lived experience of using mental health services. She has worked in a variety of consumer perspective roles since 2000, mostly at a systemic level in clinical services. These roles have included Consumer Consultant, consumer researcher, educator, senior advisor, freelance worker and Senior Policy Advisor - consumer portfolio holder at Department of Health and Human Services. Her current role is Senior Consumer Consultant for Independent Mental Health Advocacy (IMHA). She also does some casual work as a consumer academic for the Centre for Psychiatric Nursing.

DR MIRIAM LARSEN-BARR

Title: Beyond the Consultant Position: Service-User Led Research

Affiliation: Waitemata DHB, New Zealand

Abstract

For decades the service-user movement has advocated for a partnership-based approach to mental-health research, treatment delivery, and policy. Many strides have been made, but clinicians and researchers remain in an expert position with privileges not easily relinquished to their service-user consultants. The clinician chooses when to consult and what to consult about. It is the lead researcher who will choose the subject of interest, and it is the lead researcher who will ultimately choose which advice to use and which advice to discard. However, people with lived experience of recovery possess many areas of expertise in addition to their personal insights; many already possess, or can acquire, the knowledge and skills to lead the research themselves. Like any researcher, they too can build a team of other specialists to consult as needed. Would they build their teams the same way? Would they ask different questions? What challenges would they face? Using The Experiences of Antipsychotic Medication Study as an example, this talk explores what happens when a service-user activist trains as a clinical psychologist and has the chance to lead the research from its inception.

Biography

Dr Miriam Larsen Barr is a newly qualified clinical psychologist with lived experience of recovery, a second life as a poet, and a twelve-year history as an activist within the service-user movement in New Zealand. Her doctoral research garnered international attention, and she recently began writing for Mad in America.

DR SARAH CARR

Title: 'I am not your nutter': Reflections on commodification and comradeship in service user and survivor research

Affiliation: Middlesex University London, UK

Abstract

This paper borrows its title from James Baldwin, the African American civil rights activist and writer, who argued that 'What white people have to do is try and find in their own hearts why it was necessary to have a n*gger in the first place'. In the paper, I will use Baldwin's idea about how a powerful group of people invent an 'other' to serve their own needs. It will frame a critical examination of what current mental health research producers and policy agendas in the UK need service users and survivors – or 'nutters' – to be, and what we are requiring of ourselves.

I will explore a number of key questions: Are we being positioned as commodities with required roles, identities and behaviours, or do we have sufficient influence and agency to determine who we are and what we do as equals? As mental health service user and survivor movements or communities, do we ourselves require certain identities and behaviours from our members? If so, does this affect cultures of comradeship, and our capacity for gaining collective power and knowledge? Who is determining legitimacy and authenticity, and how? How can service user and survivor researchers navigate the ever more complex and competitive landscape of mental health research, and address the tensions between the rhetoric and reality of co-production and public and patient involvement?

To illustrate the discussion, I will draw on case examples from UK mental health research policy development and non user-led research charities. I will also draw on my personal experience as a service user/survivor researcher working in academia. Finally, I will conclude with thoughts on how strategic collectivity and activist scholarship could work for service user and survivor researchers and advance our practice.

Biography

Dr Sarah Carr is Associate Professor of Mental Health Research and Co-Director of the Centre for Co-production in Mental Health at Middlesex University London. She also runs her own independent mental health and social care knowledge consultancy. She has experience of mental distress and mental health service use and uses this to inform all her work. Sarah is Vice Chair of the National Survivor User Network (NSUN), a former trustee of the LGBT Consortium and a member of the editorial boards of Disability and Society and The Lancet Psychiatry. In 2012 Sarah co-edited the book Social Care, Service Users and User Involvement with Professor Peter Beresford and was a member of the NICE Guideline Development Group for NICE CG136: Service user experience in adult mental health. She is a Fellow of the Royal Society of Arts, Honorary Senior Lecturer at the School for Social Policy, Birmingham University and Visiting Fellow at the School of Social Policy and Social Work at the University of York.

Plenaries

Title: Conversations for Change: Creating a Like Minds, Like Mine resource for community use.
Presenter: Sheree Veysey
Affiliation: Mind and Body Consultants, New Zealand

This presentation will introduce "Conversations for Change", a project whose end goal was to create a downloadable resource for facilitators to use with young people to shift stigma and discrimination. The resource had to stand-alone and be accessible. At the same time, it needed to be robust enough to be used safely in the community by any individual with a passion for youth, wellbeing and human rights.

How to go about creating such a resource? How could we make it youth friendly and suitable in a multi-cultural and bicultural society? Given the dominance of the bio-medical model, how could we make sure that future facilitators were onboard with the messages? If there was no guarantee that people with lived experience of mental distress would be facilitating the resource, how could we harness the power of contact to shift attitudes – and for facilitators who did have lived experience, how could we try and make sure that any disclosure they made worked to decrease stigma rather than inadvertently increase it? Importantly how could we assess whether it worked to shift stigma and discrimination and increase social inclusion?

Be introduced to the journey of how this unique service-user led initiative navigated these questions, including findings from the pilot study which utilised the Reported and Intended Behaviour Scale (RIBS 10) (Thornicroft 2009). The project was completed mid-2017 as part of the Like Minds, Like Mine campaign and is available for download at rethink.org.nz.

Title: Piri Pono - peer led acute alternative in action
Presenter: Karyn Munday
Affiliation: Connect Supporting Recovery

Abstract
Connect Supporting Recovery had a vision for a Peer run Acute Alternative. This vision became a reality in September 2013 when Piri Pono a 6 bed service was established.

Its purpose to provide a hope-filled place, and relationships where crises can be turned into opportunities; where people use opportunities to experience change and, to learn new responses through relationships with peers and peer support staff. We believe that everyone is competent and capable and inherently know what they need.

Relationships in Piri Pono will strive to be free from coercion and power imbalances, building relationships based on a new framework that redefines what "help" might look like in a mutual relationship. New and different relationships will be part of what encourages people to become active participants rather than passive recipients within all relationships they have with others. Mutuality is not something that "just happens".

The Intentional Peer Support model informs service delivery. Our presentation will take you through the beginnings of Piri Pono and share some of the challenges and highlights of this remarkable service, you will hear quotes from staff and users of the service about the support and impact of the service this through the results of our most recent evaluation.

Title: Investigating the feasibility of a service user research advisory committee

Presenters: Sarah Gordon & Brenda Happell

Affiliation: Sarah (University of Otago Wellington) and Brenda (SYNERGY: Nursing and Midwifery Research Centre, University of Canberra and ACT Health).

Abstract

To date the active involvement of consumers in mental health research has been limited.

Difficulty in accessing consumers with the skills and expertise required for participation has been identified as one barrier to participation.

The establishment of an expert group of mental health consumers able to contribute a consumer perspective is one potential strategy to address this barrier. The success of such an initiative would require mental health researchers who would willingly include this expertise in their team.

This paper with present the results of an exploratory study that involved three stages:

1. Interviews with mental health researchers with a track record in actively involving consumers in research to explore the benefits of including consumers, and whether access to a group of consumer research experts would be valuable.

2. Survey of mental health researchers in Australia and New Zealand to explore their attitudes to involving consumers in research and the potential benefits (if any) of an expert group.

3. Individual interviews with major health research funding bodies, including Health Research Council New Zealand, National Health and Medical Research Council and The Australian Research Council, Australia to explore their perspectives about the potential value of an expert consumer research group, and any barriers or limitations they would anticipate.

Based on the results of the research, the need for, and feasibility of, establishing a service user research advisory committee will be discussed.