

7Th SERVICE USER ACADEMIA SYMPOSIUM PROGRAMME & ABSTRACTS

20TH AND 21ST NOVEMBER, 2017

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

CO-HOSTS



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DAY 1

From 8.00am Registration/Tea and coffee available – Lobby, Level D

9.00am Mihi Whakatau

9.30am Welcome and housekeeping - Small lecture theatre, Level D

10:00am **KEY-NOTE:** Wanda Bennetts , Independent Mental Health Advocacy (IMHA), Australia
Title: *To be or not to be a representative – that is the question.*
Venue: *Small lecture theatre, Level D*
Chairperson: Sarah Gordon

11:00am **Morning tea**

11.30am **SESSION A**
Small lecture theatre, Level D
Chairperson: Brenda Happell

Karen Wells

Title: *A shock to the system: service-user lead research using lived experience knowledge to inform ECT practices*

Flick Grey

Title: *Service users, lived experience and Madness Studies: troubling positionality*

Daniel Pintado

Title: *"Saying versus Doing: Bridging the gap between Values, Policy, and Practice for Consumer Consultants in Mental Health"*

SESSION B

C02/C05, Level C
Chairperson: Brett Scholz

Steven Davey

Title: *Building bridges by 're-anchoring': new avenues for the way mental distress is understood by the public*

Sue Anderson

Title: *Co-designing Care - Stories from a shared 18-year therapeutic journey*

Mike Sukolski

Title: *My Madness, And Why I Can't Tell You About It.*

1.00pm **Lunch** - Lobby, Level D

1:45pm	World café – presentation session <i>Small lecture theatre, Level D</i> Chairperson: Julia Bocking	
	Dasha Fedchuk – Title: <i>Addressing minorities: Self-injury in LGBTQ service users</i>	
	Gabrielle Jenkin – Title: <i>Designer mental health facilities: What do service users want from the design of the adult inpatient facility?</i>	
	Katie Rickson – Title: <i>Lullabies in a time of psychosis</i>	
	Kevin Harper and Amanda Luckman – Title: <i>Consumer conversations to influence a people powered mental health system and service development</i>	
	Ngā Hau e Whā – Title: <i>'Nothing about us without us'</i>	
	Denise Omar – Title: <i>DRIVING Consumer Voices</i>	
2:45pm	World café – discussion session <i>Various 'stations'</i>	
3.30pm	Afternoon Tea	
3.45pm	SESSION A <i>Small lecture theatre, Level D</i> Chairperson: Bridget Hamilton	SESSION B <i>C02/C05, Level C</i> Chairperson: Brian McKenna
	Joanne Taylor Title: <i>Evaluating the teaching of mental health recovery concepts in clinical psychology training</i>	Johnnie Potiki Title: <i>Pilot study to evaluate implementation and outcomes of advance directives in mental health services</i>
	Lisa Malihi-Shoja and Heather List Title: <i>Service users and carers in the classroom – right where they ought to be</i>	Maria Stubbe Title: <i>Diabetes patients' experiences of communication with health providers – empowerment, agency and mental wellbeing</i>
	Katie Owen Title: <i>Using narrative and the lived experience to address stigma and discrimination in the classroom</i>	Shannon Calvert Title: <i>Compassion, Dignity and Respect: How Values Supporting Treatment Interventions Can Promote Recovery</i>
	Tracey Cannon, Susan Hatters Friedman and Sigourney Taylor Title: <i>Satisfaction Guaranteed ? A forensic service user perspective;</i>	Giles Newton-Howes and Sarah Gordon Title: <i>When at an impasse with co-production: Press on for consensus or proceed with divergent views?</i>
5.45pm	Close of Day 1	

DAY 2

8:30am	KEY-NOTE: Dr Sarah Carr , Middlesex University London, UK Title: <i>'I am not your nutter': Reflections on commodification and comradeship in service user and survivor research</i> Venue: <i>Small lecture theatre, Level D</i> Chairperson: Sarah Gordon	
9:30am	PLENARY SESSION Sheree Veysey , Mind and Body Consultants, New Zealand Title: <i>Conversations for Change: Creating a Like Minds, Like Mine resource for community use</i> Karyn Munday , Connect Supporting Recovery, New Zealand Title: <i>Piri Pono - peer led acute alternative in action</i> Chairperson: Bridget Hamilton	
10:30am	Morning Tea	
11:00am	SESSION A <i>Small lecture theatre, Level D</i> Chairperson: Pete Ellis Einar Björnsson Title: <i>Power differentials in the coproduction of research: A tangata motuhake perspective</i> Julia Bocking and Brenda Happell Title: <i>Co-production in action: Experts by Experiences and Mental Health Nurses working together, sharing a vision</i> Lisa Archibald, Suzy Stevens, & Steven Morgan Title: <i>Intentional Peer Support - A framework for social change</i> Andrea Bates, Giles Newton-Howes, & Sarah O'Connor Title: <i>Researching if Interventions Work: Using all our knowledge and skills</i>	SESSION B <i>C02/C05, Level C</i> Chairperson: Brett Scholz Anne Scott, Don Quick and Kelly Pope Title: <i>Understandings of 'Recovery' amongst child protection socialworkers</i> Rachel Tester Title: <i>Service user narratives as a tool for raising consciousness on addiction recovery</i> David Burnside Title: <i>'Recovery Contagions'</i>
1:00pm	Lunch	
1:45pm	KEY-NOTE Dr Miriam Larsen-Barr , Waitemata DHB, New Zealand Title: <i>Beyond the Consultant Position: Service-User Led Research</i> Venue: <i>Small lecture theatre, Level D</i> Chairperson: Julia Bocking	

2:45pm

SESSION A

Small lecture theatre, Level D

Chairperson: Brenda Happell

Brett Scholz

Title: Improving understandings of how allies can support service users' work in mental health

Jackie Liggins

Title: Breaking the Silence

SESSION B

C02/C05, Level C

Chairperson: Brian McKenna

Chris Hocken

Title: 'One Team Network'

Jonathan Beazer

Title: Dangerous Gifts? Spiritual experiences and subjectivity in people diagnosed with "bipolar disorder".

3:45pm

Afternoon Tea

4:15pm

PLENARY SESSION

Sarah Gordon & Brenda Happell

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

Chairperson: Pete Ellis

4:45pm

Sarah Gordon Award recipient announced and farewells

5:00pm

Close of symposium

ABSTRACTS

DAY 1, 10AM, Small lecture theatre, Level D

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.

DAY 1, 11.30AM, Session A, Small lecture theatre, Level D

Karen Wells

Title: *A shock to the system: service-user lead research using lived experience knowledge to inform ECT practices*

Authors: Karen Wells and Nicola Hancock

Affiliation: University of Sydney (Student)

Abstract : ECT is a topic of great controversy and consumer voices continue to be predominantly excluded from ECT focused research. This presentation will report on two innovative, consumer-led research projects focus on ECT.

The “ECT Let’s talk about it!!” project was led by people with a lived experience of ECT (electro-convulsive therapy) and involved collaboration with a number of mental health services. Consumers directed all aspects of the project: from funding application, project management and data collection through to data analysis. By interviewing 17 people about their experiences of ECT, we identified what consumers needed prior to and during any ECT experience. We also identified an almost non-existent body of knowledge around living life after ECT; the ways people are impacted and the ways they successfully manage in their daily lives. This is being addressed in my Masters research: What is the lived experience of people who have had or continue to have ECT as they participate in daily life? How do people perceive and adapt to the consequences of ECT for their daily lives?.

Rich narratives of consumers in both studies will hopefully result in better practice, greater support and lived-experience informed recommendations for living life post ECT.

Flick Grey**Title:** *Service users, lived experience and Madness Studies: troubling positionality***Affiliation:** University of Melbourne

Abstract: It is an exciting – and troubling – time to be working as a service user/lived experience/consumer-perspective/mad-identified academic. On the one hand, there are an increasing number of opportunities for us to work in research, policy, consulting, education and training (etc) roles. On the other hand, the disciplinary basis from which we speak is unsettled and unsettling. What does it mean to be positioned “as a service user” if we have not “used” services, but rather have found other ways to navigate our experiences, or have been repeatedly excluded from services when desperately seeking support, or have experienced coercive, involuntary treatment? How does the term “lived experience” serve us when it is increasingly being used to blur the (considerable) differences in positionality between consumers and carers? What is “consumer-perspective” if we position ourselves not as “consumers” but as mad folk/mentally diverse/spiritually emergent/trauma survivors/voice hearers/eating distressed/(etc)? What might Madness Studies have to offer? These questions are both philosophical and material, with “lived experience” jobs often being constructed in ways that either include people with no direct, personal experiences, or require additional credentials (such as clinical training). (How) can we construct a coherent discipline?

Daniel Pintado**Title:** *Saying versus Doing: Bridging the gap between Values, Practice and Policy for Consumer Consultants in Mental Health***Affiliation:** University of Melbourne

Abstract: In Australia, there is a trend for mental health services to employ service users as Consumer Consultants to help inform their overarching strategies, policies, and practices. This trend is affirmed by the National Mental Health Standards, which guide organisations to use consumers’ “lived experiences” to contribute to planning, delivery, and evaluation of services. Consistent with these standards, many mental health services purport to be recovery-oriented and trauma-informed in their values and priorities. However Consumer Consultants, many of which identify with experiences of trauma (often understood as their ‘lived experience’), may become aware of incongruity between what an organisation claims to do and what it actually does. For instance, services may say they uphold a recovery-oriented philosophy that does not match actual policies/practices. This inconsistency can be ‘crazy-making’ for the Consumer Consultant, and may lead to re-traumatization, which can be devastating for personal recovery. The cost for the organisation is also high; with reduced productivity, use of sick leave, and potential for higher turnover of service-user staff. This presentation explores how trauma-informed policy, process and adequate supervision can mitigate the negative effects that the discrepancy between an organisation’s stated values and their actual practices can have on a Consumer Consultant.

DAY 1, 11.30AM, Session B, C02/C05, Level C**Steven Davey****Title:** *Building bridges by 're-anchoring': new avenues for the way mental distress is understood by the public***Affiliation:** University of Otago, Wellington

Abstract: The psychosocial history of mental illness is for many societies defined by notions of negative spiritual possession and the need for social exile, including physically to the asylum. This drive to physically exclude is arguably still present in contemporary psychiatric contexts. Social exile is, however, broader than physical exile: the relatively recent concept of social exclusion is illuminating, incorporating

subtler forms of 'exile' (e.g. inhibited access to work opportunities or social networks, or yet subtler forms of exclusion within the workplace). Despite progress in how the phenomena underlying expressions such as "mental illness" are understood, the dominant perceptions remain decidedly negative and continue to drive social exclusion. The current paper draws on a study undertaken for the Health Promotion Agency, and on the work of social psychologist Serge Moscovici to suggest the need to develop a new "anchor" point for how mental distress is understood within society if the pervasive negativity of "mental illness" is to be addressed and the social exclusion that arises from it. A further suggestion is that Aotearoa/New Zealand is a special social context in this respect, given its bicultural status: European and Maori perspectives on mental distress are distinct yet co-exist within onenation.

Sue Anderson

Title: *Co-designing Care - Stories from a shared 18-year therapeutic journey*

Authors: Sue Anderson and Ruth Dunn

Abstract: Sue and Ruth have together traversed a 18 year therapeutic relationship, due to end soon on Ruth's retirement. Since the very beginning, when Sue brought herself to Ruth's office after experiencing 15 years of undiagnosed bipolar, they have actively co-designed their relationship, blurring some counsellor-client boundaries while establishing others.

Sue has presented numerous challenges to Ruth. Possessing a voracious intellect, Sue is not one to passively accept that which she is told. In turn, such 'push back' and querying has informed and shaped Ruth's provision of care. Their relationship has encompassed –

- Sue's forced admission to hospital and bipolar diagnosis;
- the death of her prescription drug-addicted mother and care for her bipolar father;
- Sue's readmission to a psych ward on experiencing a hormonal surge post childbirth, separating her for a period from her first-born child; and
- child rearing and relationship challenges with families, friends and colleagues.

Ruth has had to set boundaries for Sue, and Sue has taken Ruth to task. But importantly too, for nearly 2 decades now, they have shared their love of natural beauty and laughed hard at many of life's absurdities. For they understand that without laughter, we might all indeed go mad. Their shared knowledge and insight of their relationship is now the legacy Sue and Ruth wish to leave to benefit others within the mental health sector. Here, they tell their tale. The proposed paper is a performance of two voices where Sue (a service user,) and Ruth (a counsellor) tell their tale and use their lived experience to critically reflect on what they have learned about co-design of mental health care during their journey together. Sue will perform her narrative live and Ruth's story will be projected on screen.

Mike Sukolski

Title: *My Madness, And Why I Can't Tell You About It.*

Affiliation: Hutt Valley DHB

Abstract: *Madness. Mental Illness.* These terms have become almost interchangeable; as if they were two perspectives on, two aspects of, two positions from which to look at, come to understand and talk about, one substantive thing, a definitive understanding of which may turn out to be a matter of personal preference. It may suit us ideologically that we can ultimately be defined by how we see ourselves. Madness and mental illness would then be distinguished only by our own view of the matter, our personal take, there no longer being any actual substantial difference between them; between, that is, experiencing madness and experiencing a mental illness. Nor in how we should construct our responses to them. But is this really what we want to mean? What do we lose, if anything, when we reduce categories of

human experience to a bare minimum, casting aside as irrelevant its subtlest distinctions? Does it matter? Is this question important? Can we not just get on with the job and research paths to wellness, to worthwhile lives, without becoming entangled in yet more mystery and obfuscation? Can we not, do we not, should we not, leave it to other people to define their own experience?

DAY 1, 1.45PM, World café – presentation session, Small lecture theatre, Level D

Dasha Fedchuk

Title: *Addressing minorities: Self-injury in LGBTQ service users*

Affiliation: Massey University

Abstract: Recently the Ministry of Health published a draft suicide prevention strategy, detailing that specific groups need to be targeted. LGBTQ (lesbian, gay, bisexual, transgender and queer) individuals and service users who engage in self-injury were amongst those.

Non-suicidal self-injury (NSSI) is the purposeful destruction of one's own body tissue performed in absence of suicidal intent or social custom. Research suggests that NSSI is a risk factor for suicidal ideation and attempts. LGBTQ individuals are at a higher risk for experiencing mental distress and NSSI. The Youth'12: The Health and Wellbeing of Secondary School Students in New Zealand survey found that LGBTQ adolescents were about 41% more likely to experience depressive symptoms, had significantly higher NSSI rates (46% transgender, 59% LGB vs 23% non-trans and non-LGB) and five times more likely to attempt suicide than their heterosexual, cisgender counterparts.

This research addresses how LGBTQ service users who engaged in NSSI make sense of their experience. Six individuals interviewed share their perspectives on the discrimination they received as consumers, stigma attached to self-injury and underlying concerns in their experience as LGBTQ people receiving treatment for NSSI. Implications for future directions based on the result of this research will be discussed.

Gabrielle Jenkin

Title: *Designer mental health facilities: What do service users want from the design of the adult inpatient facility?*

Authors: Gabrielle Jenkin, Susanna Every-Palmer

Affiliation: University of Otago Wellington

Abstract: The acute mental health ward is the modern equivalent of the old mental asylum but what and who informs its design? Drawing on a Marsden funded research project to look at acute psychiatric facility design in NZ, service user activists and artists, and ideas from state of the art mental health inpatient units, this world café will ask participants to think about and imagine an ideal adult inpatient facility. We will brainstorm with you to see what a service user model of design might look and function like. Participant responses will be incorporated into a service user inspired vision of a transformative contemporary New Zealand mental health facility.

Katie Rickson

Title: *Lullabies in a time of psychosis*

Abstract: I am a writer. I usually find a safe haven amongst language. But last year I had a psychotic experience, as a result of having a postpartum bipolar episode. Then language became a threat to me. There was too much of it as thoughts collapsed on thoughts. And yet, when it came to explaining myself to others, there was not enough. I found myself fixating on words and feeling like lyrics on the radio were speaking directly to me. And when reading a psychiatric report, I missed whole sentences. During this time though, I received solace and grounding from listening to world lullabies in languages I didn't understand, or from songs without words. Taking a personal perspective, I want to discuss the implications of this from a therapy perspective - what does it mean to not be able to articulate or make sense of your experience using traditional means, and what potential do the arts hold as an expressive medium to aid in the management of and recovery from psychotic experience?

Kevin Harper and Amanda Luckman

Title: *Consumer conversations to influence a people powered mental health system and service development*

Affiliation: Ministry of Health

Abstract: 'He who begins a conversation, does not foresee the end' - Mauritania proverb.

I like to think that ongoing, open and visionary conversation will build trust, understanding and unity and help facilitate change that all people who want better mental health and addiction outcomes can contribute to.

I believe that we need a national consumer conversation to understand what it means and what is needed to build a people powered mental health system and services. Participants would listen to the experience and knowledge of others, create new connections and be open about how these impact on their own thinking and action. To be most effective, this must be an ongoing conversation, one that is allowed to build its own momentum as well as support others to develop their contribution.

Through the World Café format, I seek feedback from Symposium attendees about whether there is support for my belief in a consumer conversation and the assumptions I cannot afford to make and the things I must consider; how to facilitate the conversation or build on those already happening; and what is needed to build the conversation?

Ngā Hau e Whā

Title: *'Nothing about us without us'*

Presenters: Victoria Roberts, Kieran Moorhead, Jak Wild, Julie Whitla, Guy Baker, Tui Taurua-Peihopa

Affiliations: Changing Minds, MHAPS, Otago MH Support Trust, Tekupenga Net Trust

Abstract: Ngā Hau e Whā (NHEW) is the national voice of people with lived experience of psychosocial disability/mental distress. Currently NHEW operates as an advisory group to the Ministry of Health and is made up of individuals from across Aotearoa who raise with the Ministry issues, concerns or positive initiatives identified by people with lived experience in their respective regions. NHEW has a good track record of working strongly with the Ministry of Health to ensure that the voices of people are represented in important pieces of work for example: The Suicide Mortality Review Committee, The Mental Health Act and Human Rights discussion document, Fit for the Future, The Commissioning and Outcomes Frameworks. This world café session is a chance for us at NHEW to listen and hear people's experiences of mental health in New Zealand as well as to give input into how NHEW can improve the

way it undertakes national advocacy for people with lived experience. Ngā Hau e Whā wants to grow its influence and capacity in the future and continue its vision to champion many voices and “Nothing about us without us”.

Denise Omar

Title: *DRIVING Consumer Voices*

Affiliation: Connect Supporting Recovery Inc

Abstract: DRIVE is an amalgamation of Mental Health and Addictions Service User Networks under the DRIVE brand. DRIVE, an acronym for Development, Recovery, Information, Voice, Education, offers to members, whanau and community, the opportunity to increase capacity and skills building, to build resilience to access services, and to get help to gain knowledge of what services are available. There is great social engagement amongst members because of the inclusive way that DRIVE works running hui, sending out newsletters, having a strong Social Media presence, strong networking capabilities, drop-in arrangements and onsite training provision. DRIVE makes a fresh contribution by network members attaining positions of leadership in the sector which has made a difference to how services are developed and ultimately accessed by service users. DRIVE adopts an holistic approach where members can get training, attend sector events, get fit, find a hobby, learn new work skills, engage in a process of change through which to improve our health and wellness, learn a skill to strive to live a self-directed life and achieve our full potential. DRIVE is overseen by a steering group and supports two coordinators which is a collaboration of providers and network members with lived experience.

DAY 1, 3.45PM, Session A, Small lecture theatre, Level D

Joanne Taylor

Title: *Evaluating the teaching of mental health recovery concepts in clinical psychology training*

Authors: Joanne E. Taylor and Sarah E. Gordon

Affiliations: School of Psychology, Massey University; Department of Psychological Medicine, University of Otago.

Abstract: Mental health service user perspectives are a critical part of training people to work in the various disciplines involved in providing mental health services. For example, nursing, social work, and psychiatry disciplines are increasingly engaging service users to develop, implement, and evaluate service user-led and recovery-focused teaching into their training programmes. However, the teaching of psychology has not typically included service users in this capacity, which is especially problematic when the teaching involves professional training, such as in clinical psychology. It is crucial that students who are training to become clinical psychologists are exposed to service users' views of their experiences as well as the principles and practice of recovery. This paper briefly describes the initiatives taken in the clinical psychology training programme at Massey University since 2015 to start to address this need, and presents preliminary results from an ongoing evaluation of the outcomes of a service user-led and recovery-focused tutorial on students' attitudes about mental illness.

Lisa Malihi-Shoja and Heather List

Title: *Service users and carers in the classroom – right where they ought to be*

Institutional affiliation: University of Central Lancashire (UCLan)

Abstract: The presentation will overview the work of Comensus and the range of involvement we support. Emphasis will be on the development of co-produced materials and teaching activities. We will look at the intricacies of engaging and supporting people with mental health issues, exploring how we have overcome barriers in engaging those with seldom-heard voices.

We will look at how we have continued to champion user engagement across a number of years responding to the many political changes within a HEI arena. The session will overview service user and carer designed sessions around mental health and explore a dedicated user led mental health film festival, which continues to challenge myths of mental health through film. We will draw upon key ways in which students learn from the personal nature of service user and carer experiences and how this allows students to reflect upon their own values, beliefs and practice. We will also demonstrate how building authentic connections with service users contributes to the development of health and social care professionals. The pure nature of this work produces strong connected communities who engage with the wider university on a number of initiatives resulting in shared benefits for the University and the community.

Katie Owen

Title: *Using narrative and the lived experience to address stigma and discrimination in the classroom*

Authors: Katie Owen, Vicky Jennings and Leanne Pool

Affiliation: Whitireia NZ

Abstract: Stigma and discrimination related to mental illness is known to contribute significantly to poor health outcomes. With almost 50% of New Zealanders experiencing mental ill health at some point in their lifetime, negative attitudes that contribute to stigma and discrimination in both general medical and mental health settings needs to be addressed. The role of consumers and their stories are central to challenging the assumption and construction of mental illness and supporting and embedding attitudinal change.

This presentation will explore the integration of narrative pedagogy into mental health nursing curricula in the BN Programme at Whitireia NZ, creating a platform for sharing various perspectives including the lived experience of distress. The authors will present examples of narrative and its usefulness in nursing education to address stigma and discrimination by undergraduate nurses will be explored. A variety of modalities including storytelling, structured dialogue, film and print narratives, simulated experiences and reflective journaling will be discussed.

Through narratives, students are developing the skills, values and attitudes to respond to the contemporary needs of service users and to address stigma towards people experiencing mental distress. Participants will gain an understanding of these different narrative approaches and their impact on reducing stigma in the classroom.

Tracey Cannon, Susan Hatters Friedman and Sigourney Taylor

Title: *Satisfaction Guaranteed? A forensic service user perspective*

Affiliation: Waitemata DHB

Abstract:

Background: Despite the significant numbers of people in forensic psychiatric hospitals worldwide there is limited research on consumers' views of the care they receive.

Methods: We describe consumer satisfaction and areas for improvement by quantitatively and qualitatively analysing 541 satisfaction surveys collected over eleven years within the forensic hospital.

Results: The majority of forensic patients believed that their views were valued in their care and treatment. Most felt physically and emotionally safe at the hospital, and believed that staff knew how to support them in times of distress. The majority felt that their culture and spirituality were respected. However, some areas for improvement were also noted, such as regarding staff attitudes.

Discussion: This consumer survey demonstrated a reasonably high level of satisfaction with forensic care, over the course of eleven years, despite this population of people being subject to lengthy

hospitalisations. Within the quantitative data, statistically significant differences between the acute and rehabilitation units were found in areas of involvement in care, respect for spiritual beliefs, feeling comfortable about making complaints and feeling staff help with recovery. Qualitative themes were strongly focused on the significance of relationships.

The Consumer advisors have been able to use both quantitative and qualitative data from the surveys to highlight patient concerns, draw attention to consistent areas of satisfaction and dissatisfaction, and propose changes. Utilising satisfaction surveys with forensic patients can be a regular and useful part of forensic care, and can help guide improvements in this care.

DAY 1, 3.45PM, Session B, C02/C05, Level C

Johnnie Potiki

Title: *Pilot study to evaluate implementation and outcomes of advance directives in mental health services*

Authors: Paul Glue, Anthony O'Brien, Katey Thom, Heather Casey, Johnnie Potiki

Affiliation: Southern DHB

Abstract: Advance directives have been proposed as a means of increasing the autonomy of service users concerning decisions about their care, especially in crisis situations where they may be too unwell or distressed to communicate their choices (Health and Disability Commissioner and Mental Health Commission). In light of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), recent literature considers ADs an important instrument for realising human rights. For ADs to be successful, they need to be well-accepted by clinicians and service users. A recent national survey (Thom et al. 2015) indicated strong support among clinicians and service users for ADs. Most service users (n=100, 93%) and clinicians (n=160, 93%) agreed that they supported advance directives in mental health. The majority of service users (n=81, 87%) and clinicians (79%, n=135) reported they would personally participate in an advance directive initiative should it be developed, and 80% (n=132) of clinicians suggested their service would be interested in such an initiative. The current paper will present on the progress of an initiative, supported by Southern DHB, studying the development and implementation of ADs and informing the process of national implementation with research findings.

Maria Stubbe

Title: *Diabetes patients' experiences of communication with health providers – empowerment, agency and mental wellbeing*

Authors: Maria Stubbe, Lindsay Macdonald, Rachel Tester and Tony Dowell

Affiliation: University of Otago Wellington

Abstract: This paper explores how a diverse group of New Zealanders living with diabetes describe their communication with health professionals along the journey from the point of diagnosis to becoming 'self-managing' service users. A diagnosis of diabetes can be a life-changing event with far-reaching emotional and psychological consequences. The people we talked to often mentioned experiencing high levels of stress around the time of diagnosis, along with negative feelings like guilt or shame or feeling overwhelmed. Some also reported ongoing issues with anxiety and depression. They often had remarkably clear memories of what was said and how they felt when they received the diagnosis, and reflected freely on the nature of their health consultations, and the extent to which they felt clinicians did or didn't understand and take account of their lived reality. Experiences of communication with health providers varied, and there were shifts in perspective over time as people adjusted to their changed lifestyles. However, some clear 'messages' for health professionals emerged, including the importance of fostering resilience and mental wellbeing by being non-judgmental, respecting patients' right and ability to make their own informed choices, and acknowledging their individual preferences and the social and cultural contexts of their lives.

Shannon Calvert

Title: *Compassion, Dignity and Respect: How Values Supporting Treatment Interventions Can Promote Recovery*

Abstract:

Methods: Focusing on key aims with opportunity to upskill clinicians to expand their capabilities treating patients in mental health units. Adopting a narrative approach of personal experience.

Aims to demonstrate:

- Where interventions can be supportive vs. detrimental in treatment.
- Where practices are deemed necessary, application must be in context of supportive intervention, not as coercive or threatening forms of treatment.
- The importance of treatment teams being aware of empathy, compassion and open, honest communication with the individual.
- The importance of providing the individual with explanation about the need for intervention.

Content: I will discuss aspects of my treatment history (severe enduring anorexia nervosa) in a public mental health unit which involved many interventions. Practices were effective when treated with respect, however detrimental to my mental health when used coercively. This included denying communication, applying punishment if non-compliant, and requiring me to earn privileges. These practices can contradict hope for recovery, self-worth and self-respect placing stigma on diagnosis. How treatment is approached can add to pre-existing trauma, hindering one's physical and mental recovery.

Conclusions: Intervention is crucial and sometimes necessary in treatment. When necessary, so is equal importance of compassion and dignity towards the individual. That equal balance saved my life.

Giles Newton-Howes and Sarah Gordon

Title: *When at an impasse with co-production: Press on for consensus or proceed with divergent views?*

Authors: Newton-Howes G; Gordon S; Beverley G

Affiliation: University of Otago Wellington

Abstract:

Background: Development and implementation of a recovery program as part of the teaching of psychological medicine to medical students is not common despite the support of recovery by services being the expectation of mental health policy in many western countries internationally. The progressive development and implementation of a recovery teaching and learning program has been occurring at University of Otago Wellington now for a number of years. **Aim:** To co-productively examine the themes represented by final year medical students as part of the learning process and assess them against a recovery framework. **Method:** The routine assessments of medical students engaged in this learning process were examined from student, clinical and service user perspectives using an iterative grounded theory informed qualitative approach. **Results:** Six major themes emerged from the recovery reflections from final year medical students: 1) recovery as a person-centered approach, 2) the need for social integration, 3) non-diagnostic framing of mental illness, 4) tensions between the medical model and personal recovery, 5) a patient's willingness to engage with mental health services and 6) the development of a positive sense of self. However the co-producers had different perspectives as to what each of the themes actually entailed and signified and the co-production process involved some tension in working to reconcile those different perspectives, and ultimately, an impasse where it was questioned – should we press on for consensus or proceed with divergent views? **Conclusion:** An intensive collaborative and communicative process resulted in consensus of results and conclusion. This paper will present perspectives on the process from clinical and service user perspectives, highlight the crux of the tensions and impasse, our thinking in deciding to pursue consensus over divergent views, the implications for each of us of pursuing consensus and ultimately, the conclusion of the fully co-produced research.

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.

Sheree Veysey

Title: *Conversations for Change: Creating a Like Minds, Like Mine resource for community use*

Affiliation: Mind and Body Consultants, New Zealand

Abstract: 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.

Karyn Munday

Title: *Piri Pono - peer led acute alternative in action*

Affiliation: Connect Supporting Recovery, New Zealand

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.

DAY 2, 11AM, Session A, Small lecture theatre, Level D

Einar Björnsson

Title: *Power differentials in the coproduction of research: A tangata motuhake perspective*

Affiliation: Icelandic Mental Health Alliance/COMMUNE project

Abstract: The Coproduction of Mental Health Nursing Education (COMMUNE) project is an innovative collaboration between nursing academics and service users. It aims to create a unique module of the nursing curricula which explores the service user perspective of mental distress. The team was formed from universities based in six European countries, and Australia. I want to talk about my expectations when asked to join the COMMUNE project, and the reality that I faced when we began working together. The background of participants and the structure of the work environment created a power differential, and placed service users in a different position than the academics. How can power imbalances be mitigated? Is it just the reality that we have to live in or can something be done? Can we really co produce research?

Julia Bocking and Brenda Happell (on behalf of the COMMUNE project)

Title: *Co-production in action: Experts by Experiences and Mental Health Nurses working together, sharing a vision*

Affiliation: SYNERGY: Nursing and Midwifery Research Centre, University of Canberra and ACT Health

Abstract: Mental health policy in Australia has called for increased involvement of consumers in all aspects of mental health service delivery and design to promote recovery oriented practice. Attitudes of health professionals have been a major barrier to achieving this goal. Involving consumers in teaching health professionals has shown positive effects however the research is limited, and the involvement of consumers is often related to classroom teaching only. The aim of this presentation is to provide an overview of process and findings to date of COMMUNE, an innovative research project between five European universities and SYNERGY. It will include an overview of findings from focus groups with service users regarding "what makes an excellent mental health nurse?". A co-produced consensus process was subsequently undertaken by the broader team to develop the consumer taught curriculum which will be briefly discussed. The next stage of the project involves a qualitative and quantitative evaluation of the co-produced manual. It is intended this work will contribute to the evidence base supporting experts by experience as genuine partners in mental health nursing education.

Lisa Archibald, Suzy Stevens, & Steven Morgan

Title: *Intentional Peer Support - A framework for social change*

Abstract: We will offer answers to the question: *What is Peer Support anyway?* and introduce the three principles of Intentional Peer Support : Learning versus Helping, Relationship versus the Individual, Hope and Possibility versus Fear.

In this way participants will be able to realise how Intentional Peer Support can provide a framework for social change as we describe ways of being which foster connecting & reconnecting with each other, our cultures and communities. By putting energy into mutual learning relationships and applying critical thinking we can look at how we've come to make sense of the world.

Intentional Peer Support moves us away from reliance on psychiatry and the medical model towards re-defining what kind of help we may require and the kinds of services we want to use. It can assist in us together figuring out how to make things work for us so we can take up the challenge to move towards living the life we want.

In short, Intentional Peer Support can change the world!

Andrea Bates, Giles Newton-Howes, & Sarah O'Connor

Title: Researching if Interventions Work: Using all our knowledge and skills

Affiliation: Wellbeing Wellington (Bates and O'Connor); University of Otago Wellington (Newton-Howes)

Abstract: People who use mental health services by and large know, or come to know, what it is that they want and need from any service they may access, or be made to access. A lot of the interventions people say they would like to use are not available through publicly funded mental health services. This is largely due to a lack of research validating their efficacy and scalability. One way to address these gaps is to undertake research into the kinds of interventions people say they would like, and see if the outcomes meet the needs of service users and servicefunders.

Wellbeing Wellington approached Giles and William with an intervention idea, that had been researched in a limited fashion overseas, and asked if this was work that we could do together. Giles and William exercised their expertise and concluded it was worth pursuing academically. Sarah and I asked around our communities if people thought it was an idea worth pursuing, and interest was sizeable and positive.

Even in the proposal process we have all learnt a great deal about each other's perspectives and approaches. Whatever we produce will be a meeting of people and minds, and a creation of value for our wider communities.

DAY 2, 11AM, Session B, C02/C05, Level C

Anne Scott, Don Quick and Kelly Pope

Title: *Understandings of 'Recovery' amongst child protection social workers*

Institutional affiliations: University of Canterbury (Scott and Quick); Awareness (Pope and Scott)

Abstract: How do people working in the field of child protection understand "mental illness"? The concept of "recovery" has both a clinical discourse of meaning, and a discourse that arises out of the consumers/survivors movement; which of these two discourses are deployed by child protection workers? In this talk, we will draw on the narratives of 12-14 parents who are involved with child protection services, and we will also draw on "recovery" writings emerging out of the consumers/survivors movement, to provide positive templates for ways that "recovery" can be imagined.

We will use these to investigate the way "recovery" is used by care and protection social workers.

Rachel Tester

Title: *Service user narratives as a tool for raising consciousness on addiction recovery*

Affiliation: University of Otago Wellington

Abstract: The concept of addiction and how one might recover from it cannot be fully understood without examination of another closely related concept: consciousness. This includes an individual's ability to hold consciousness under adverse conditions and service providers' ability to hear their clients' stories, to hold consciousness of what is required for their recovery and to advocate for that support. These tasks are difficult given that the ordinary response to atrocities is to banish them from consciousness, which allows denial, repression and dissociation to occur at the societal as well as individual level.

This presentation reflects on the narratives from 21 in-depth interviews with service users and 11 interviews with key healthcare service provider stakeholders (including some with lived experience). An interpretative qualitative framework was used to conduct a secondary analysis on data collected over the course of three independent projects. A common theme identified was the description of a recovery process that closely resembles the three stage process of recovery from psychological trauma (establishment of safety; reconstruction of the trauma narrative; and with the narrative fully integrated). This analysis suggests that service user narratives may be a useful tool for raising consciousness both individually and collectively.

David Burnside

Title: *'Recovery Contagions'*

Affiliation: Odyssey House

Abstract: The value of peers and consumer advocates working in the community is invaluable. There are many working in both paid and unpaid roles within organizations. They are bringing about change in how communities work together. The AODTC (Drug Court) has several groups who provide effective engagement with the community. Some of these are aligned to iwi, church and recovery groups and are run by people who understand the importance of connection, and building bridges between people. The foundation of these groups are the "Champions of recovery" who role model, signpost and lead by example. These champions come from many diverse backgrounds, and how they transmit their recovery message can vary, but they all have in common the belief that life is precious and there is an inherent desire in all of us to connect, to support, to grow and to live life to best of our abilities.

During this presentation I will explore, within the context of current knowledge, the 'Champions of Recovery/ Recovery Contagions', and the opportunities for further research in this area to strengthen their use within addiction recovery service delivery.

DAY 2, 1.45pm, Small lecture theatre, Level D

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.

DAY 2, 2.45pm, Session A, Small lecture theatre, Level D

Brett Scholz

Title: *Improving understandings of how allies can support service users' work in mental health*

Authors: Brett Scholz, Piyada Juntanamalaga, Julia Bocking, Brenda Happell

Affiliation: University of Canberra and ACT Health

Abstract

Background: Little research has been conducted about allies to the service user movement. This study conceptualises allies as individuals are not service users but who use their power to influence organisations and advocate for improved recognition of the value of service users' work in mental health academia, policy, and practice. The aim of this study is to explore how allies' contributions to the service user movement are understood by service users and allies.

Method: Interviews were conducted with service users working across the mental health sector, and with people identified as allies. Data were analysed using discursive psychological principles that enable deep exploration of issues related to power.

Results: The work of allies was discussed in three main ways. First, allies can be seen as a valuable support for breaking through the sanist-normativity of the mental health sector. Second, there were problematic constructions of allies' part in the service user movement as 'rescuers'. Last, participants identified ways in which allies could improve their allyship.

Discussion: Allies represent a powerful tool for the service user movement. Reframing their work as 'supporting' rather than 'rescuing' should be promoted to challenge stigma and improve understandings about the roles allies can play.

Jackie Liggins

Title: *Breaking the Silence*

Affiliation: Psychological Medicine, Counties Manukau Health

Abstract: Mental health services have increasingly recognized the contribution that people with lived experience of mental illness can make to service provision and development; the professional body for psychiatrists in New Zealand and Australia (RANZCP) has had consumer/carer participation on its organizational committees for a number of years. Antithetically, for most mental health professionals, with respect to their own experiences of illness, "silence remains the order of the day" (Hinshaw, 2008, p.5), this silence being largely attributed to associated stigma. This silence has been questioned by consumer/users who contribute to College activities. In late 2016 the College adopted the position statement: 'The Contribution to Practice made by Psychiatrists who have a Personal Experience of Mental Illness'. This position statement acknowledged 'the contribution that can be made... and provide(s) a basis for further examination and study'.

There is very limited research and published literature considering the positive aspects of the experience of illness for psychiatrists and their work, the main focus being managing impairment. This paper will reflect on what it means to be a psychiatrist with lived experience of mental illness, and explore possibilities for a future research agenda.

References

Hinshaw, S. P. (Ed.) (2008). *Breaking the silence: mental health professionals disclose their personal and family experiences of mental illness*. New York, NY: Oxford University Press.

RANZCP, 2016: *The contribution to practice made by psychiatrists who have a personal experience of mental illness*. https://www.ranzcp.org/Files/Resources/College_Statements/Position_Statements/PS-85-The-contribution-to-practice-of-psychiatrist.aspx

DAY 2, 2.45pm, Session B, CO2/C05, Level C

Chris Hocken

Title: *'One Team Network'*

Affiliation: MidCentral Health

Abstract: Mental Health and Addiction Services in MidCentral are community-based, providing treatment and care across all age ranges in all parts of the sector, including the primary sector. They are delivered by a diverse range of agencies including the public and private sectors, NGO's, and community groups.

To effectively deliver quality outcomes for service users and their families / whānau requires collaboration amongst providers and stakeholders in a number of different settings. Integration of services and establishing a continuum of care for clients and families is achieved by providers and stakeholders through communication, collaboration and efficient coordination of services.

This presentation will profile the process and outcome of a co-produced mental health and addictions service planning matrix that provides for a one team network.

Jonathan Beazer

Title: *Dangerous Gifts? Spiritual experiences and subjectivity in people diagnosed with "bipolar disorder"*.

Institutional affiliation: Sociology department, Victoria University of Wellington

Abstract: How do people living with "bipolar disorder" make sense of their religious and spiritual experiences? And how can these illuminate what it means to be a subject? Mystical experiences may be more common in the "sane" population today than previously thought, and in the "insane" population, people often have profound religious or spiritual experiences. Initial results of my doctoral research will be presented. For this research I conducted in-depth interviews with 15 people who identify as having a diagnosis of "bipolar disorder", and have spiritual experiences. My particular focus is on how they interpret these experiences, what this may tell us about mad experiences in general, and how this may shape understandings of subjectivity. Themes include their desire to speak and not be silenced; the surprising "non-weirdness" of their experiences; and their use of normalising discourses to integrate. I use work from Mad Studies, Judith Butler, Michel Foucault, Rosi Braidotti, and others to theorise a phenomenological study of unusual experiences. Perhaps the displacement and alternate states of the mad can lead us closer to understanding the social origins of sanity.

Sarah Gordon & Brenda Happell

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

Affiliations: University of Otago Wellington (Gordon) and SYNERGY: Nursing and Midwifery Research Centre, University of Canberra and ACT Health (Happell).

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 will 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.