



ACACIA's Mental Health Research Newsletter

National Institute for Mental Health Research, Research School of Population Health

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A message from the Director



It's been another busy period here at ACACIA. With Dr Banfield taking up her new DECRA Fellowship, we are pleased to welcome Bethany Jones to the academic consumer researcher position at ACACIA. Bethany, who also has lived experience as a carer is proving a wonderful asset to the unit. You can read more about Bethany – who has recently completed her PhD - in this edition of Insight.

Like most other mental health organisations in Australia, we awaited with some anticipation the release of the National Mental Health Commission's review of mental health programs and services. In addition to its important recommendations around services reform the Review addresses the issue of mental health research. In short it emphasises its importance, suggesting that funding of mental health research should be doubled over the next 5 years.

However, the Commission is not talking about business as usual. Rather the review stresses the importance of ensuring that research addresses the needs of the population and that the research

is translated into action. Pointing out that services and programs are typically not informed by evaluations and research, the Commission emphasizes the importance of forging connections between research and service systems. There are studies of stand alone clinical treatments but too often we know little about 'complex, multi-faceted programmes and services' [1] according to the review. Finally, the Commission concludes that there is no systematic method for involving consumers, carers or others in research. We are pleased to say that the recommendations align very closely with the values, mission and activities of ACACIA.

I'm not quite sure how it happened but I am the Program Convenor of this year's 2015 THEMHS conference to be held in Canberra in late August. As a result I was recently tasked with reading all the Abstracts submitted to the conference program. What an inspiring experience. I was impressed by the enthusiasm of the Australian mental health sector to share new ideas and programs. I was particularly struck by the very extensive engagement of those with lived experience in the main program and the number of papers focused on the development of Mental Health Peer Workforce programs. This coincides with the findings from ACACIA's research priorities forum last year where consumers and carers pointed to the need for research focused on the peer workforce. Keep an eye out to find out more about ACACIA's work in this area in the future. Meanwhile, please let us know if you have any ideas for particular empirical research projects in this area by contacting us at ACACIA.

Professor Kathy Griffiths,
 Director, National Institute for Mental Health Research

[1] National Mental Health Commission. (2014). Report of the National Review of Mental Health Services and Programmes. Volume 1. Sydney: NMHC, p. 117.

Meet ACACIA Advisory Group Member

Sharon Leigh-Hazell, Carer representative for Carers ACT

I left Sydney for Canberra in 1987 as a single parent of two little girls. Canberra has provided opportunities for me and my family. I was able to complete a degree and postgraduate study and have a career in the public service. My children are now grown and have careers and families of their own.

Part of the reason for the move was for family support from my sister who lived in Canberra at the time. Not to help care for my children although this came in handy! But to help support our mother who had bipolar disorder and who moved with me to Canberra. As I grew up I had become more aware of mum's illness and by the time I was a teenager I was one of her main supports. I didn't know then that I was a "carer". I've seen what works well and what doesn't. After a particularly bad episode, not long after arriving in Canberra, my mother received excellent care that enabled her to manage her mental health for over 20 years. When she was older though – now in her 70s, changes in her anti-psychotic medication and deterioration of her physical health meant that she needed more support once again. I felt the frustration of inadequate discharge planning and my inadequacy and



distress while I watched my mother become weaker and frailer. Although I had worked for many years in health policy I was at times confused and other times angry with the health system but always beholden to it. I felt the lack of control that many carers feel. This was in 2009, the year my mother died. It was around this time that I started my work as a carer representative for Carers ACT on various committees for ACT Health and also an independent mental health carers representative and volunteer for several community organisations. I have left the public service and am now a PhD student at the National Institute for Mental Health Research focussing on models of care for older people with chronic mental illness and their carers. I hope that my involvement with ACACIA will contribute to its development of partnerships with consumers and carers in mental health research as well as the research itself.

Consumer and carer research priorities: Where are we now?

In November 2013 ACACIA held its inaugural mental health consumer and carer forum. The purpose of the forum was to identify areas for research that are of particular interest to consumers and carers. The forum was held over an entire day with fantastic participation from the ACT community. There were an enormous number of ideas generated, which participants then voted on to determine their relative importance to the community.

It is the aim of ACACIA to promote or pursue research in these areas. There were an extremely large number of research topics of interest to the community, so we will only look at those which received 3 or more votes from consumers and/or carers. A table of research priorities and projects is listed on page 3.

We have a number of projects that are currently running under the auspices of ACACIA, or are being run by ACACIA staff independently. In particular, ACACIA's investigation of 'recovery' and its usefulness in an NDIS service environment will be commencing later this year. We will be seeking participants for that one! We have a couple of staff projects that are currently running. Michelle Banfield was awarded a Fellowship through the Australian Research Council to investigate service navigation and access for people with serious mental illness. Sharon Leigh-Hazell is conducting research into older people with serious mental illness and their carers as part of her PhD program. We will also be investigating attitudes to treatments, and treatment stigma through a research project run by Bethany Jones. We also have service evaluations for the Transitions to Recovery Program and Partners in Recovery Program currently running in the ACT.

Across these projects, ACACIA is investigating or planning to investigate all of the top issues for consumers and carers in the ACT by mid-2016. (see research projects table on next page)

Staff of ACACIA

Professor Kathy Griffiths, Director

Dr Michelle Banfield, Research Fellow

Dr Bethany Jones, Postdoctoral Fellow

ACACIA Advisory Board

Maureen Bell, Independent Carer

Julia Bocking, ACT Health Consumer Consultant

Dalane Drexler, ACT Mental Health Consumer Network

Sharon Leigh-Hazell, Carers ACT

David Lovegrove, ACT Mental Health Consumer Network

Mariana Oppermann, Independent Consumer

Dr Doris Kordes, Carers ACT

Mr Graham Ramsay, ACT Mental Health Policy Unit

Prof Brenda Happell, Academic Adviser

Consumer and carer research priorities: Where are we now? (...continued)

Research Topics prioritised by Consumers and Carers	
Research in progress	Project
Service pathways: first access, how do they go about it, what is the access to information, benefit of hindsight?	Michelle's DECRA
Impacts on specific age groups (young people, older people)	Sharon's PhD (older people)
Disconnection of services	Michelle's DECRA
Monitoring and evaluation: to what extent is it built into program/pre-post-during evaluation from participants	PIR evaluation TReC evaluation
2015/ 2016 Research	
Peer-led services	Systematic review for NDIS on peer services (under consideration for grant funding)
Recovery and fulfilling potential	Consumer perceptions of recovery: utility and applicability in healthcare with respect to the NDIS TReC evaluation
Alternative treatments: what are they? Holistic approaches, meditation, exercise	Study investigating consumer perspectives on medication/ treatment (included in treatment stigma project)
By health providers (mental health and others): what do they believe and how does it impact?	Treatment stigma project 2016. Treatment stigma in health providers
What changes do people make in their own lives as a result of stigma?	Treatment stigma project
How to recruit and train peer workers. What programs are going where? Where are they embedded? How are they being supported?	Systematic review for NDIS on peer services (under consideration for grant funding)
Future Research	
Peer-to-peer: what are the gaps? e.g. support groups	
To what extent do we follow human rights legislation on mental illness?	
Is care traumatising?	
Impact of NDIS – longitudinal study. Scope: who is included? How is it defined? What are the effects on consumers and carers and on service funding?	
People out of NDIS scope: what can be done to reach them?	
Trauma informed care: how is it integrated into service delivery?	
Accommodation	
Learned helplessness (experience with services)	

TheMHS Pre-Conference Consumer Forum

25th August 2015

Innovative Applications of Practice for Consumers

Every year in August The Mental Health Services (TheMHS) Learning Network holds a mental health conference in a major Australian or New Zealand city. This year is the 25th anniversary of TheMHS conferences and the conference and associated events will be held in Canberra at the National Convention Centre. The theme for this year's events is 'Translating Best Practice into Reality'.

Each year on the day before the main conference a series of forums and workshops are held to complement the events held over the conference days. The Consumer Forum is one of the concurrent events that occur on this day, this year being held on 25 August ahead of the conference on 26-28 August. The Forum is being driven by a small working group of dedicated consumers, with coordination support from ACT Mental Health Consumer Network and MI Fellowship. The following is a draft outline of what the Consumer Forum is expected to cover over the span of the day.

Facilitator: Indigo Daya – Mental Health and Trauma Speaker and Writer

10:00am Welcome (combined with Carer Forum)	Welcome to Country Recognition of consumers and carers past Do NO Harm presentation by Mental Illness Education ACT
10:30am MORNING TEA	
10:45am – Presentation	Mindfulness - A look at the theory behind mindfulness approaches and how they have successfully helped consumers in their recovery - A brief guided session (secular)
11:30am – Presentation	Differentiating between suicide and self-harm - A look at the work of 'Spectrum' - The impacts of suicide and self-harm – a consumer perspective
12:15pm – Panel	Consumer-led/focussed radio programs
1:00pm LUNCH	
2:00pm – Presentation	Dr Patrick Corrigan – Consumer and conference keynote - Structural stigma in mental health and what can be done to overcome it
2:30pm – Panel	Celebrating Diversity
3:15pm – Presentation	mindDog - The benefits of mental health service dogs
4:00pm – Panel	Innovative employment programs and supports
4:45pm Closing Remarks	Summary of the day's proceedings
5pm CLOSE	

TheMHS Pre-Conference Carer Forum 25th August 2015

Holistic approaches to health and wellbeing

This year's Carer Forum will be looking at the benefits of holistic approaches to health and wellbeing. We will hear from carers and practitioners about best practice approaches for:

- integrating mental and physical health care;
- family interventions; and
- collaborations between service providers and families in the development of mental health resources and services.

The Forum will include a guided Dialectical Behavioural Therapy (DBT) session for carers. This session will focus on mindfulness and distress tolerance strategies, both key modules of the therapy.

The Forum's program (below) has been developed by a reference group of carers and Carers ACT staff. Carers ACT will sponsor a limited number of carers to attend the Carer Forum. For more information about the sponsorships contact Doris Kordes, Mental Health Carers Policy Officer, Carers ACT, doris.kordes@carersact.org.au or by phoning 02 6296 9936.

10.00 Welcome (combined with the Consumer Forum)
10.35 Commencement of the Carer Forum
Outline, Aims and Objectives - Facilitator: Barry Telford
10.40 Defining the problem – Carer and Practitioner key note speakers
11.30 MORNING TEA
11.45 Developing solutions: integrating physical and mental health care
1.00 LUNCH
2.00 Holistic approaches: working with families
3.15 AFTERNOON TEA
3.30 Carer Wellbeing Session
4.30 Launch of Carers ACT Position Statement: Working with Families
4.50 Closing remarks
5.00 CLOSE



Demystifying Research - how is research funded?

In the last issue of Insight (December 2014) we described what scientific research is by discussing the stages of the research process. These include the type of methods we use for collecting and analysing data, and how to share the findings. This issue, we'll take a look at how scientific research is funded, and where the money comes from.

There are a lot of different ways that research is funded, but it is very hard to secure money to carry out research. You might come up with a great question, and work out what methods you will use to go about finding the answers. However, you have to convince someone with the purse strings that your question is an important one worth funding.

Some of the types of funding include scholarships, fellowships and grants. Scholarships provide funding for a student to undertake a PhD, which is usually three years research on their chosen topic. When a student has passed their PhD, they are eligible to become a post-doctoral researcher. However, there are only a limited number of these research positions.

A fellowship is a type of research funding that supports a researcher's salary. Some fellowships also have a small amount of money available to cover project costs. For example, Dr Michelle Banfield's DECRA fellowship provides her salary and some project funds for the next three years.

Grants are usually a lump sum of money that is awarded to researchers to fund the costs of carrying out a research project. The money covers costs such as research assistants, payment for reference groups and participants and project materials.

In Australia, research funding is very competitive as there is a limited amount of money dedicated to the area. What money there is needs to be spread across many fields. As a result, funding is usually short term and at the end of one project, you need to show how successful

your research was to be able to receive more funding to continue research in this area, or to carry out new research. There are never any guarantees, even for the best researchers and the most relevant projects for improving health.

Given this environment, ACACIA is very grateful for the support that ACT Health Directorate provides in funding our consumer and carer mental health research unit. This funding is a little different to the types already mentioned, as it is not tied to specific projects. Rather, the money employs staff who can work with consumers and carers to find the answers to the questions you identify and prioritise for research. Thank you ACT Health.

We would love to hear from you if you have questions about research. Just send your questions to acacia@anu.edu.au and we will do our best to answer in a future issue of Insight.



Meet Bethany Jones



Bethany Jones is an early career researcher in population health. She holds an honours degree in psychology and undertook her PhD part-time as a primary carer for young children. Her thesis was submitted in January 2015. She works as a Postdoctoral Fellow with the National Institute for Mental Health Research. She is also studying statistics for health research through the University of Sydney.

Bethany has worked in a range of mental health settings. She has worked in community mental health with a disability employment service. She has also worked with a private mental health service provider and in an inpatient eating disorders unit. Additionally, she has worked with a number of research organisations, including beyondblue: the national depression initiative, the Brain and Mind Research Institute, The University of Sydney and the University of New South Wales.

She has lived experience of depression and is primary support for a person with serious mental illness. Bethany's research interests include consumer and carer focused research, gender issues in mental health, mental illness prevention and e-mental health. In January this year, her work in genital satisfaction and pornography consumption was widely reported through the press. She was awarded the Korten Prize for best paper published by a NIMHR PhD student in both 2013 and 2014.

A step up for consumer-led mental health

As announced by Kathy (Director, NIMHR) in the last issue of Insight, late last year I was awarded a fellowship by the Australian Research Council (ARC).

A fellowship is a type of research funding that supports a researcher's salary. Some fellowships also have a small amount of money available to cover project costs. My fellowship provides my salary and some project funds for the next three years.

The title of my project is Finding the Path: Service access and navigation for serious mental illness. The purpose of the research is to inform changes to our system so that people with serious mental illness can access quality services. Improved access to quality services has been a key target in Australian health policy for over 20 years.

However, we know that accessing and navigating the complex service system is still a major problem. The people who know most about the shortfalls, the consumers and service providers, are rarely involved in trying to find the solutions.

Finding the Path is a four part study as displayed (right).

To me, the most important thing about this success is that it's a step up in recognition for consumer-led and consumer-focused research. Only 14% of applications for these fellowships were successful last year. To have a project that puts consumer experiences front and centre for informing service and policy change is a big step in the right direction.

Dr Michelle Banfield
ARC DECRA Research Fellow and
academic consumer researcher

Part 1

Mental health policy: looking at what the National Mental Health Strategy has been trying to achieve for service access and navigation.

Part 2

National outcomes and mapping of workforce: a look at service system records to see what information has been collected on access and navigation. I will also be creating maps of mental health service providers. These will help to explore where people's experiences depend on availability of service providers.

Part 3

Case studies of service experiences: using a method called a "consumer journey" to look in-depth at the experiences of people with schizophrenia or bipolar disorder. The main part of the journey will involve interviews with consumers, carers and service providers several times over the course of six months. The journeys will also include questionnaires on service quality and mapping the consumer's contacts with the system.

Part 4

Informing system change: mental health consumers, carers and service providers actively involved in developing final recommendations for policy to ensure system change reflects their knowledge.



Get involved

Would you like to get involved in ACACIA's research?

Why should I participate?

ACACIA values the perspectives of consumers and carers. We are committed to identifying and researching the issues that affect you. By participating in ACACIA's activities you can contribute to research that is relevant and designed to improve the mental health and wellbeing of ACT consumers and carers.

Benefits

By becoming involved in ACACIA's research activities you will have opportunities to:

- > Share your ideas (eg, for research topics) in forums, surveys or discussion groups
- > Contribute to research designed to make a difference to the lives of consumers and carers
- > Learn about research
- > Meet other consumers and carers

How do I get involved?

Join ACACIA's Consumer and Carer Research Register

If you are a consumer or carer and you would like to become involved in ACACIA's research or training opportunities please fill in the form below. Please then return the form to ACACIA. There is no obligation for members of the register to become involved in ACACIA's research. However, if you put your name on the register we will let you know of opportunities as they arise.

Yes, I would like to add my details to the ACACIA register!

Name _____

Address _____

Phone _____

Email _____

I am a:

Consumer Carer Consumer & Carer

Preferred newsletter format:

Email Regular mail (hard copy)

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