



# Insight

## Message from the Head of ACACIA

It's been a while since I fronted an Insight issue with a message from the Head, but there is so much happening in ACACIA right now that we can't possibly cover it all in our short newsletter. Here's a snapshot.

After a few years of battling for the value of consumer- and carer-led research in the peer review system, we finally have some papers published. Inside you will find a summary of our Partners in Recovery evaluation, which is now published in two journal articles. We also had a paper on our co-production efforts published in June. Last issue we described the protocol paper for the peer worker-led e-mental health program. In this issue, we describe the study findings which we hope to have published by early next year. Results from the priorities project, "Whose story is it?" and "Finding the Path" are also currently under review. This is a huge effort on the part of our small team.

All of the team have new projects under way. Amelia received funding from the Excellence in Population Health Research Award scheme to evaluate the Music Engagement Program with aged care residents. You'll find an outline of her project in this issue. Alyssa is leading a project to understand consumer and carer participation in our health system. Identified as a priority in our survey last year, this ambitious project aims to understand and measure how participation is valued. My own research is focused on peer work. I received funding from the Medical Research Future Fund to undertake training as a peer worker and implement a peer-led program in various service settings. The study will look at the factors that help (or hinder) peer workers to become valued parts of the mental health system with their own unique scope of practice.

We've had a few changes of faces in our Advisory Group. There's an introduction from Jodie Fisher at Carers ACT in this issue and we have a new member representative from the ACT Mental Health Consumer Network. We are on the lookout for an independent carer rep to fill a casual vacancy until June 2019. See our website if you'd like to apply.

There is so much more to say and no more space, so I will end by saying be sure to check out our website for project summaries and links to our articles if you'd like to read them.

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This issue of *Insight* was written and produced by members of ACACIA.

Edited by Alyssa Morse



## Meet the ACACIA Advisory Group Member: Jodie Fisher

### ACACIA Staff

Dr Michelle Banfield, Head

Dr Amelia Gulliver, Research  
Fellow

Alyssa Morse, Research  
Officer

Natasha Katruss, Research  
Assistant

### ACACIA Advisory Board

Dalane Drexler, ACT Mental  
Health Consumer Network

Graham Jackson, ACTMHCN  
Consumer Representative

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Carer Representative

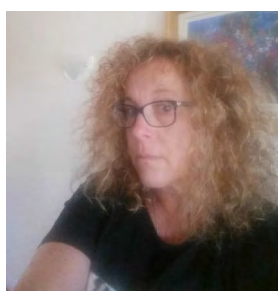
Matthew Wafer, ACT Mental  
Health Policy Unit

David Lovegrove, Invited  
Member

My name is Jodie Fisher and I am the Carers ACT Mental Health Carers Voice representative on the ACACIA Advisory Group.

The ACT and region has been my home for almost 48 years and I have never tired of the abundance of natural beauty which surrounds us here in Canberra. Lots of memories of camping and exploring the Brindabellas and of family holidays on the South Coast. Canberra is where I raised my son and where my family live. I currently live in Queanbeyan overlooking the river.

I went to school in Canberra and started professional life as an Enrolled Nurse at the then Woden Valley Hospital, at the tender age of seventeen. Nursing fuelled my passion for prevention and early intervention, leading to a career in health promotion and community development. After ten years I left nursing to commence my first degree at University of Canberra and completed a Bachelor of Applied Science in Health Education. Over ten years I went on to complete another two degrees, a Graduate Diploma in Adult Education and a Master of Applied Science: Social Ecology.



My professional life has been varied and interesting, and mostly focused in the not-for-profit sector. After graduating with my undergraduate degree, I started work with Psychiatric Rehabilitation Services which was part of ACT Mental Health at the time. Then on to alcohol and other drug services in Western Sydney where I lived in the Blue

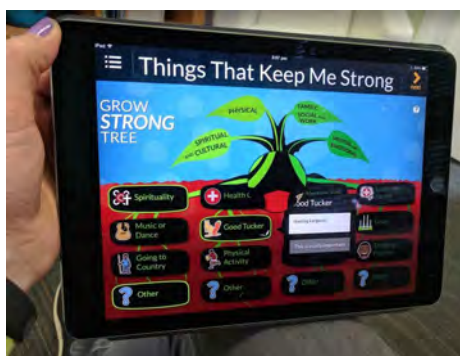
Mountains for a couple of years. I returned to Canberra to work in general practice training, then almost 13 years working in Aboriginal and Torres Strait Islander Health. This included working with Winnunga Nimmytijah Aboriginal Health Service and General Practice Registrar training in Aboriginal and Torres Strait Islander Health and the National Aboriginal Community Controlled Health Service. I worked for nearly three years with Mental Health Australia and had the honour of working with the Consumer Reference Group on a project to establish a National Mental Health Consumer Organisation (unfortunately a change of Government saw funding withdrawn and the new organisation was unable to begin independent operations).

Currently I am the Policy and Program Officer for the Mental Health Carers Voice Program with Carers ACT. I commenced in January 2018 for a 12 month maternity leave contract, and am looking forward to contributing to activity which supports and builds the capacity of carers who care for people with mental health problems, mental illness and psychosocial disability.

## Evaluating peer work in real world health care settings

Peer work in mental health care is becoming increasingly important. *Peer workers* are people with lived experience of mental health problems who use their experiences to support others. There is now more demand for peer workers to work alongside consumers in health care services to improve recovery and outcomes. This study looked at the effect of a peer worker in an adult mental health recovery program. We also decided to explore new forms of technology such as tablet and mobile apps. This is because they can deliver services in an engaging and innovative way. Many of these programs are only studied in trials, and there is a need to assess these apps in 'real world' settings.

The intervention we studied was a peer worker who was providing a mental health recovery program using an iPad app called Stay Strong. We wanted to find out if this was feasible, acceptable and effective for people with moderate to severe mental illness in addition to their usual care.



### What we did

Six consumers, and five health service staff participated. The outcomes we wanted to measure for consumers included recovery, and the acceptability of the program and its delivery, including the peer worker role. Our interviews with staff focused on how acceptable and feasible they thought the program was, and their views on including a peer worker in the health care team.

### What we found

Overall, views on the delivery of this program from both consumers and health care staff were very positive. People especially liked the role of the peer worker. The study found that consumers were highly satisfied with the program. They really liked the delivery aspects including using the iPad, working with the peer worker, and completing the program during time they would normally just wait around.

The participants were somewhat satisfied with the effect of the program on their recovery. Health care staff overall believed that the addition of the peer worker was highly useful for both consumers and staff. However, some minor problems were reported around ensuring the peer worker role was clearly defined, educating consumers on technology, and integrating the peer worker into the health care team.

### What we learned

The findings from this study may be useful for future work involving peer workers using e-mental health programs. However, we know there is much work to be done in this field to improve the uptake of peer work. The Head of ACACIA, Dr Michelle Banfield is conducting a larger scale peer work trial during the next two years as part of her Translating Practice into Research (TRIP) fellowship awarded by the Medical Research Future Fund.

For more information about ACACIA's research projects, head to the "Our Research" page on the ACACIA website (<http://cmhr.anu.edu.au/acacia>).



# Partners in Recovery: Impacts and Experiences in the Australian Capital Territory

The Partners in Recovery (PIR) program is an Australia-wide mental health care coordination program. The program began in 2013 with funding from the Australian Government. PIR was created to provide tailored, wrap-around care for people with severe and persistent mental illness and complex care needs. It is made up of a group of local organisations and service providers and aims to connect community health and social services. The program tries to address gaps in service delivery by:

1. Helping clinical and social support services to work together to provide people with tailored care.
2. Creating strong links between clinical and social support services.
3. Improving referral pathways to and between services.
4. Promoting a community-based recovery model.

A key part of the program is the Support Facilitators. Their role is to find out what a person needs (e.g. stable housing), find the right services, and help the person to access those services. This helps to make sure that a person's care is meeting their needs. It also stops people getting lost in the gaps between services.

For clients of the program, the goals of PIR were to improve quality of life, social inclusion, and recovery. For the health and social care systems, the goal of PIR was to improve the links between different service providers. Strong links between providers would then improve care for people with severe and persistent mental illness and complex needs.

ACACIA ran a study to measure the impact of the PIR program in the Australian Capital Territory (ACT). We aimed to find out what the effects of the program were for clients and service providers. We also wanted to know how satisfied people were with PIR and what made it easier or harder for the program to work.

## What we did

The design and measures for the study were developed in consultation with consumers, carers, PIR Support Facilitators, service providers and other key ACT mental health stakeholders. This made sure that the study measured effects that were important to all these groups and used tools that would work well.

Twenty-five clients of the PIR program completed a survey at two different time points to measure changes in their quality of life, social inclusion, perceptions of recovery, and experience with the program. In the last survey, these clients were also asked how they would have rated themselves on these items before participating in the PIR program. Fourteen service providers also completed a survey about their experiences, and what they thought made PIR work well or not. Six PIR clients, two carers, and four service providers were also interviewed about their experiences.

## What we found

### Recovery

Compared to how clients rated themselves before they started the PIR program, their quality of life, social inclusion, and attitudes towards recovery all significantly improved over time. This suggests that the PIR program was able to achieve its goals for clients.

### Confidence in the health system

Clients' confidence in the health system also improved over the course of the study. The increase in confidence was strongest in the middle of the study, and weaker at the end of the study. At the end of the study, clients may have been leaving the PIR program.





Most clients also said that their Support Facilitator had organised some or all of the care they received through PIR. By looking at the service use of two clients, we found that there were strong links between the Support Facilitator and client. The Support Facilitators were also connected to nearly all the services that the client was accessing. Together, these results suggest that having a Support Facilitator to manage care and organise services is what made participants feel more confident in the health system.

### Client and carer experiences

Most clients and carers said they had a positive experience participating in the PIR program. Experience was measured in four areas:

1. **Interpersonal communication:** whether a client felt listened to, involved in decision making and actively included in making recovery plans.
2. **Continuity and coordination:** whether different services worked well together for a client and shared necessary information (e.g. client's history, changes in a recovery plan).
3. **Comprehensiveness of services:** whether PIR met client expectations and provided enough support.
4. **Impacts of care:** whether PIR enabled clients to feel in control of their health.

PIR clients felt they were a central part of their recovery-oriented care. This was helped by a good match and relationship between the client and the Support Facilitator. A poor match could cause problems for clients and their carers.

Most clients felt that different services worked together and communicated well. However, a quarter of clients in the study had problems with their history not being available at all service providers. The way services worked together for a client improved over the program and gave clients a feeling of holistic care.

Most clients got what they expected from the program and felt they had been given enough support. Support Facilitators were praised for being proactive about finding the right services for their clients. They also had a 'modern' understanding of mental illness and used shared-decision making.

Clients felt that participating in PIR was destigmatising and helped to improve their self-efficacy. However, clients' confidence that their recovery plan would make a difference reduced at the end of the study. This might have been because future funding and support for the PIR program was uncertain at this time.

### Service provider experiences

According to service providers, uncertain funding was the biggest problem preventing the PIR program from being sustainable. The transition of PIR into the National Disability Insurance Scheme was difficult for staff. PIR was seen as a successful program and people were disappointed to be losing a program that could have had long-term benefits. Other challenges included frequent staff changes, trouble sharing information, a lack of clear leadership, and a lack of role clarity for staff, including the Support Facilitators.

Despite these issues, service providers felt that the PIR program succeeded in building relationships between services. These relationships were created through the personal approach of the Support Facilitators. A unique benefit of the PIR program was having flexible funds available to help clients take care of their immediate needs. Service providers said that this made the referral process easier.

### What we learned

The results of our study suggest that the PIR program was able to achieve its goals in the ACT. We also found that the Support Facilitators were the driving force behind the program's success. This is an important lesson for future programs: good care coordination relies on the relationships between clients, families and service providers. Care coordinators still have an important role to play in the current health and social care systems.

For more information about ACACIA's research projects, head to the "Our Research" page on the ACACIA website (<http://cmhr.anu.edu.au/acacia>).

## The Music Engagement Program: Evaluating participation in music-making with aged care residents.

Alzheimer's disease and dementia are very common conditions. Over 1 million Australians are expected to be living with these conditions by 2050. Dementia can be extremely disabling. It can reduce an individual's wellbeing, physical functioning, and mental health. We know that using music can improve mood and functioning in this group but most of these studies do not also look at other 'positive' outcomes. These outcomes include overall quality of life, and social outcomes.



The Music Engagement Program (MEP) is an established program in the ACT. It was developed by leading researchers at the ANU School of Music. The MEP is targeted at increasing engagement in the act of making music. The program uses a unique approach informed by a social philosophy of shared, active music-making. This is known as the Music Outreach Principle.

The aim of this project is to investigate the effects of the Music Engagement Program for people living with Alzheimer's disease and dementia. We hope to improve residents' quality of life, wellbeing, and symptoms of depression. We also will find out whether the program is acceptable, feasible, and sustainable.

This study is a partnership project between researchers from ACACIA, the Centre for Research on Ageing, Health & Wellbeing (CRAHW), and the National Centre for Epidemiology & Population Health (NCEPH). The project also has input from researchers across the ANU, including the ANU School of Music, and the ANU Medical School.

### Proposed study

The program will comprise group singing sessions with residents of an aged care facility. Sessions will last around 45-60 minutes and will be conducted weekly for 8 weeks. The program will be led by Dr Georgia Pike, who is a highly experienced music facilitator. We expect up to 20 residents will participate. Aged care staff will also be involved in the MEP sessions. We will conduct measures of quality of life, and feelings of social connection with residents. We will collect these before and after each session. Measures of residents' mental health will be conducted before and after the 8-week program. We will also interview any staff who wish to participate about their views of the program overall.

We hope to find out if the MEP is effective in improving quality of life, wellbeing, and depression in aged care residents. We also want to find out if the program is acceptable and sustainable in this setting.

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# The Mental Health Services Conference 2018

## Hear the Whisper, Not the Roar: Reform, Reflect and Review

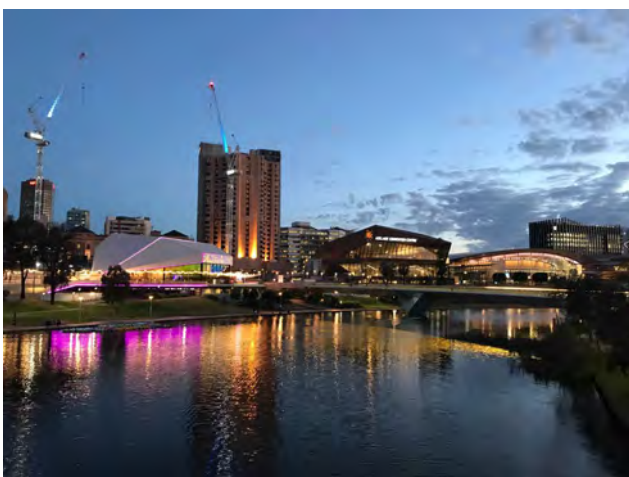
The Mental Health Services (TheMHS) Conference 2018 was held in Adelaide, Australia, from 28th to 31st of August. TheMHS is a diverse and welcoming conference. This year it featured 300 presenters across 10 different streams, as well as lived experience forums and creative performances and displays. The conference brings together consumers, carers, professionals, managers, researchers and policy makers to talk about mental health care and mental health systems.

The conference theme was: “Hear the Whisper, Not the Roar: Reform, Reflect and Review”. There was a focus on listening to the voices that are not often heard. This was showcased in the three keynote presentations. Keynote presenters challenged the audience to think from new points of view. Shannon Jaccard (CEO & Co-Founder of Ballast Health, past CEO of National Health Alliance on Mental Illness) spoke from the perspective of the siblings of people with a mental illness. A group of people who often feel unseen, unheard and unsupported. Matt Ball (2017 ACMHN Mental Health Nurse of the Year) encouraged the audience to think about psychosis in a new way. He also talked about the value and impact of compassion and human connection when supporting people who are experiencing psychosis. Michael Brown (Chief Inspector for the UK National Police Chief’s Council and College of Policing) talked about his views on responding to mental health issues and crises in the community as a police officer. He described the challenges and restrictions in the role of the police. He also suggested that it was important for the police, health and social services to work well together.

One ACACIA member, Alyssa Morse, was selected to present some of ACACIA’s research at the conference. Alyssa talked about consumer and carer views on ethics in mental health research. The talk included ideas about how these views could be used to improve research practice and ethical review processes.

Many of the presentations at TheMHS 2018 focused on coproduction. How to do “real” coproduction and how to do it well. It was inspiring to see so much commitment to working with consumers, carers and other stakeholders in service design, research, and producing policy and guidelines. It was especially interesting to hear about the creative methods people had used to gather information from a variety of people. Thinking outside the box can help people to provide input and feedback in the way that makes the most sense for them.

Some of the most memorable presentations were the personal stories of lived experience of mental health issues. It was a special opportunity to hear stories of people’s persistence and recovery. Many speakers had used their experiences to create new positive programs and other resources for their community.



The Adelaide Convention Centre at sunset



The Hon. Julia Gillard presenting at the TheMHS Awards

# Join the ACACIA Register

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 (e.g. 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 \_\_\_\_\_

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\_\_\_\_\_  
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