

Insight

Message from Head of ACACIA

Welcome to the June 2016 issue of *Insight*. The past six months have seen a lot of changes for ACACIA as outlined below, but I'm pleased to say we have a strong team of consumer and carer researchers who have put together a great newsletter to update you on our work.

The first big change is that Director of the National Institute for Mental Health Research and ACACIA Founding Director Professor Kathy Griffiths is retiring this year. Kathy has been a staunch advocate for consumer and carer involvement in mental health research for many years and her retirement will leave a significant gap. We wish her well for a fulfilling retirement. With Kathy's departure, I have taken on the position of Head of ACACIA. I feel like I have very big shoes to fill, but I have a great team helping me out.

As part of a restructure following Kathy's departure, the research centre in which ACACIA sits has had a name change. Starting this month, we have returned to the name Centre for Mental Health Research, so you'll start seeing this on our marketing and work instead of National Institute for Mental Health Research.

2016 has seen two new additions to the ACACIA team. Alyssa Morse is our new Research Officer and Owen Forbes is our first research intern. Alyssa and Owen are introduced in the staff profiles in this issue of *Insight*. Owen's position is a particularly exciting development for ACACIA. At our 2013 forum, consumers and carers put forward the idea of structured training on research methods as a way of building research capacity in the community. We have been able to find some funding to support an "internship" role within ACACIA, which we hope to continue as a series of fixed-term positions. Make sure you're on our mailing list if you want to hear about these opportunities as they come up.

We have also said farewell to a number of ACACIA regulars this year. Bethany Jones left us early in the year to take up a position in the public service. The academic position is currently being filled, so there will be another new staff member to meet next issue. Mearon O'Brien and Rebecca Randall, both of whom have been helping out with ACACIA activities as casual Research Assistants, finished up with us in June. Mearon is headed off to live in Canada. Becca is completing her PhD and will still be around ACACIA as a volunteer.

The best news I saved for last. ACACIA has entered into a new contract with ACT Health to continue our work for the next three years. This is testament to the hard work of the staff, Advisory Group and all our consumer and carer participants who have helped get things off the ground since 2013. A look at what we have achieved in the past three years is included in this newsletter. I look forward to working with everyone to see this grow in the next three years.

Dr Michelle Banfield
Head, ACACIA



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



Alyssa Morse

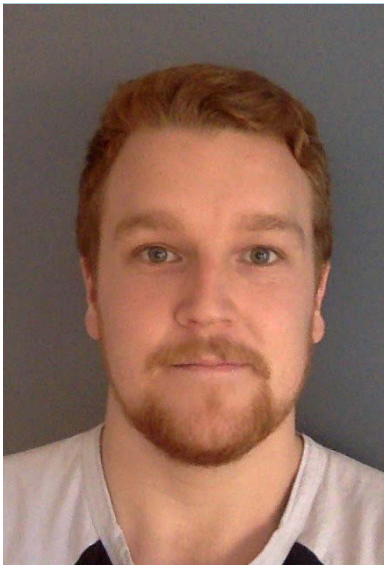
Alyssa is a Research Officer at ACACIA and a part-time PhD student at the John Curtin School of Medical Research at ANU. She also completed her undergraduate studies at ANU and graduated with a Bachelor of Psychology with Honours in 2011. Alyssa has a passion for teaching, as well as research, and has worked as Problem Based Learning tutor at the ANU Medical School for several years. She has also previously worked as an Applied Behavioural Analysis therapist for children with Autism Spectrum Disorders.

Alyssa's research interests are diverse and are inspired both by her university training and by her personal lived experience with mental illness. As a PhD student, she is interested in understanding the biological basis of human social behaviour. Her PhD project focuses on determining whether a few key genes can predict individual differ-

ences in empathy. She is also currently exploring whether or not these genes can affect people's experiences of social support and social stress. Alyssa's PhD project developed from an original interest in understanding the biological and genetic basis of Autism Spectrum Disorders. She is also interested in evaluating the tools we use to measure individual differences in psychological traits and in improving these tools for use in research applications.

As part of the ACACIA team, Alyssa values the opportunity to contrast the biological and quantitative work of her PhD with the practical, community focused and qualitative work of the Unit. She is excited to have the opportunity to be involved in research that is driven by mental health consumers and carers for the benefit of mental health consumers and carers.

Meet the ACACIA Research Team



Owen Forbes

Owen is an undergraduate psychology student at the ANU. He is working in the position of Research Support Officer, supporting ACACIA's work for the National Institute for Mental Health Research. Owen is also involved with NIMHR as a member of the Student Leadership Group for the development of the uniVirtual Clinic, a new online resource for student mental health.

With lived experience of depression and anxiety, Owen's interest in mental health research and policy grew out of his own experiences with accessing mental health support services. Owen is passionate about helping others to access the support and information that have been so crucial to his own experience in managing mental ill health. Alongside acting in carer roles for peers and friends, he has been active in advocacy and pastoral care positions in his

time living at an ANU hall of residence. From these experiences he has developed a keen interest in the mental health of students and young people, and has been a vocal supporter of the work of community mental health organisations like Youth in ACTION for Suicide Prevention.

Owen hopes to pursue a career in research, and is excited for the opportunities that are made available through a position with ACACIA. His research interests include mental health stigma among young people, pathways to service access, and the development of diagnostic standards. Having experience in informal and formal roles as both a mental health consumer and carer, Owen believes that carers and consumers both benefit when their perspectives are heard and integrated in research and policy development.

Demystifying Research: Academic journal articles and the peer review process

The main way that researchers in universities share their research is through peer-reviewed journal articles. Academic journals collect and publish research in a certain topic area. A paper could be something like a review article of past research, or a report on the findings of a current study. In research, the process of 'peer review' selects researchers to edit and make comments on a paper before it is published.

For at least the last 200 years, academic journals have used the peer review process to improve the content and quality of published work. When a paper is submitted to a journal, it is sent out for review by several topic experts in the field. The editor or board for a journal will usually be responsible for selecting reviewers. Editors will often select reviewers from a list of researchers who have volunteered to review articles in a subject area. Authors can also submit a list of peers who they would like to review their paper. Reviewers return anonymous feedback on the paper. The review process helps journals and their boards to decide if an article should be accepted, revised or rejected from publication.

An advantage of peer review is that it allows 'fresh eyes' from other researchers to look for errors or room for improvement in a piece of research. These could

include spelling errors, mistakes in data analysis or comments on the design of a project. This process allows journals to outsource some of their work, so that a small team is able to manage a large volume of papers. Thankfully, dishonest conduct such as suggesting friends or colleagues as reviewers is rare and journals usually have strategies to combat abuse of the system.

Some researchers have noted that the peer review system may favour mainstream theories and make it difficult for new ideas to be published. This can happen where reviewers may give harsher criticism to new or different ideas. However, most journals have guidelines to promote ethical conduct among reviewers and the peer review system continues to improve.

The peer review process is a widespread and long standing practice within research, and it is a crucial part of the way research functions. Whilst not foolproof, it provides some confidence that published research is credible. It will be important going forward to continue to reflect and improve upon the peer review process wherever possible.



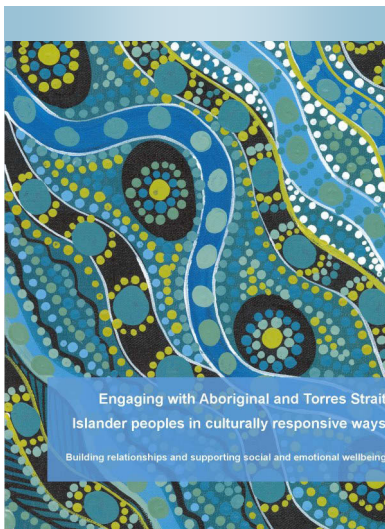
Meet Advisory Group Member:

Dalane Drexler

I have been studying and working with vulnerable people in the community sector for the past 20 years, the last seven years of which in my current role. As a person with a long history of post-traumatic stress disorder, I am keenly aware of the barriers people continue to face when trying to seek support for themselves and people they care for both in Australia and New Zealand where I was raised.

While I am currently planning a move into international development in mid-2017, I have and always will maintain a keen interest in community mental health. This area is very close to my own heart due to personal experience as a consumer and as a carer for several family members and friends. These experiences led me to wanting to make a real and lasting difference for people with lived experience of mental illness and their carers. I strongly believe in the capacity for ACACIA to make a real difference in this space and am keen to see it succeed with the support of the highly committed Advisory Group of which I take pride in being a part.

Dalane Drexler, Executive Officer of
ACT Mental Health Consumer
Network Inc.



ACTMHCN News

In 2015 from August through to November, ACT Mental Health Consumer Network hosted Dianne Perkins, a student on placement from the Australian Catholic University.

As part of her studies in social work for her degree, Dianne conducted a project for the Network that aimed to identify and examine culturally appropriate practices that the Network can use to actively engage with Aboriginal and Torres Strait Islander peoples who identify as having lived experience of mental illness.

The final report, entitled 'Engaging with Aboriginal and Torres Strait Islander peoples in culturally responsive ways: Building relationships and supporting social and emotional wellbeing' is now available for viewing and can be accessed from the Network's website (www.actmhc.org.au) under Publications: Reports. Alternatively, the Network has hard copies available from our Library for consumers to come in and read.

ACACIA's First Three Years

ACACIA was established in 2013 to undertake research that would benefit mental health consumers and carers in the ACT. Many things have happened in the three years since the Unit was established. We would like to take this chance to look back on some of ACACIA's achievements to date.

ACACIA's aim is to conduct research that actively encourages ACT mental health consumers and carers to take part in the research process. The Unit has four main goals:

- ◇ To promote consumers and carers taking part in research beyond the role of the subject or participant;
- ◇ To do research that aims to benefit ACT mental health consumers and carers and that has real-world uses for them;
- ◇ To report research results to the community; and
- ◇ To provide opportunities for training consumers and carers in research skills.

Many of ACACIA's activities have contributed to achieving these goals and the ACT mental health consumer, carer and stakeholder community has helped us to do this. We aim to continue to contribute to consumer- and carer-focused research and its real-world uses. Let's look back at the ways that ACACIA and the community have worked toward these goals.

Consumer and Carer involvement in research

ACACIA is committed to doing research with consumers and carers that allows them to contribute in a range of roles. The researchers at ACACIA all identify as mental health consumers and/or carers. They use their research skills alongside their lived experience when designing and conducting research. The Unit also has an Advisory Group made up of representatives from consumer and carer organisations, independent representa-

tives and policy makers. The Advisory Group provides practical advice from carer, consumer and policy perspectives.

We also strive to include members of the wider community in different parts of the research process. An example of this is the Inaugural Forum for ACT Mental Health Consumers and Carers held in November 2013. The forum invited ACT mental health carers and consumers to talk about their views on what the key research priorities for ACACIA should be. Carers and consumers brainstormed research ideas, workshoped research questions and voted on research priorities. The group also discussed how we could best get consumers and carers involved in research.

The research questions from this forum became the questions that ACACIA has aimed to answer over the three years since. We have been working on a number of research projects based on these questions that aim to benefit the community that asked them.

Research of benefit to the ACT community

One of the high priority research topics raised at the forum was "Recovery and fulfilling potential". We are exploring this topic with a project that aims to increase our understanding of how consumers, carers and service providers interpret the term 'recovery'. To meet this aim, we will be interviewing consumers, carers and service providers later this year. Knowing more about how the community views recovery will help us understand how recovery-oriented practices fit into programs like the National Disability Insurance Scheme.

Another high priority research topic was monitoring and evaluating programs that provide mental health services. In 2015, staff at ACACIA completed an evaluation of the Transition to Recovery (TRec) Step-Up/Step-Down program run by Woden Community Service. The evaluation provided information about the

outcomes of the program for consumers to groups like funding bodies and policy makers. Some of the goals of this evaluation were to help the program to continue its operations and to improve the services it provides.

An evaluation of the Partners in Recovery (PIR) program in the ACT is also underway. PIR is a program that helps people with severe and persistent mental illness to coordinate their complex care needs across multiple services. The evaluation process began in early 2015. A focus group of consumers and carers gave input into the development of the evaluation framework, which ensured its focus on issues that were important to ACT mental health carers and consumers. The evaluation aims to contribute to improvements in the quality of services and inform the mental health reform process in the ACT.

In 2015, Dr Michelle Banfield was awarded a Fellowship through the Australian Research Council to investigate service navigation and access for mental health consumers. This project addresses another high priority research topic raised at the forum: service pathways. The research aims to inform changes to our system so that consumers are able to access quality services. It will involve consumers and service providers using their expertise to help find solutions to the problems of accessing and navigating the service system.

When designing these research studies, the ACACIA team have needed to think through a number of ethical issues. Some of these issues apply to all research but others are specific to doing research with mental health consumers and their carers or support people. In doing our research, we found that the guidelines for mental health carers taking part in research were unclear. In 2015, ACACIA held a forum about the ethics of doing research with mental health carers. This forum allowed consumers and carers to talk about which ethical issues they thought were more or less important. The forum raised a range of interesting ideas, such as how research participation can affect the relationship between a consumer and their carer, and the importance of communicating about information sharing boundaries. In-depth interviews with consumers and carers are currently underway – contact acacia@anu.edu.au if you would like to take part, or see page 6 for more details. The results of this research will inform ethics committees about the views and concerns of the community and could inform changes in ethics guidelines, policies and practices.

Reporting results

ACACIA has reported the results of these research projects in a variety of ways, including through this newsletter! *Insight* keeps you up to date with our current research and other activities. The forums we run are another opportunity to communicate about who we are and what we do. They

are also a space where we can provide information about the process of doing research.

Staff at ACACIA have given presentations at conferences to tell the mental health community about the methods and results of their research. They have also given talks about working with mental health consumers and carers in the research process and about the frameworks and findings from the PIR and TRec program evaluations.

Sometimes research results are reported directly to the community or organisation where the research was done. For example, the TRec program evaluation results were presented to TRec staff so that they could understand the effects of their program and improve the services they provide.

Members of the ACACIA team have also run workshops about how to do effective research in partnership with consumers, carers and other stakeholders. These workshops aim to inform consumers, carers and other stakeholders about the how the research process works and how to get involved.

Research Training

ACACIA provides other opportunities for consumers and carers to receive research training. Staff and students at the Unit are all consumer and carer researchers who use their lived experiences and research skills to guide their practice.

This year there is a new position at the unit, the Research Support Officer. This internship role aims to provide a mental health consumer or carer with experience and training to help them produce quality academic research. Owen Forbes took up this position in March this year. You can read more about Owen and his research interests in the 'Meet the Researcher' section of this edition of *Insight*.

Future Directions

Looking into the future, the team at ACACIA hopes to continue to produce research in partnership with carers and consumers that will benefit the ACT community. In the near future, we will be conducting interviews to learn more about consumer and carer views on recovery and research ethics in the context of mental illness. The evaluation of the PIR program will also continue. Beyond these projects, we will continue to develop research projects based on the issues identified by the community as most important to you.



Whose story is it?

Research Participation Opportunity:

Mental Health Consumer and Carer Perspectives on Ethics in Research.

ACACIA is inviting mental health consumers and carers to take part in an interview exploring your views on carer involvement in mental health research.

Carers of people with a chronic mental illness (consumers) have a story to tell. But whose story is it? This one-on-one interview will take about 60-90 minutes and will cover topics such as:

- Can consumers and carers participate in research if the other declines?
- How can carers of people who disagree with their diagnosis participate in research?
- Can consumers and carers participate without the knowledge of the other?

If you choose to be involved you will be given a detailed information sheet and be asked to sign a form in order to participate. **People who participate in the interview will receive a \$20 gift voucher.**

Participation in this interview is completely voluntary. **For more information, please contact: acacia@anu.edu.au**

Service Users in Academia Symposium in Canberra 2016

If you only attend one conference this year make it this one! The Service Users in Academia symposium has been run annually since 2011 for the purposes of advancing the discipline of service user academia - the meaningful involvement of service users in mental health and addiction research and teaching.

The conference is relevant to service users currently holding positions as academics or educators in tertiary institutions and mental health services. It is also very relevant to those who aspire to these roles or are just interested in finding out more about them. It is also relevant to health professionals in academic and clinical roles who want to introduce or increase the involvement of service users in their education programs. In fact, it is relevant to anyone who wants to see the health professionals of the future educated in a more consumer focused and recovery oriented manner, and who believes this is best achieved through involving service users.

This year we are holding the symposium in Canberra, with a record number of universities as co-hosts, including Synergy (University of Canberra and ACT Health), Australian National University, University of Otago, Central Queensland University and Auckland University of Technology. Mark **November 21 and 22** in your diaries for what we hope will be the biggest and the best symposium yet. It will be held at the beautiful ANU Commons, 26 Barry Drive, Acton. The theme is: **Creating Connections and Building Bridges Together: the Journey Continues**. If you need more convincing, hopefully the words of former participants will seal the deal.

The symposium was not only very stimulating and educational for us it has also created opportunities for us in terms of work. We have made valuable connections and conversations are abuzz with thoughts of further study and potential learning opportunities - WOW, service users in academia, AMAZINGwhen I think cost for 2 days compared with cost for other conferences. So hard to pick what to go to, so many totally outstanding people.....

- 2014 symposium attendee

I feel very lucky to have had the opportunity to attend and meet so many amazing people who opened my eyes to the role that service users have in academia in NZ and overseas. It also firmed up my awareness of the lack of involvement of service users in teaching and research in psychology, and next year I'm starting the process of gradually building up that aspect in the paper I teach

- 2014 symposium attendee.

For further information please contact Lisa Haigh: Lisa.Haigh@act.gov.au



Research Bites

In this edition of Insight, we are introducing a new section! This section called 'Research Bites' will provide short summaries of interesting mental health research that has been published relatively recently for your interest. Please note that inclusion of research within this section does not mean that it is associated with or endorsed by ACACIA. If you would like information about the research in this section, and don't know where to start to find it, please contact ACACIA using the details on the back page.

Biogenetic Explanations of Mental Disorder: The Mixed-Blessings Model

Nick Haslam and Erlend P. Kvaale
Current Directions in Psychological Science
2015, Vol. 24(5) 399-404

There is a growing recent trend in psychology research to focus on biology and genetics in explaining mental health issues. In a recent article, Haslam and colleagues considered how this trend might affect attitudes towards mental health. Looking at the views of clinicians, mental health consumers, and the public, they found varying effects. Explaining mental health in biology terms reduced public stigma towards mental health consumers, by reducing the blame placed on them for their problems. However, the authors also found that this approach increased the public's view that consumers were dangerous and erratic. Consumers were also more likely to feel negative and helpless about their problems if they were explained in these terms. When primed with

biological accounts for mental health, clinicians were more likely to give negative outlooks and feel less empathy towards consumers.

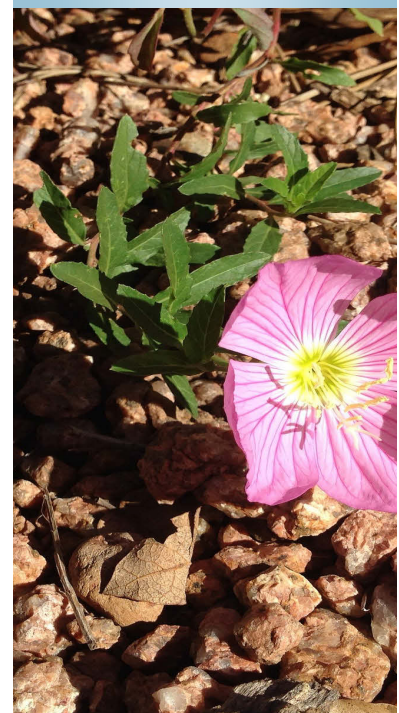
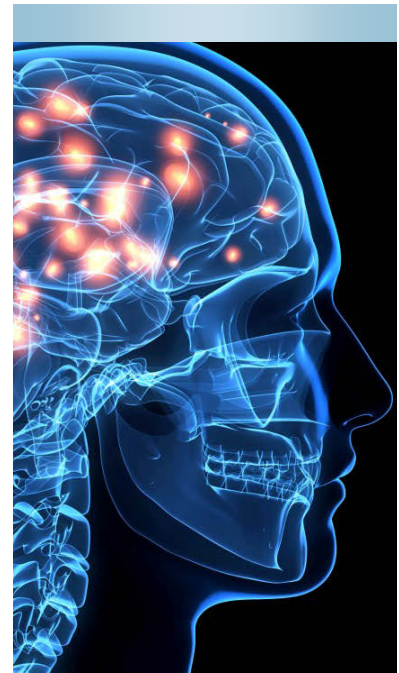
The biological approach seems to explain mental health issues as if they are out of the consumer's control. This may promote ideas that mentally ill people are 'different', unable to recover, and less able to control themselves. For these reasons, explaining mental health issues in biology terms both helps and worsens stigma. It is a double edged sword, as blaming may be reduced but consumers may then be seen as 'broken instruments' with reduced control. Moving forward, it will be crucial to balance a focus on biology with an awareness of the negative attitudes that can result.

Resilience to Major Life Stressors Is Not as Common as Thought

Frank J. Infurna and Suniya S. Luthar
Perspectives on Psychological Science
2016, Vol. 11(2) 175-194

Resilience is an important concept in psychology research. It describes one of the ways that people can react when they experience a traumatic situation (e.g. a serious car accident) or a difficult life event (e.g. a divorce or losing a job). We describe people as resilient when they respond to these types of events with healthy levels of well-being and suffer very few negative effects. Past research has suggested that most people are resilient when faced with traumatic or difficult events. However, many of the research studies supporting this claim were conducted in similar ways. Infurna and Luther conducted a study to find out whether analysing the same information in different ways would lead to the same results. They explored how people reacted to three difficult life events: loss of a spouse, di-

vorce and unemployment. When they used the same methods as earlier studies, Infurna and Luther also found that most people were resilient. However, when they used a different analysis method, they found that resilience was the least common response to difficult events. Infurna and Luther's study shows us how the research methods we use can affect the results we find. This is why it is important to repeat research studies and see whether the results hold up. The study also highlights the importance of being careful when applying the results of research in real-life settings. This is important in research about resilience because these studies could influence the kinds of support services that are available to the people who experience traumatic events.



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

ACACIA Staff

Dr Michelle Banfield,
Research Fellow

Alyssa Morse, Research
Officer

Owen Forbes, Research
Support Officer

ACACIA Advisory Board

David Lovegrove, ACT
Mental Health Consumer
Network

John Franklin, Carers ACT

Mariana Oppermann,
Independent Consumer

Dalane Drexler, ACT Mental
Health Consumer Network

Sarah Patching, Carers ACT

Julia Bocking, ACT Health
Consumer Consultant

Prof Brenda Happell,
Academic Advisor

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

I don't want a newsletter

Mail To:

ACACIA at CMHR
Building 63
The Australian National University
Acton ACT 2601,
AUSTRALIA

Or email us at:

acacia@anu.edu.au

For more information about ACACIA,
please visit [http://nimhr.anu.edu.au/
acacia](http://nimhr.anu.edu.au/acacia)