



ACACIA's Mental Health Research Newsletter

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

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This newsletter was written by members of ACACIA with layout by NIMHR Media and ANU Media Office.

A message from the Director



Woden Community Services TRec Step-Up Step-down program. Thank you to those people who assisted with ACACIA PhD student Sharon Leigh-Hazell's project on ethical research and mental health carers. Watch out for future newsletters and visit ACACIA website at the National Institute for Mental Health Research to read about ACACIA's activities and research findings.

Last week I attended the annual conference of Australia's Society for Mental Health Research (SMHR). You may recall that the Society joined forces with the ABC in October to raise awareness and funds for mental health research. The ABC campaign succeeded in raising almost 1.5 million dollars. The Society has decided to use these funds to provide one-year fellowships to 10 to 12 early career mental health researchers. This is wonderful news because the future of mental health research lies in the hands of the next generation of researchers. Wouldn't it be great if one or more of these fellowships was awarded to a researcher with lived experience of a mental illness! I will suggest this to the President of the Society, former Australian of the Year, Professor Pat McGorry.

At the end of the SMHR conference I was privileged to speak about ACACIA's sister organization, the Consumer Research Unit (CRU) and to announce this year's winner of the CRU medal. I established the CRU award to recognise the achievements of an Australian academic consumer researcher. This year the medal went to Dr Claire Kelly. Now the Melbourne-based manager of Teen Mental Health First Aid, Claire an active researcher is passionate about consumer research. A former PhD student at our Institute and one of the original members of CRU, she wrote in her application:

Well, as I write this Christmas is fast approaching and in no time at all 2015 will make its appearance.

One of ACACIA's best Christmas presents this year was the announcement by the Australian Research Council that ACACIA staff member Dr Michelle Banfield has been awarded a prestigious DECRA Fellowship. Over the next three years Michelle will undertake research on the journeys of mental health consumers in the ACT health system. Congratulations Michelle. A fantastic achievement and a wonderful opportunity to undertake innovative consumer-oriented research that will be of benefit not only to consumers in the ACT, but also to our colleagues around Australia and the world. We look forward to hearing about the research over the next three years.

ACACIA staff and students have been busy over the last six months developing an evaluation framework for ACT Partners in Recovery, finishing the report on the ACACIA Forum on consumer and carer priorities for research, and completing data collection for an evaluation of

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“Consumer oriented research matters to me on every level. In particular, involving young consumers in research that affects young people is a passion of mine. Involving consumers in research, and leading research as a consumer, creates more robust results and makes an important difference in the lives of consumers all over the world.”

Well said Claire!

So that's it from me for this newsletter. Thankyou to everyone who has supported and taken an interest in the work of ACACIA this year. Special thanks to the members of the ACACIA Advisory Board for their expertise, wisdom and support. Stay safe and may the New Year bring good things to all.

Professor Kathy Griffiths,

Director, National Institute for Mental Health Research

Why the name ACACIA?



ACACIA takes its name from the Acacia or Wattle blossom and is intended to symbolise the diversity of the consumer and carer experience. There are over 1300 different species of ACACIA around the world¹.

Similarly, those who are touched by mental illness can come from any age group, culture, religion, and political, socio-economic or educational background.

¹worldwidewattle.com/infogallery/species



News from ACACIA

It has been a busy year for ACACIA: The ACT Consumer & Carer Mental Health Research Unit. We have been working on ways to get the research ideas raised by consumers and carers at last year's forum under way. Some examples are:

- Creating a consumer-centred framework for evaluation of the ACT Partners in Recovery (PIR) Program. The framework builds consumer feedback into PIR. It uses methods and questions developed with consumers in other studies. We will hold a consumer and carer focus group for local feedback on the questions soon.
- Working on a proposal with Peers ACT and the Mental Health Community Coalition ACT (MHCC) to research the role of mental health peer workers under the National Disability Insurance Scheme (NDIS). If funded, this project will combine evidence

from around the world on models of peer work. This will then frame a model of best practice for Australian peer workers.

We have also been looking at ways of improving consumer and carer involvement in mental health research. We held a workshop on research methods for consumers, carers and service providers at the MHCC conference in June. The feedback on the workshop was positive, so we will hold more of these in future. We are also planning a forum on ethics in research. We would like to know your thoughts on issues such as whether carers need consent from consumers to tell their story for research.

Please contact us to hear more about ACACIA's work or to get involved. Email us at acacia@anu.edu.au or go to our website <http://nimhr.anu.edu.au/acacia>.

Staff of ACACIA

Professor Kathy Griffiths, Director;

Dr Michelle Banfield Research Fellow

Ms Aine Tierney, Research Assistant

ACACIA Advisory Board

Maureen Bell, Independent carer

Julia Bocking, ACT Health Mental Health Policy Unit

Dalane Drexler, ACT Mental Health Consumer Network

Sharon Leigh-Hazell, Carers ACT

David Lovegrove, ACT Mental Health Consumer Network

Mariana Oppermann, Independent Consumer

Doris Kordes, Carers ACT

Taking a closer look at mental health law

This year I had the pleasure of presenting at two legal conferences on issues related to mental health law. I attended the Mental Health and Capacity Law stream of the Socio-Legal Studies Association (UK) Conference in Scotland in April, and the Law and Society Association of Australia and New Zealand Annual Conference in December.

Both conferences looked at a range of issues, including the implications for people with a mental illness of the Convention on the Rights of Persons with Disabilities (CRPD). The CRPD is a fairly new UN treaty (it came into force in 2008). Its interpretation, particularly in the area of mental health, is very controversial. There was some robust debate at the UK conference about whether, at international law, the CRPD forbids countries from having legislation that restricts rights based on whether a person has a mental illness.

The position of the UK government (and that of Australia) is that the CRPD does allow for compulsory detention and treatment of people with a mental illness in some situations. Yet as some conference participants pointed out there are increasingly strong statements coming from the UN to the contrary (for example, in 2009 the UN High Commissioner for Human Rights stated that the CRPD required “the repeal of provisions authorising institutionalisation ... in all cases in which such grounds of care, treatment and public security are linked in legislation to an apparent or diagnosed mental illness”). At the very least, the CRPD requires us to engage more deeply around the rights of people with a mental illness.

The UK conference also involved many presentations on the European Court of Human Rights. In much of Europe a person who has good reasons for thinking that their rights have been breached can, in some circumstances, take their case to the European Court of Human Rights. It is a difficult and slow process, but it allows a court to look into what happened, decide whether the person’s rights were breached and, if they were, to award compensation.

This is a very different approach to what we have in Australia; here there are very limited recourses for people who have had their human rights breached. One of the things that I found really interesting at the UK conference was meeting people from many countries in Europe (and beyond) who specialise in mental health law and learning about the laws in their countries. Even though many of the laws were very different on paper, in practice people with a mental illness faced very similar problems; lack of access to the treatment and support that they did want, discrimination and poverty, forced treatment and poor quality care and abuse.

The difficulty that our legal systems have in helping address these problems was noted by many presenters. In most countries the legal system is far more adept at forcing people to undergo treatment than it is at ensuring that forcible treatment is of good quality, or at ensuring that good quality treatment is widely available to those who desire it.

Mariana Oppermann is a member of the ACACIA Advisory Group



Meet ACACIA Advisory Group Member

Mariana Oppermann, Independent Consumer Representative

BA/LIB(hons), GDLP, DLun

I came to Australia from Brazil with my family over 20 years ago, and since then I have lived in the Canberra region. I am a lawyer and anthropologist by training, and I am currently a postgraduate student in the Culture, Health and Medicine program at the ANU, with a focus on Mental Health research.

Ten years ago life took an unexpected turn when I developed a serious mental illness during the final stages of my degree. It has been a very difficult road, including many prolonged periods of acute inpatient care. This long road has left me with a physical disability (as the result of a suicide attempt). Whilst some days are still a struggle, those days have become less and less frequent and I am glad to be here!

I have seen the difference that being respected and having access to good quality care, treatment and support can make, as well as how damaging it can be when these are denied.

My experiences of mental illness and physical disability have made me keenly aware that we still have a long way to go in order to secure social justice for people with a mental illness. I believe to do so it is essential that the voices of people with a mental illness are heard and respected, and that we have genuine options for participation and control in all issues that affect our lives.



Demystifying Research

What is scientific research?

Put simply, research is about asking questions and looking for the answers. Scientific research usually involves collecting new information ('data') using specific methods. However, sometimes it involves thinking about existing data in a different way.

There are a number of stages in the research process. First the researchers must decide on a question. Next they need to work out how to answer it (the study methods). They can then start the process of collecting the data. These data are just collections of unorganised pieces of information. So, the researchers need to work out what they mean. This may involve using special analysis methods such as statistical techniques. Finally, the researchers let as many people as possible know about the results. For example, they may report the findings in medical journals, conferences, in the media, to policy makers, and to consumers and carers.

Researchers use different methods for collecting and interpreting the data. Research can involve qualitative methods or quantitative methods. Qualitative research methods rely mostly on data collected from talking to people through activities such as focus groups, consultations, and interviews. These often involve open-ended questions and discussion. For example, if a researcher wishes to know what consumers and carers think about a mental health service they might ask them to talk about: What if anything did you like about the program? What did you dislike or what could be improved? The researchers then look for patterns or themes in this information. It might emerge for example, that some people found that the program was too short or that it was held at the wrong time of the day. Without asking the people who used the program it might not have occurred to the researchers ask about length or the time of day for the course.

By comparison, quantitative research methods usually involve a fixed set pre-



determined questions and count up numbers or percentages or conduct statistical analyses. For example, to find out about consumers' and carers' views about a mental health service they might ask: Was the content of the course clear? Yes or No. Were you satisfied with the course? Yes or No. The researchers would then draw conclusions based on the numbers of people who responded yes to each question.

We would love to hear from you if 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 Professor Kathy Griffiths

National Institute for Mental Health Research (NIMHR) Director, Professor Kathy Griffiths, is passionate about improving mental health through research. Kathy, a consumer and academic researcher founded ACACIA in 2013 and its predecessor, the Consumer Research Unit in 2003 to increase the relevance of mental health research by engaging consumers as active participants in the research process.

Kathy was also a pioneer in the development and evaluation of automated online self-help programs for

of automated online self-help programs for depression and anxiety. She co-founded and leads ANU's e-hub Mental Health, a self-help service that empowers consumers by providing evidence-based online help to citizens from over 220 nation states across the world. E-hub's original program, MoodGYM, has over 800,000 registrants worldwide and is available in 6 languages including Chinese. MoodGYM and other programs in the e-hub suite are important because NIMHR and other groups around the world have undertaken high quality scientific research demonstrating that e-hub programs improve mental health outcomes. Kathy's program of research has also focused on stigma reduction. Her scales for measuring stigma have been used around the world and translated into 12 languages. She has investigated what segments of the population hold the most stigmatizing views. She has also developed online programs that are effective in reducing stigma.

Kathy has published over 200 scientific journal articles, books and websites, most since her return to academia in 2001. Prior to that she was the primary writer of the NHMRC Clinical Practice Guidelines for Depression in Young People and the Consultant Editor of the original National Action Plan for the Promotion of Mental Health and the Prevention of Mental Illness. Kathy sits on many national committees and is on the Editorial Boards of international journals. She has delivered many invited talks in Australia and around the world including plenaries and keynotes. She spends a great deal of her time seeking funding for research at NIMHR, with over 90% of staff supported on 'soft money' gained from funding sources outside the ANU. Kathy herself is supported by a prestigious National Health & Medical Research Council Senior Research Fellowship.

Her aim is to continue to undertake high quality, relevant research and translate it into practice so that it makes a difference to the lives of other consumers and to carers.

Carers are a diverse bunch!

I attended the Australian National Carer Conference at the Gold Coast on 16-18 November. The theme of the Conference was “Keeping Carers Connected” and the conference cast a spotlight on

- the diverse range of carers including young carers, Aboriginal and Torres Strait Islander carers, carers from culturally and linguistically diverse background and “sandwich carers” – those looking after their parent and children;
- the issues facing carers including their own mental health and wellbeing, isolation, the barriers in completing education and reduced capacity to participate in the workforce; and
- improving support for carers including new technologies and services

Although I would have liked to see a stronger spotlight on mental health and research into issues for carers in navigating services for people with mental illness, there were some take home messages. It is apparent that more effective research is required about why people with severe and persistent mental illness continue to experience gaps in services and support. Frank Quinlan, Chief Executive Officer, Mental Health Australia pointed out that people with severe and persistent mental illness are falling through the gaps of major reforms. This is despite mental health being regularly reviewed - on average about every 18 months since World War II. Mr Quinlan suggested that there are new opportunities in supporting mental health services and programs through the Federation whitepaper process. He also raised concern that the focus of the National Disability Insurance Scheme (NDIS) is on Tier 3 recipients. However many people with serious mental illness fall into Tier 2 and are at risk of falling through the gaps. Monitoring and research is required around this emerging issue to ensure that people with severe mental illness are appropriately supported.

The conference provided insight into the issues for young people who are carers. Dr Tim Moore, Senior Research Fellow at the Australian Catholic University pointed out that young carers don't often have support and experience poverty, isolation, family breakdown and mental illness – particularly depression and anxiety. Most young carers don't seek or receive help even though they might realise they need it. And when they do the services often target adults and there is little connection between services. Ms Chantelle Day, Carers Australia Young Carer Ambassador emphasised the impact caregiving has on reduced education attainment and the young carers' future wellbeing.

Ms Karen Wilson, Disability and Carers Policy Branch Manager, Department of Social Services (DSS) pointed out that silos exist in many programs and the current approach targets people over 65 in aged care and under 65 with



a disability. Research undertaken in 2013 highlighted the difficulty carers experienced in navigating the service system and there is:

- a need for a more streamlined and coordinated systems approach to carers support and to make it easier for carers to identify appropriate services and the point of access
- a lack of alignment across key frameworks regarding how carers are identified, assessed

- limited communications and coordination between different levels of government and between agencies.

To address these issues, DSS is developing an Integrated Carer Support Model. It will be incorporating a co-design approach with carers in its development and will aim to provide a consolidated stream of carer services regardless of who the care recipient is.

We were fortunate to hear from Ms Madeleine Starr, Director of Business Development and Innovation about the Employers for Carers program which aims for employers to hold on to their experienced staff by creating a supportive working environment for carers. This is achieved through embedding carer friendly policies in the workplace, reducing stigma by creating a culture which allows disclosure of caring, tips and tools for managers and setting up and supporting employee carer networks. Employers for Carers currently has 85 employer members who in turn employ over 1.5 million people – 1 in 9 of whom will be carers.

What struck me was the diverse range of carers and issues presented at the conference and the opportunities for further research. The new service landscape provided by the NDIS is a clear contender, particularly around service provision for mental health consumers and carers and gaps that may emerge. Psycho-social disability and its impacts on the consumer and family was a real concern – a number of parents of people with psycho-social disabilities expressed their frustrations about inadequate accommodation and inappropriate services and their fear of what the future holds for their adult child after they are gone. More research is also needed around specific groups including young carers, older carers, Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds.

Sharon Leigh-Hazell was funded to attend the conference by Carers ACT and is the Carers ACT representative on the ACACIA advisory committee. Any opinions expressed are her own and not of Carers ACT.



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

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