

Plotting the course for research at Mind

t Mind, we are committed to changing the face of mental health services by shifting the focus away from old institutional practices and more towards recovery oriented healing. We understand the need for a solid, credible knowledge base to drive these changes.

In response we established the position of Director of Research in partnership with the Centre for Mental Health in the Melbourne School of Population and Global Health at the University of Melbourne. This innovative in-reach position, held by Dr Lisa Brophy, has enabled Mind to form a direct connection to the university and supported

the development of other academic partnerships, enabling us to be competitive in applying for funding grants.

Dr Brophy's role has embedded a strong research culture in Mind over the last four years. This is represented by the number of solid and sustainable evaluation and research projects we are currently undertaking. A robust Research and Evaluation Framework is the foundation for these positive outcomes. Developed with our partners at the University of Melbourne, it prioritises drawing on lived experience, partnerships with other organisations, and sharing amongst communities of practice. ► (continued on pg 3)



Supporting mental health recovery

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Dear friend,

hope the new year is shaping up well for you.

We have another busy agenda set for 2016. We are buckling down with preparations for new opportunities to serve consumers and looking at how we can further improve our service delivery. This edition is focused on sharing some of the research work we are undertaking or participating in. Our research and evaluation team are exploring some really innovative practices that I am excited to share

I am guite proud of the research work we do at Mind. Through funding and supporting the Director of Research and also providing extra funding for specific projects, in kind support and financial contributions in partnership, Mind Australia is now a leading organisation in supporting consumer research activity and recovery oriented research. We were awarded the 2015 Tom Trauer Research and Evaluation Award for our submission: Mind Australia's

Director of Research: investing in recovery and social inclusion research activity, which is testament to the impressive body of work to come out of Lisa's leadership of Mind's research agenda.

Late last year I myself presented a paper at the Claiming Full Citizenship Conference in Vancouver, Canada. This conference personalisation and individualised funding and was attended by well over 500 people. The conference was a great opportunity for me to learn from people from around the world how they are trying to improve consumer choice and empowerment. It was helpful for me in benchmarking how Mind is performing against overseas trends. I feel we are standing up pretty well in terms of service approach.

control, it is with great joy that I announce that Mind was the winner of the choice and control category in the National Disability

Awards which were announced at Federal Parliament late last year. These awards are highly contested across the country and we were thrilled that the Mind Recovery College was recognised in this way.

I wanted to especially welcome our new readers in Queensland. Mind has been successful in winning a number of tenders in Queensland and is now operating - or about to - services in Cairns, Townsville, Toowoomba and Ipswich. I encourage you to sign up to any and all of our publications via our website (in addition to Mind View we circulate a co-produced consumer newsletter and a carers newsletter).

I hope you enjoy this edition and can share in the optimism and excitement that our research endeavours present.

Warm regards,





Mind Australia

PO Box 592 Heidelberg Vic 3084 | mindaustralia.org.au | 1300 286 463









Supporting mental health recovery

To contact the editor, Jess Shulman, email communications@mindaustralia.org.au If you no longer wish to receive this newsletter contact communications@mindaustralia.org.au

Mind cares for the environment and uses environmentally-friendly inks on recycled paper.



We ensure that staff and consumers are active participants and leaders in research and evaluation. For instance, consumer researcher and consultant, Nadine Cocks, helped to write Mind's report, People making choices: the support needs and preferences of people with psychosocial disability and contributed to a Mind-authored book chapter in Community research for participation: from theory to method (2012). Consumer Academic in the Centre for Psychiatric

"The collaborative research partnership between Mind and the University has proven to be extremely successful, and other non-government agencies like Mind have expressed interest in forging similar arrangements. Under this model, Dr Brophy is supported by a vibrant academic environment and able to lead research and evaluation work that can make a real difference 'on the ground'. Her work has been recognised by various awards and she is making a major contribution to new policy and practice directions that will have a significant impact on people with mental ill-health."

- Professor Jane Pirkis Director, Centre for Mental Health, Melbourne School of Population and Global Health

At Mind, we believe investing in finding better ways to support people living with mental ill-health benefits those affected, but also us as an organisation.

Nursing at the University of Melbourne, Catherine Roper, worked alongside Dr Brophy on the National Restraint and Seclusion Project, and our Senior Advisor Lived Experience, Anthony Stratford, has co-authored four peer reviewed papers. Both Catherine and Nadine worked on an evaluation of the effectiveness of Mind's Peer Recovery Communities.

We recognise the importance of supporting lived experience research with a financial contribution to an academic lived experience positon at the University of South Australia. Mind has also extended its academic activity in relation to consumer engagement and peer support through its Memorandum of Understanding with the Yale University's Program for Recovery and Community Health, and Yale Professor Larry Davidson has been an important contributor to the development of Mind's Model of Recovery Oriented Practice.

In addition to researcher-led projects, we commission evaluation for all our service streams. We evaluate the work that we do, so that we can continue to better our practice and make a meaningful contribution to the lives of our clients and their families and carers. For example, last year, Mind changed the way its adult residential rehabilitation services worked and renamed them Peer Recovery Communities. As the name suggests, Mind wanted to achieve

a more positive culture of mutual support and community, and focus on recovery in these services. The evaluation revealed that the new model is working to improve on past practices and that residents are better supported to identify and achieve their personal recovery goals.

At Mind, we believe investing in finding better ways to support people living with mental ill-health benefits those affected, but also us as an organisation. Our recent expansion into Queensland with a Prevention and Recovery Care (PARC) service and Community Care Unit (CCU) is testament to this. We were called upon to partner with hospital clinical staff to address the breadth of needs of clients transitioning out of acute care. The way we deliver recovery services in sub-acute settings is evidence-informed and a successful tried and tested model. What we do works.

Some of our most exciting research projects are highlighted in the following pages. They are centred around themes that are directly relevant to our consumers and of interest to those who support them.

More information about research and evaluation at Mind can be found on our website:

www.mindaustralia.org.au/ research.html



upported decision-making empowers those with mental ill-health to have a say in their own treatment and have their opinions heard and respected. After all, making decisions is what allows us independence. It allows us to have control over our lives as we wish to live them, and engage with society in a meaningful way.

So, in partnership with Monash University and Melbourne University, the Department of Health and Human Services and other service delivery partners, we are currently conducting research into supported

decision-making for people with serious mental health challenges.

This research is about encouraging clients to make their own decisions – with support where necessary – about the fundamental day-to-day things that might often seem out of their control. Things like: medical or psychosocial treatment, property, finances, family, employment and participation in community activities.

Promoting a supported decision-making model as best practice can also improve

communication between practitioners and consumers and their families and carers, leading to improved treatment outcomes and recovery.

Leading the investigation is Associate Professor Renata Kokanovic, a Monash Fellow in the School of Social Sciences, Monash University, and a Foundation Co-Director of Healthtalk Australia. She is also Director of the Social Studies in Health and Medicine (SSHM) Research Program, a unique research program dedicated to understanding health and illness experiences in their social context. A/Prof Kokanovic straddles both the clinical and community aspects of mental health, making this work crucial to current efforts to humanise those struggling with mental health.

So far the research team have interviewed nearly 100 consumers, carers, mental health practitioners and psychiatrists and gained many useful insights into how to best support consumers and carers in making

This is the first Australian interdisciplinary study to investigate how supported decision-making can be used to align Australian laws and practices with international human rights obligations.





decisions about an array of important aspects of their lives. Enabling consumers and carers to exercise greater agency will result in them feeling more valued and better heard. This is what some of our participants have said about the value of supported decision-making:

"[in the beginning] I just followed the psychiatrist ... [later] I realised that I needed to sort of stand up for myself a bit better." (Consumer)

"I think that supported decision-making kind of makes a lot of sense with mental illness because, I guess, in our first instance of it, it's a bit of the unknown, and you're given this information, but you're not quite sure what to do with it. So that really that care team and supported decision-making is vital in actual recovery processes." (Carer)

"I think it's really helpful that people get a chance to express what they want. And even if, you know, it doesn't necessarily occur because of ... situations that I've spoken about earlier...it's still good for someone to have the opportunity and to be empowered and feel that they're able to, to do things." (Nurse)

"It keeps coming back to me time and time again, which I keep in the heart of hearts is that the more information you give a person the more, the better they're going to - the outcome's going to be." (Peer Support Worker)

Findings from this research will be presented as two unique online resources detailing participants' experiences. The first will be focused on people with lived experience of psychiatric diagnoses, and the second on carers. These will be Australia's first internet resources based on narrative research to support people diagnosed with severe mental health problems and their carers. We hope they will inform policy development and improvement of mental health services in Australia. The resources will be added to Healthtalk Australia (healthtalkaustralia. org), a national leader in promoting narrative research of people's experiences of health and illness. Healthtalk Australia is the only research group in Australia collaborating with Oxford University's highly regarded Health Experiences Research Group (HERG).

This project has already gained ground both locally and internationally, with findings shared at the Future Directions in Supported Decision-Making Research Symposium in

Victoria, the International Academy of Law and Mental Health conference in Vienna, the Australian and New Zealand Association of Psychiatry, Psychology and Law conference in Canberra, and the Melbourne Social Equity conference in Melbourne.

To find out more about this research or to become involved, visit: http://artsonline.monash.edu.au/ supported-decision-making/

Also on the project team are:

- Professor Bernadette McSherry, Foundation Director of the Melbourne Social Equity Institute at the University of Melbourne and an Adjunct Professor in the Melbourne Law School and the Faculty of Law, Monash University.
- Professor Helen Herrman, Director of Research at Orygen (The National Centre of Excellence in Youth Mental Health) and Professor of Psychiatry in the Centre for Youth Mental Health, University of Melhourne
- Dr Lisa Brophy, Director of Research at Mind and Senior Research Fellow at the Centre for Mental Health, School of Population and Global Health, University of Melbourne.

As with all our endeavours, we embrace our service delivery partners in this project: Tandem, Neami National, MI Fellowship and the Victorian Mental Illness Awareness Council (VMIAC).



Where carers are concerned

arers are both excited and apprehensive about the introduction of the National Disability Insurance Scheme (NDIS). There has been much talk on the individual focus of the funded items and news coming out of the trial sites. While individualised funding programs typically assess and address a consumer's needs, the needs of **family and carers** are not explicitly considered under NDIS. Family and carers have a right to access information and receive support themselves.

Mind wanted to find out how carers experienced similar schemes internationally, so we commissioned an extensive international literature review of the impact of individualised funding on family and carers of people with psychosocial disability.

The literature review found that certain conditions were necessary in order for packages to have a positive impact on carers:

- · Access to information
- · Support to consider their needs and aspirations as well as their family member's needs
- · Adequate funds
- · Staff attitudes that encourage power sharing rather than being patronising
- Support to match the level of administrative responsibility carers are expected to carry
- · Access to services for themselves

It was also found that carers were able to lobby for and secure better funding and support for their loved one when they had confidence and skills. Peer support through

education programs and informal groups was a key factor in developing these abilities.

informal carer.

An important gap has been recognised in the literature across the board: so far, minimal attention has been paid to the specific needs of ethnic and minority groups in society. The challenge will be to reach out to these groups in language and culturally appropriate ways.

Benefits

In NSW NDIS trial sites it was found that the benefits to carers receiving individualised funding outweighed those receiving support under more traditional service provision models.

David cares for his adult son Gary David now gets four times as much respite as he did

Individualised funding

- · Individualised funding packages are allocated to people with all types of disability.
- Individualised funding programs have existed in countries other than Australia for over 40 years.
- · With a 'package', government funding that was previously allocated to block funded services is redirected and allocated to people on an individual basis, according to their needs.

previously and Gary has sufficient therapy, personal care and domestic help for the first time.

"Recently we opted for direct payment and direct employment of support workers and this is FANTASTIC. ... We have more choice and control, support is totally tailored to my undertake the training we want and we get more bang for our buck."

"Able to access to the therapies required without putting a financial strain on family income."

"Allows me to perform part-time work."

Similar sentiments came from carers in the UK (Larkin, 2015). Three quarters of the carers interviewed reported positive outcomes such as having more control over their lives, more free time, feeling happier and less stressed.

"...it freed my life up."

In the same study, a third of carers said their increased happiness was due to the person they cared for being happier:

"Well, if he's happy, I'm happy. It rubs off, doesn't it?"

In the USA Cash and Counselling program (Brown, Carson et al., 2007), it was found that carers of people using individualised funding were: less likely to report emotional or physical strain; more satisfied with their life and less worried about their loved one.

Concerns

Many carers in the NSW NDIS trial sites and in overseas studies felt that their needs were not sufficiently focused on or met.

In NSW they also felt that the administrative responsibilities involved in NDIS planning and implementation were difficult and tedious, with too many steps to complete and too many hoops to jump through. These feelings were echoed in other studies in the USA and UK:

"'What if I overspend?' 'I don't want to owe people money," 'What if I don't fill the form in right?' 'What if there is no money left?' 'What if they cut my budget?' 'I can't recruit anyone!'" (Glendinning, Challis et al., 2008)

"My husband, who has his own health problems, does his best to help me in the absence of my PA and does paperwork such as time sheets, account sheets, holiday sheets, logs all monies in and out, and all of this is unpaid which if an outsider was doing this would be paid. Why this difference because he is a family member? This is not physical but it is time consuming and somewhat costly paper, ink, disc etc. for computer." (Cheshire West & Chester Council, 2010)

What does it mean in NDIS-land?

The NDIS shows a commitment to carers by stating that supports to maintain a carer's health and wellbeing can be included in an NDIS participant's plans. This support might include participation in a support group or special interest network. However, it is still unclear what level of care-giving NDIS expects of them in order for them to qualify as people requiring support in their own right.

Commissioned research such as this is invaluable to organisations like Mind as we enter a whole new service delivery paradigm.

For more information or to read the full literature review go to: www.mindaustralia.org.au/ mind-literature-review





he Mind Model of Recovery Oriented Practice guides our work. This, and similar kinds of practice needs to be taught and shared. The PULSAR (Principles Unite Local Services Assisting Recovery) project aims to do just that: implement and evaluate recovery oriented practice in mental health across Primary Health Networks and specialist mental health services.

Project lead, Professor Graham Meadows (Monash University), is the Director of Southern Synergy - the Monash Health Adult Psychiatry Research, Training and Evaluation Centre. He is working with Mind and Eastern Regions Mental Health Association (ERMHA), Monash Health and Primary Health Networks to conduct this research.

Consumer academic, Vrinda Edan explains the project as such: "What we're doing is a particular way of teaching recovery oriented practice. We're duplicating training done in the UK, but with some changes to tailor for an Australian particularly Victorian - group."

One of the key differences in this study is that it includes general practitioners (the primary care sector). As a central conduit to navigating the mental health system in Australia, it is incredibly important that general practitioners (GPs) bring their care in line with recovery oriented practice. Professor Meadows says, "This is different from other mental health training that GPs will have done, and aims to build on the experience of GPs who are treating patients with a range of mental health conditions."

Dr Tony Atkins from Berwick Healthcare is a GP who has signed up to be part of the project. He said recovery orientation was an approach that had been established in specialist circles but hadn't been translated into primary care:

"We see PULSAR as an opportunity to participate in learning and applying the recovery orientation mode of helping mental health patients."

Promoting connectedness, hope, identity, meaning, and empowerment will hopefully inspire GPs and mental health workers to adopt a more patient-centred approach. So PULSAR is working to develop and deliver training in this sort of care.

In the UK version of this study it was found that people needed opportunities to continue to talk about recovery oriented practice, so in addition to the initial 2 days of training, PULSAR participants have monthly review meetings for 12 months. Those monthly meetings are opportunities for staff to reflect on their practice and reflect on how they're supporting their consumers in recovery.

These 'interventions' (as they're referred to in the project) allow for constant check-in and appraisal, and a space for staff to broach issues as they arise. And not just as they arise, but to continually revisit and revise.

Vrinda says, "Often people come to things after time. If you don't come back to the person a week or two weeks later, and say 'what have you been reflecting on?', then all you've done is relieve the immediate stress of the situation at a certain point, but not made any attempt to change practice."

"People need time to think about what the implications are in their workplace. Give something a bit of a go; come back and reflect; and then go back and try again."

The PULSAR project will show us how to both support consumers' and practitioners' progress towards recovery goals.



To find out more or to take part in the project, contact the research team on 03 9902 9695 or pulsar.admin@monash.edu or check out the website at: www.pulsarrecovery.org.au

PULSAR project partners

- Mind Australia
- Monash University
- ERMHA (Eastern Regions Mental Health Association)
- Monash Health
- Primary Health Networks

The science of people

Early career researcher embraces recovery principles; 'balancing out' the social and the clinical.

ooking forward, it is exciting and encouraging to see the theme of recovery gain potency in academic research. Another emergent trend in mental health research is a growing focus on carers. These are both themes at the core of Mind's work, so we caught up with early career researcher, Samantha Mignon who incorporated both in her thesis titled: 'Who cares for carers?'

Samantha recently went back to university as a mature age student to complete her Honours in social work because she is passionate about driving positive change in the mental health sector. Prior to this, she worked for a mental health unit in South Australia as a project officer, developing a uniform policy and procedure around the administration of Electroconvulsive Therapy (ECT) in public hospitals.

It was there that she recognised a significant gap in both research and practice: while there was plenty of support for those receiving treatment (consumers), there was very little available to support those caring for them.

"That always stayed in my mind. When I enrolled in social work I knew that this was a gap that needed to be acknowledged. The stigma around mental illness is still so prevalent. Not only do the consumers

receive a lot of that stigma, but so do their families."

As a carer herself, she wanted to be an advocate for them and a voice: "I wanted them to feel recognised and appreciated." She approached Mind in order to find some carers and says it was encouraging to discover how carer-focused Mind was. "I didn't realise that carers were such a big part of Mind's practice and strategic planning and innovation."

As an early career researcher with handson experience working in the field, it was important to Samantha to use modern models of practice when it came to her research, like the psychosocial and the recovery oriented models of mental health.

Particularly with something as clinical as ECT, Samantha was conscious of 'balancing out' the social and clinical aspects:

"While we trust and respect the clinical model - and have for centuries - I don't really feel that the social implications are considered accurately. And that's what I think social workers can bring to the field."

As specialists in the recovery model, Mind's research team were only too happy to act as advisors to Samantha - reading drafts,

offering feedback and fostering discussion. Her budding partnership with our research team gave her access to a vast knowledge base, and in turn, we will be able draw upon some of her findings to inform our future work.

We are also looking to invite her to present as part of our Mind Colloquium Series in 2016.

Samantha's work is due to be published in The Journal of Social Work and she hopes to be able to use her research in a practical sense to influence change:

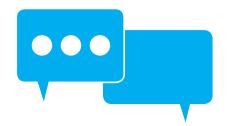
"My ultimate goal is to be given an employment opportunity by an agency or department to develop an ECT-specific carers group. To design it and co-facilitate it in conjunction with my findings and with those carers that participated in my research. They all came with fantastic knowledge."

Ticking all the boxes of what we see as important: a recovery focused ethos; co-production principles, and carersympathetic practice, the future is bright for mental health research.



If you are interested in getting involved with research at Mind visit www.mindaustralia.org.au/ research.html

In brief



This time, it's personal

Much of our research is focused on shaking up traditional, restrictive practices when it comes to mental health, in favour of developing personalised, empowering support services. One of our latest publications discusses just that: How social work can contribute to the shift to personalised, recovery oriented psychosocial disability support services. Mental health recovery is shown to be maximised when consumers and carers are consulted about their own priorities for treatment and care.

This publication is the result of the combined efforts of Dr Brophy; Consumer Consultants Nadine Cocks and Michael Stylianou; Psychology Research Fellow Annie Bruxner (University of Melbourne); and Associate Professor of Disability and Inclusion, Erin Wilson (Deakin University).

Service expansion

Along with our Cairns Prevention and Recovery Care (PARC) unit and Toowoomba Community Care Unit (CCU), Mind has picked up two new tenders in Townsville and Ipswich, Queensland. We're also excited to announce that we are expanding our Recovery College and we anticipate the opening of our first **headspace** in north east Melbourne in April.



Brought to you by renowned consumer movement advocate Mary O'Hagan, in conjunction with Mind and other service organisations, Swell is an online and paper-based recovery toolkit for mental health service workers and service users.

They can use it collaboratively or independently of each other. The toolkit is being developed in response to a need for service workers to have easy access to best practice information and conflict and resolution skills. Similarly, clients can use the toolkit as a way to deeply engage with their recovery - completing, sharing and storing activities or strategies that they find useful. Mind's Housing and Accommodation Supported Partnership service in Burnside (SA) and Peer Recovery Communities in Williamstown and Brunswick (VIC) are trialling the toolkit and will work with Mary to give insight into its effectiveness.



www.swelltoolkit.com

Risk and recovery: competing or complementary?

A preoccupation with symptoms and risk has persisted in the mental health sector, despite tendencies towards more recovery focused models of treatment. This well-intentioned but negative focus has contributed to stigma, discrimination, and exclusion experienced by service users. Dr Brophy's recent paper, 'Risk, recovery and capacity: Competing or complementary approaches to mental health social work', published in the journal of Australian Social Work, looks at how mental health social workers can balance the core tenets of recovery with meeting the requirements of risk assessment in their practice.



Despite positive developments in policy, it was found that in most countries the focus of mental health services and the relevant legal frameworks remains on symptoms and risk. This research argued that the most effective way to manage symptoms and risks may be to concentrate on strengths, hopes, and supported decision-making.

Abuse in the disability sector

The Victorian Ombudsman's report on is a comprehensive review, focused on issues related to the mismanagement of abuse and inadequate reporting systems.

One million Victorians live with a disability and 365,000 of those are defined as having experience sexual assault and a recent survey of workers in disability facilities abuse or neglect of clients by other staff.

These statistics are concerning, and in response to this, Mind is embarking on a project to strengthen the positive reporting culture that exists in our services.

Get SMART

The SMART (Self-Management and Recovery Technology) research program is investigating how digital technology can be integrated within mental health services for people with serious mental illness. The premise is that digital technology provides a means of empowering consumers in promoting their own recovery, and empowering mental health staff with tools to help them.

Led by Dr Neil Thomas at Swinburne University of Technology, we are working in partnership with the MI Fellowship, Alfred Health, NorthWestern Mental Health, St Vincent's Mental Health, and La Trobe and Deakin universities to deliver this project.

Through consultation with consumers, workers and carers, an online resource has been developed, to be used on tablet computers during consultations between mental health workers and their clients, as well as being accessible by consumers at home or on a mobile phone. This provides resources, exercises and tools to promote personal recovery.



In early 2015 a pilot study of the SMART-Therapy intervention was completed, with positive results and wonderful feedback from 10 participants:

"I think the technology was a guide; it kept our discussion going in a direction that we wanted it to go in. And it would raise the topic or it would raise the next discussion. But we did do a lot of talking ... and I felt the two worked together really, really well."

"It was good because we had something to look at and then something to discuss about. So we had website time and then we had people time, so it helped. Having that tablet, or that iPad, was good in a way. They don't use that enough in the clinics so it's a very good idea.'

This project is funded by the Mental Illness Research Fund. Contact (03) 9214 5304 or smartonline@swin.edu.au for more information.

Discrimination in the workplace

New research commissioned by SANE Australia highlights discrimination experienced by people with mental health challenges looking for work. An Australian survey, the first of its kind in the world, has asked people with mental ill-health or high symptom levels how they have been treated by different groups of people including friends, partners, co-workers and others in the community.

SANE CEO Jack Heath says, "Improved understanding of mental health conditions



in the workplace can reduce stigma a major barrier for employees, let alone potential employees, who feel they can't disclose their mental health concerns without fear of discrimination."

Το read more go to: https://www.sane. org/images/PDFs/1405 info rb18.pdf



Recovery a core subject at university

Mind's Senior Advisor Lived Experience, Anthony Stratford, has been changing the face of psychiatric studies using his lived experience and expert knowledge. After many years of planning and road testing, recovery oriented practice is now - for the first time ever - a core subject in the Master of Psychological Medicine/Master of Psychiatry degree (delivered through Monash University and the University of Melbourne). Anthony, who is a Visiting Scholar at Yale University, will teach the subject himself.

Putting recovery at the core of a psychiatry degree gives these students the opportunity to usher in a new age of psychiatric practice that places as much value on hope and agency as any other clinical element. The course fosters attitudes of tolerance and equity, and encourages practitioners to consider sociocultural factors in their interactions with patients and their broader community.

Anthony will also be delivering a paper on integrating recovery oriented practice into psychiatric registrar training at the 2016 **RANZCP International Congress of** Psychiatry in Hong Kong in May this year.

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