



# newparadigm

RESEARCH  
INTO PRACTICE

THE AUSTRALIAN JOURNAL  
ON PSYCHOSOCIAL  
REHABILITATION

Summer  
2017/18



Psychiatric Disability Services  
of Victoria (VICSERV)



# CONTENTS

## EDITORIAL

Debra Parnell

04

**Community managed mental health and the NDIS – learning from the past and working towards a good life**

Amanda Bresnan

06

**Trends in research and the mental health sector: an update**

Dr Lisa Brophy

09

**Building capacity for spiritual care and wellbeing in the mental health workforce**

Cheryl Holmes and Jenny Greenham

11

**Supporting choice and control: skills for mental health and psychosocial support workers**

Corinne Henderson

16

**Occupational therapy for mental health in an NDIS framework: Exploring the evidence**

Gayle Kissonergis, Anita Volkert and Michael Barrett

21

**The Reasons for Use Package: how mentoring aids implementation of dual diagnosis practice**

Kevan Myers, Simon Kroes, Sarah O'Connor and Dr Melissa Petrakis

25

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**Cultural humility training in mental health service provision**  
Mayio Konidaris and Dr Melissa Petrakis

30

**Recovery co-design and peer workforce development in the acute inpatient setting**  
Jacinta Chavulak, Liam Buckley and Dr Melissa Petrakis

34

**Using consumer engaged evaluation to support service innovation**  
Dr Lisa Brophy, Cassandra Politanski and Mark Heeney

40

**Somewhere to be safe: women's experiences of a women only Prevention and Recovery Care service**  
Karen Dixon, Alys Boase, Professor Ellie Fossey and Dr Melissa Petrakis

45

**Creating an environment that cultivates meaningful consumer led or co-produced research. Are we there yet?**  
Dr Katherine H Gill

49

**Research News**

53

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We very much welcome contributions to *newparadigm* on issues relevant to psychiatric disability support, psychosocial rehabilitation and mental health issues, but the editor retains the right to edit or reject contributions.

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## EDITORIAL

Welcome to the Summer 2017/18 edition of **newparadigm** – *Research into Practice*



**Debra Parnell** is the Policy and Communications Manager at VICSERV

In this edition we present a number of current and recent research projects and explore the impact they have had or can have on practice in mental health.

This work covers a number of areas and exciting developments. While the implications for service delivery under the National Disability Insurance Scheme (NDIS) continues as a strong area of interest, it is important that other areas of mental health practice, and particularly outcomes for consumers, are also being taken up in research.

The Community Mental Health Australia (CMHA) National NDIS Mental Health Conference, held last November, echoed this idea that the NDIS is only part of the broader picture. CMHA Executive Director, Amanda Bresnan, opens this issue with a summary of the key issues arising from the CMHA Conference. There is clearly a need to view the current systemic issues from the perspective of people with a lived experience and to take this opportunity to create a system that consumers and carers need.

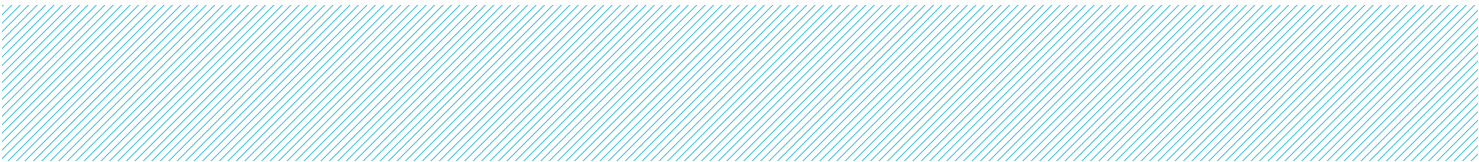
Across the diversity of research we have included in this edition it is apparent that there is a focus on personal recovery and wellbeing outcomes. Alongside this there is also an emphasis on active consumer participation in research, such as engaging consumer researchers and lived experience advisory panels.

Lisa Brophy provides an update on trends in research in the mental health sector in Victoria, highlighting the strong focus and commitment to research that is currently impacting across the sector:

*There is no turning back. There are now high expectations from government, funders and all participants that research will demonstrate commitment to collaborative partnerships and interdisciplinary research that includes consumer and carer researchers and co-design.*

A number of the research initiatives presented in this edition focus on building capacity in order to improve practice and outcomes:

- The first of these outlines the application of evidence-based approaches to address the spiritual needs of consumers. In its pilot program, the East Gippsland Mental Health Initiative provided training to mental health workers and evaluated the capacity of workers as well as outcomes for consumers.
- Similarly a research collaboration between Nexus, Neami National and Monash University resulted in the development of a new approach to dual diagnosis capacity through the provision of training to improve dual diagnosis practice.



In this research a dual diagnosis package – the *Reasons for Use Package* – employed a mentoring component, which assisted in confidence and knowledge following the training.

- Corrine Henderson from the Mental Health Coordinating Council (MHCC) outlines a program designed to improve understanding by mental health and psychosocial workers about supported decision making and to increase their capacity to work better with consumers to increase their decision-making autonomy. This has particular application in the NDIS environment, where choice and control are central concepts and the ability of people to develop goals and make decisions could have significant outcomes.

Another strong theme in the research showcased is around innovative models:

- Mayo Konidaris and Dr Melissa Petrakis outline the delivery of training on 'cultural humility' to enable mental health workers to critically reflect on their own values, attitudes and behaviours when working with culturally diverse consumers, carers and families. The evaluation of this innovative approach to improve assessment and recovery outcomes for people from culturally diverse communities found there were benefits to be gained at both individual worker and organisation levels, as well as for practice.
- After identifying that half the number of people who were admitted to in-patient units through Emergency Departments were first time admissions and that half of those people experienced seclusion, an innovative pre-admission liaison program was established at St Vincent's Hospital in Melbourne, using a peer worker as a central component of the intervention. Although the project drew on a small sample, it identified and confirmed that participants valued being informed, having contact with people who have a shared experience and having safe and positive links in the ward.

Across the research themes there is a focus on consumer perspectives as well as active participation in research:

- In undertaking an assessment of Mind Australia's Peer Recovery Communities, researchers evaluated the process of changing to a new model, and the experience and satisfaction of consumers, and their families and carers. The evaluation found great support for the model and in particular for having a strong peer support component. Consideration is also given to the role of the PRCs in Supported Independent Living under the NDIS.
- Researchers from Monash University, in collaboration with Ermha, analysed the feedback from women who accessed Victoria's first women-only Prevention and Recovery Care (PARC) service, to inform further development of the program. The research found that residents had overwhelmingly high satisfaction levels with the program. This and other benefits identified from the model strengthen the calls for more women-only PARCs and other gender specific programs.
- Providing a strong overview, Dr Katherine Gill, Chair of the Consumer-Led Research Network, discusses the need for cultivation of meaningful consumer-led and co-produced research. She warns that lack of clear frameworks, guidelines and funding structures leads to haphazard and ad hoc processes of consumer involvement.

Also in this edition, rather than our customary Vox Pop, we have provided briefs on new research.

We hope that you enjoy the edition and find the information and ideas presented through these articles to be thought provoking and valuable.

I would like to thank the contributors who have made this a very interesting and stimulating edition of *newparadigm* and to the new Journal Editorial Group, with representatives from CMHA and each State and Territory member organisation, who have endeavored to reflect the issues and interests of the mental health sector across the country.

Finally I thank the VICSERV team for their valuable assistance in the production process.

## Community managed mental health and the NDIS – learning from the past and working towards a good life



**Amanda Bresnan** is the executive director of Community Mental Health Australia

The Community Mental Health Australia (CMHA) National NDIS Mental Health Conference on 16 and 17 November in Sydney was the first community-led and run conference on mental health and the National Disability Scheme (NDIS) in Australia.

The conference sold out, demonstrating the significant interest and need from the sector for this type of event, and marking important leadership by the community managed mental health sector in exploring and developing the potential of the NDIS.

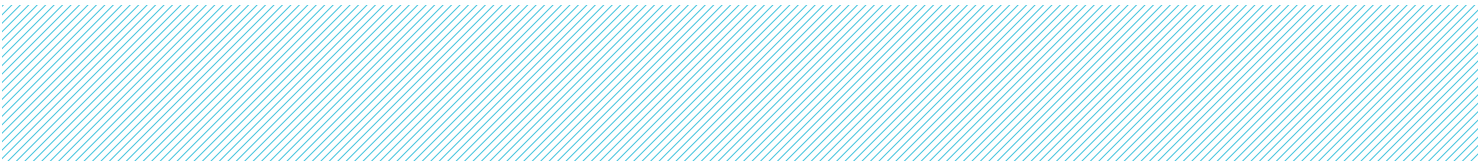
The conference was attended by consumers, carers, community sector employees – who made up the largest group of participants – and public sector employees, from across the health and community services. The feedback during the two days and since has been overwhelmingly positive, in that it was the first real opportunity for the sector across the country to engage and learn from each other on the NDIS – which is having a significant influence on how the sector will develop.

The theme of the conference was 'towards a good life', as the sector recognises the significant opportunity the NDIS presents. However, it was clear that it is vital for governments and all agencies involved with the NDIS to work in partnership with consumers, carers and the community managed mental health sector to learn from the lessons of implementation sites and confront the emerging challenges and issues. Doing this, and remembering that participants and a consumer directed scheme should be at the centre of anything that happens with the NDIS, will be the key factors in the NDIS succeeding.

This is very much a human rights issue. As a peer worker put it at the conference, "the genie is out of the bottle" and consumers want their human rights respected and voices heard. We need to make sure we use this opportunity to create a system that delivers what consumers and carers need.

Other key issues and messages to come out of the conference were:

- The central role that peer workers can play in the NDIS – across all population groups – and the impact that the NDIS pricing model is having on the workforce through casualisation, low pay and instability.
- Providers are struggling with the NDIS price structure and the impact this may have on the safety and quality of services.
- There is a problematic relationship between the recovery model of mental health and the deficit model of the NDIS, and an issue of the language used by the sector and how this works with and is understood within the NDIS context.
- The sector must educate itself on providing services to diverse populations including Aboriginal and Torres Strait Islander people, culturally and linguistically diverse groups and the LGBTIQ community. For example, Aboriginal and Torres Strait Islander people do not experience discrimination in their own communities but are disadvantaged by the broader social environment.



- The lesson from implementing Local Area Coordination in the United Kingdom was that it was vital for providers to be in a community early to establish a presence and the trust of people needing locally coordinated mental health services.

A number of speakers reminded everyone that the NDIS is only one part of the wider picture. It will provide services to a limited number of people with psychosocial disability and the significant issue is providing proper support for people living with a mental health condition who won't be eligible for the NDIS.

Governments at all levels will need to work together and provide services to people with psychosocial disability, regardless of their NDIS eligibility, as was noted by the Productivity Commission's NDIS costs inquiry.

The aim of the conference was to build the sector's capacity to respond to the NDIS transition through discussions on best practice, lessons learned at trial sites, and by looking at the broad scope of groups and areas that are a part of this significant change to service delivery across the country. The conference achieved this.

What was also clear is that we must view issues, problems and solutions through the eyes of people with lived experience, and that co-design and co-production is essential.

As Gerry Naughtin, CEO of Mind Australia and the recently announced Mental Health Adviser to the NDIA, described it, we are in the eye of a transformational storm. The NDIS is changing lives but we must look to where we have come from and use this to get us where we need to be.

CMHA looks forward to progressing the outcomes from the CMHA National NDIS Mental Health Conference and to continuing to work with the community managed mental health sector, consumers, carers and governments at all levels to ensure the NDIS fulfils its potential.



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We need to make sure we use this opportunity to create a system that delivers what consumers and carers need.

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## Trends in research and the mental health sector: an update



**Lisa Brophy** is Associate Professor and Principal Research Fellow at Mind Australia, Centre for Mental Health, Melbourne School of Population and Global Health, The University of Melbourne

It is a credit to the mental health community support sector (MHCSS) in Victoria that there is currently such a strong engagement with research. Research has ensured the sector is reporting on outcomes, raising expectations from service delivery and supporting innovation.

I would like to reference a paper thoughtfully written just this year by the late (and sadly missed) Jackie Crowe who said:

*The true measures of quality are the outcomes that matter to the people who use (or will use) the service and their families. This requires a range of measures of consumer and family experience of care that are fit for purpose, and consumer self-rated measures. These measures exist in abundance, and are conveniently and widely available on the internet. The tragedy is the longstanding indifference to collecting and publicly reporting on outcomes. When outcomes are collected and reported publicly, providers, organisations and governments face both tremendous pressure and strong incentives to improve. (Crowe 2017, p. 2)*

Due to the influence of Jackie and others we are now seeing much more emphasis on rigorous research and evaluation activities in the sector that have achieved significant funding by government. The focus on personal recovery and wellbeing outcomes ensures that we are monitoring whether changes in policy and practice are reflected in the findings of mixed methods research activity across the state.

A consumer self-rated measure of personal recovery – the Questionnaire about the Process of Recovery (the QPR) – is the primary outcome measure in three large projects in Victoria (Neil et al. 2009). The QPR has been used, for instance, in the PULSAR project and SMART (both funded by the Mental Illness Research Fund – MIRF) and more recently the statewide Prevention and Recovery Care (PARC) Services project. PULSAR is researching the impact of a recovery training intervention (Shawyer et al. 2017), SMART an online recovery resource (Thomas et al. 2016) and the PARCS project is investigating the appropriateness, effectiveness and efficiency of Victoria's adult PARC services – a major service innovation.

These projects have engaged the MHCSS as partners and have involved consumer researchers and lived experience advisory panels as core features. These are also features of the other MIRF projects – CORE (Palmer et al. 2016), Horyzon (Alvarez-Jimenez et al. 2016) and Let's Talk (Mayberry et al. 2017). These projects are focusing on the recovery and wellbeing outcomes for people using mental health services. Findings are now gradually being shared and each has important implications for building the evidence base for the MHCSS.

Currently we are learning how to interpret and understand findings from the QPR and other consumer rated measures like the INSPIRE (Williams et al. 2015) and the Perceived Need for Care Questionnaire (Meadows et al. 2000). These measures enable a person-oriented perspective on consumer's experiences of care and their recovery journey and have the potential to make a strong contribution to service reform and innovation.

The \$10 million investment from the Victorian Government towards these projects has helped to further mature non-clinical mental health research efforts in Victoria. The success of the PARCS project gaining a highly competitive National Health and Medical Research Council (NHMRC) partnerships grant was in part due to being able to build on the experience and connections formed through the MIRF projects.

There is no turning back. There are now high expectations from government, funders and all participants that research will demonstrate commitment to collaborative partnerships and interdisciplinary research that includes consumer and carer researchers and co-design.

There are future challenges in undertaking research in the National Disability Insurance Scheme (NDIS) environment – considering the resource implications and the rapidly shifting landscape. However, undertaking research regarding choice and control, social interventions and individualised funding is a current imperative to inform policy development and sector reform. Current examples include a project funded by Mind Australia investigating people with psychosocial disability as choice-makers in the context of NDIS. The sector is also now very well placed to encourage and support more consumer led research efforts and ensure that the MHCSS is actively engaged in research that is relevant, participatory and has impact.

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#### Useful Websites:

- <http://mospgh.unimelb.edu.au/research-groups/centre-for-mental-health/mental-health-policy-and-practice/building-the-evidence-base-of-prevention-and-recovery-care-parc-services-in-victoria,-australia>
- <https://www2.health.vic.gov.au/mental-health/research-and-reporting/mental-illness-research-fund>
- <https://www.mindaustralia.org.au/about-mind/research-mind/please-tell-us-your-experience-making-choices-under-ndis>

## Building capacity for spiritual care and wellbeing in the mental health workforce



**Cheryl Holmes** is Chief Executive Officer, Spiritual Health Victoria

**Jenny Greenham** is Mental Health Leader, Spiritual Health Victoria

The East Gippsland Mental Health Initiative aimed to build the capacity of mental health workers to respond to the spiritual needs of their clients/patients. Its results, supported by other studies, show that workers can benefit from training in the area of spirituality and spiritual care, and that this could provide positive outcomes for clients/patients.

### An opportunity for training development

The East Gippsland Mental Health Initiative (EGMHI) was established in 2011 to administer a funding grant from the Victorian Government which included the aim to "build capacity for spiritual work and wellbeing in community mental health support service delivery" (SNAP Gippsland 2014).

Within Australia (formerly known as SNAP Inc.) was nominated as the lead agency to facilitate various community capacity programs in the Gippsland region. On behalf of the EGMHI, it engaged Spiritual Health Victoria (SHV) to design and facilitate a training program.

A total of 46 participants took part in the training which included completion of a pre-training survey, a one day training event (offered on five separate occasions to increase opportunities for participation across the region), post-training evaluation and a follow-up evaluation six months after the training was delivered.

### Pre-training survey

A pre-training survey, distributed to each of the participants on registration, was conducted to ascertain their thoughts and understanding of the words 'spirituality' and 'spiritual care'. It was adapted from a survey developed by Wilfred McSherry in collaboration with representatives from the Royal College of Nursing in London (2010).

Parts 1 and 3 of the survey used Likert scale questions to first explore understandings of spirituality and spiritual care and then to ascertain what actions, if any, were needed to enable workers to respond to spiritual needs. Parts 2 and 4 explored the role of respondents in attending to spiritual needs of patients/clients and then collected demographic information to ascertain the religious background and/or spiritual beliefs and practices of respondents. The final section of the survey made provision for open reflections and comments by respondents.

The majority of respondents in the pre-training questionnaire understood spirituality and spiritual practice to be far broader than specific religious ritual.

## Training program

The training program 'Building capacity for spiritual care and wellbeing' was developed specifically for those people whose work involves contact with clients or patients who have a lived experience of mental illness. The training introduced concepts of spirituality and whole person theories that support people suffering mental ill health to find meaning, purpose and clarity in their lives, and to influence recovery outcomes.

The training used resources from a variety of sources including local authors and artists to ensure it was grounded in the Australian experience. These included David Tacey (author), Michael Leunig (cartoonist, author, poet) and John Watkins (counsellor, mental health worker, author). Table 1 provides an overview of the course structure.

Table 1: Overview of training

1. Understanding our context	
Policy framework	Models of mental illness
What is spirituality?	Recovery principles
2. Importance of spiritual care	
Spiritual care and wellbeing	Assessment tools
Current research	
3. How you can make a difference	
Activity	Eco-spirituality
Interventions	Staff needs
Case study	Questions

The training employed various adult learning methods including group work, role playing and opportunities to share personal experience and insights.

## Post-training evaluations

The post-training evaluation was designed to collect feedback from the participants following the one day training program. The evaluation form included questions to gather demographic information, five Likert scale questions with the option to add additional comments, and four open-ended questions. The evaluation pro forma is the standard evaluation used by SHV for all training programs and was designed for SHV by a research consultant.

## Six-month post-training evaluations

A six month post-training evaluation using Survey Monkey was emailed to participants to assess whether the training continued to have any impact on their capacities to engage with clients around their spiritual care needs. The survey consisted of one open-ended question and four Likert scale questions. The survey was developed by SHV's Mental Health Leader.

## Pre-training survey results

A total of 32 (70 per cent) pre-training surveys were completed and returned: 22 (68 per cent) respondents were female and ten (32 per cent) male.

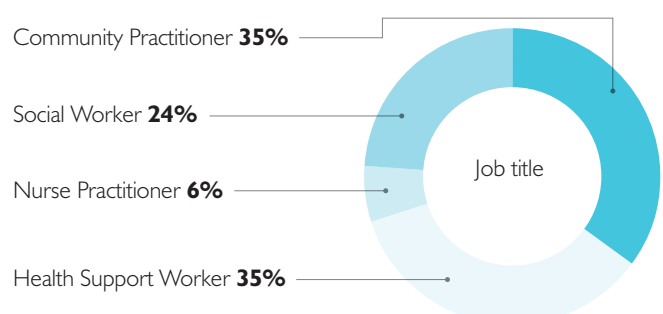
The majority of respondents were aged over 60 years (35 per cent) or between 40-49 years (28 per cent): 19 per cent were aged between 50-59 years while those aged between 20-29 years and 30-39 years each made up 9 percent of respondents.

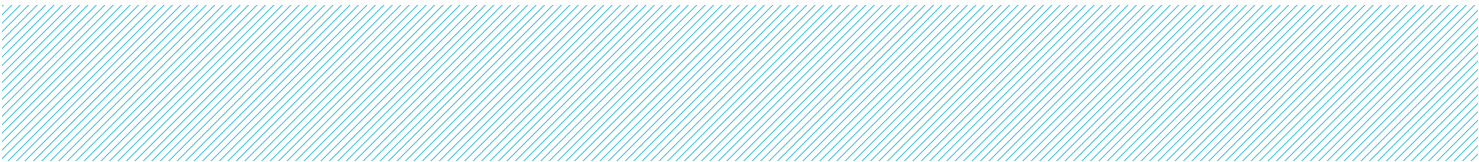
Sixteen (48 per cent) respondents nominated that they had no religion, with 14 (45 per cent) nominating Christianity and two (7 per cent) Buddhism.

The majority of respondents (77 per cent) considered themselves to be 'a spiritual person' while 23 per cent did not.

The job titles designated by respondents are outlined in Figure 2 and the places they were employed in Figure 3.

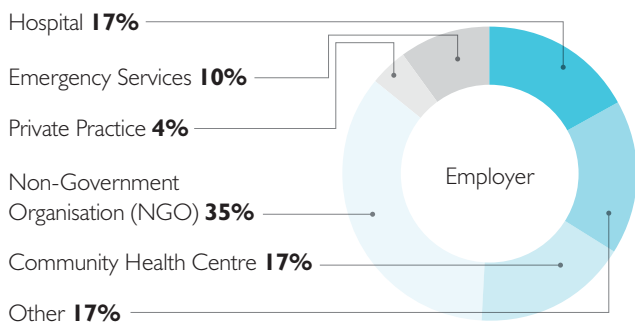
Figure 1: Job Titles nominated by respondents





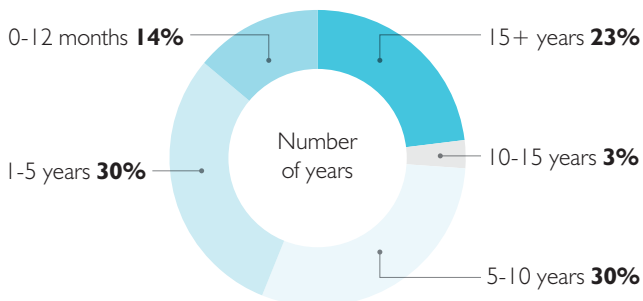
The pre-training survey showed that all participants were only 'sometimes' confident or 'never' when considering their capacity for working with the spiritual care needs of their clients/patients.

Figure 2: Respondents' places of employment



The number of years respondents had been qualified as professionals in their field is provided in Figure 4.

Figure 3: Number of years respondents have been qualified



The majority of respondents in the pre-training questionnaire understood spirituality and spiritual practice to be far broader than specific religious ritual. The survey revealed that all respondents agreed that spirituality extends beyond going to a church or a place of worship. A large majority (74 per cent) indicated that spirituality included concepts of: finding meaning in life events; having a sense of hope; contributing to feeling at

peace with oneself and the world; personal friendships and relationships; and can include areas such as art, creativity and self-expression.

Most (29, or 91 per cent) respondents understood 'spiritual care' to include: showing kindness and concern when offering care; giving support and reassurance in times of need; and having respect for privacy, dignity and the religious/cultural beliefs of a person.

Twenty-six (84 per cent) respondents said they believe that spirituality and spiritual care are fundamental aspects of health care.

Twenty-eight (90 per cent) indicated that they have encountered a client/patient with spiritual needs. They discern these needs most commonly by utilising their skills in listening and observing, sensing and 'hunching', information derived directly from the person and via referral documentation. When asked if they felt able to meet a client/patient's spiritual needs, none indicated that they were 'always' able to do so, while 89 per cent responded 'sometimes' and 11 per cent 'never'.

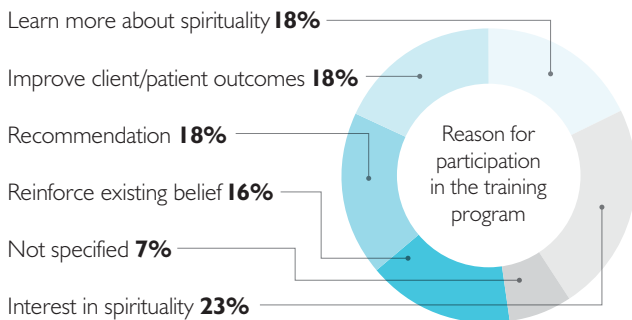
The majority of respondents felt that training and education of worker skill set deficits in the area of client/patient spiritual and religious issues should be addressed.

More than half (57 per cent) indicated that Health Departments should provide clear guidance and support while 73 per cent of respondents believed that health care provider organisations should do so.

### Post-training evaluation results

Training participants were mainly mental health professionals working full-time or part-time in the East Gippsland region of Victoria. A total of 44 out of a potential 46 evaluations were completed and returned at the end of the training program. Figure 5 outlines respondents' reasons for participation in the training program.

Figure 4: Reasons for participation in training



In terms of overall ratings for the training program, 98 per cent of participants were either 'very satisfied' or 'satisfied' with the training. Participants appreciated being offered resources and information that supported pre-existing and/or new understandings of spirituality. Suggestions to improve the training included: more in-depth knowledge; information specific to different faith groups and belief systems; the provision for more discussion, role plays and guided meditation. When the participants were asked if they felt more equipped to respond to the religious and spiritual needs of people experiencing mental illness, 93 per cent stated 'yes', with two per cent 'not sure' (stating they would like further intensive training) and 5 per cent recording 'no' because they already felt equipped before the training.

#### Six-month post-training evaluation results

A total of 11 (24 per cent) participants responded to the six month post-training evaluation, with 80 per cent indicating that the training continued 'to improve client/patient outcomes'. Ninety per cent reported that they were either 'very comfortable' or 'moderately comfortable' talking about spiritual wellbeing or spiritual matters with clients/patients. Respondents indicated that the training prompted further exploration/ reflection on their own spirituality (82 per cent) while 73 per cent responded that they would be interested in further training in this area.

One of the respondents who provided further comments wrote:

Due to encouraging a chronically suicidal person to explore their spirituality, this person is now stating that they love life and is thanking me immensely for the guidance.

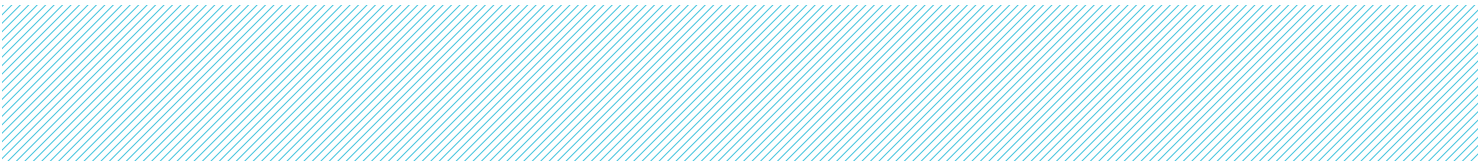
#### The importance of building capacity for spiritual care

The literature has continued to demonstrate that addressing spiritual needs is of importance to clients/patients and can be of help (Sims 2009; Lukoff 2012) and acknowledges the lack of confidence experienced by health professionals in their capacity to respond to this area of need (Haynes et al. 2007; Ledger & Bowler 2013).

While this pilot training program had a relatively small cohort of participants, the post-training evaluations indicated that the training program was of value to those workers who participated. The data suggests that the majority of mental health workers who participated had a sound understanding of the concepts of spirituality and spiritual care prior to the training. They did not conflate the concept of spirituality with religion, clearly demonstrating a broad understanding of spirituality consistent with its use in health care today (Puchalski et al 2014).

However, even within this broad understanding, workers were not always confident to respond to the spiritual needs of their clients/patients. The pre-training survey showed that all participants were only 'sometimes' confident or 'never' when considering their capacity for working with the spiritual care needs of their clients/patients. The shift to 93 per cent feeling more equipped after the training and 90 per cent feeling comfortable six months post training suggests that engaging in the training was able to build the capacity of these mental health workers to respond to client/patient spiritual care needs and is consistent with other outcomes (Ledger & Bowler 2013).

The comment from one participant, included above in the six month post-training evaluation, indicates the direct impact this training had on the outcome for one client/patient. This outcome is supported by studies that have demonstrated the positive effects of spirituality and spiritual care for mental health, including protecting some from suicide (Wilding 2007).



For this reason alone the training warrants further attention and support. This training has now been conducted with other organisations with consistent positive results.

### Conclusion

The East Gippsland Mental Health Initiative included an aim to build the capacity of mental health workers to respond to the spiritual needs of their clients/patients, clearly recognising that this was a gap for workers and important to their clients/patients.

The implementation of this pilot training program has taken a small step towards the conclusion, supported by other studies, that workers could benefit from training in the area of spirituality and spiritual care, and that this could provide a positive outcome for clients/patients.

While clearly further research is required, the results of this pilot training program do suggest that building the capacity of mental health workers to respond to the spiritual needs of their clients/patients can have life changing results.

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## Supporting choice and control: skills for mental health and psychosocial support workers



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Discussions about decision-making support are timely, given the emerging National Disability Insurance Scheme (NDIS) and other evolving mental health reform initiatives. Mental health and psychosocial support workers play an important role in building the capacity of people living with mental health conditions to develop skills that maximise decision-making autonomy.

Supported decision-making (SDM) is an approach underpinned by principles and values that acknowledge the particular difficulties people living with mental health conditions often experience that may impact their day-to-day functioning.

The Mental Health Coordinating Council's professional development course – *Supporting choice and control: skills for mental health and psychosocial support workers* – offers a practical opportunity to learn about a decision-making process that represents a comprehensive response for improved community living and recovery.

This article outlines the theory and practice of supported decision-making and why the NDIS provides an imperative for it to be considered and offered as best practice in mental health and psychosocial support.

### Background

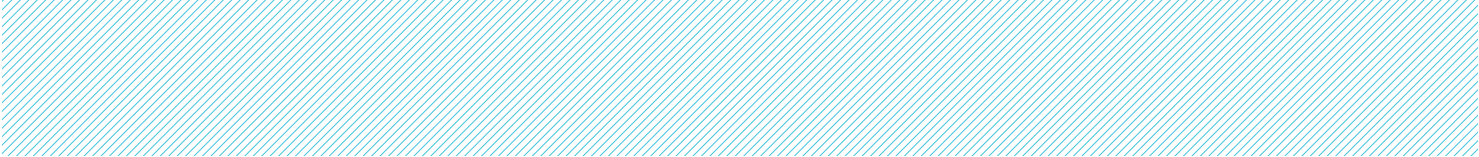
*'When you support a person to make decisions, you are enabling them to live a more independent, dignified and meaningful life'* (National Disability Insurance Scheme, 2017).

People with mental health conditions characteristically experience a complex mix of co-existing issues which can influence their progress towards achieving recovery aims. For example, obstacles that arise from problems with cognition typically present a barrier to independent living that can affect multiple facets of an individual's life, including decision-making capacity.

MHCC's research into this important but neglected area indicates that mental health and psychosocial support workers need to enhance their skills to work more effectively with clients. This particularly relates to supporting people to develop goals and make decisions that enhance quality of life and improve recovery outcomes. This is a key objective in relation to ensuring 'choice and control' in the NDIS and mental health reform environment across Australia.

Every day we make countless decisions. They are an expression of who we are – our uniqueness, our relationships with others, our achievements and hopes for the future (Pathare & Shields 2012). Through decision-making we exercise control over





our lives, experience new things and learn about ourselves. Decision-making is so important that it is generally recognised as a human right (Council of Australian Tribunals 2009).

Decision-making is a skill that can be developed and practised with support. Supported decision-making can assist a person to live with meaning, dignity and greater independence. It is an approach that embraces principles and values designed to support people make decisions, exercise legal capacity and exert greater choice and control. It is a key quality improvement area that aligns with best practice in recovery orientation.

The *Supporting choice and control* course invites participants to explore supported decision-making within a recovery paradigm, build skills and develop approaches that encourage people to exercise their right to choice and control in their lives.

### **A supported decision-making approach**

Distinct from other decision-making models and approaches, supported decision-making supports a person's right to lead and make decisions affecting them. It also reflects the way we draw upon our networks of support when making decisions. It centres on the meaningful participation and ultimate decision-making by the person (Victorian Law Reform Commission 2011).

Decision-making approaches can be presented as a continuum, ranging from independent to formal arrangements such as guardianship or financial management orders, with various levels of support occurring that are in-between and decision specific (Office of the Public Advocate 2010). A person may require different levels of support at different times. This can depend on a number of factors, including the particular decision to be made, the person's current situation, and those available to provide support.

Supported decision-making is a well-accepted approach to decision-making, although at this point in time there is no one single accepted definition and it is not entrenched in any Australian legislation. Substitute decision-making generally refers to a range of practices *'that deny or diminish the equal recognition of people with disability before the law, and their ability to exercise legal capacity'* (Australian Law Reform Commission 2014). This comment reflects a shift in contemporary thinking about how to support people with disabilities, by moving away from deficit-based models that are paternalistic. It is a social and human rights approach to empowering people to make and communicate their decisions whatever their difficulties. It is:

*'An approach that facilitates the development of decision-making skills and confidence building over time'* (NSW Public Guardian 2016)

### **Underpinning principles and values**

The Australian Law Reform Commission (ALRC) is a national body established to review Australian law to ensure it provides access to justice for all Australians. In 2012 the ALRC began a review of all the legislation that relates to individual decision-making to determine the changes necessary to embed the rights, respect and autonomy of people with a disability within the law. It determined that this could best be achieved by establishing a set of National Decision-Making Principles to guide reform (ALRC DP 81 2014). These can be simply described as:

- Everyone has the right to make decisions about the things that affect them.
- Capacity to make decisions must be assumed, and capacity is decision specific.
- Every effort should be made to support people to make decisions.
- People have the right to learn from experience, change their minds and make decisions others might not agree with.

These principles are central values that underpin and support best practice in a process that enables workers to better promote autonomy, self-determination, and self-direction, and which facilitates a process that is person-centred, flexible and retains a strengths-based focus which is respectful and acknowledges lived experience and expertise.

### **Importance for people with mental health conditions**

Decision-making is considered to be an advanced cognitive (or thinking) skill that requires a range of abilities such as concentration, memory, planning, problem solving and the ability to think through the consequences of actions. Making decisions can be hard when problems affecting cognition impact these abilities and the capacity to sustain motivation and interest.

## Through decision-making we exercise control over our lives, experience new things and learn about ourselves.

It is very common for a person with a mental health condition to experience some level of cognitive difficulty (Green et al. 2014). This can impact their ability to carry out everyday activities, and can also influence how workers, family and others perceive and judge their skills, abilities and interest in participating in activities, setting goals and making their own decisions. The beliefs of others can significantly impact the way a person views themselves and can undermine confidence in their own ability to make decisions that affect their lives.

### Cognition and people living with mental health conditions

There are a number of reasons why people may experience problems with cognition which can affect decision-making capacity. These can include the symptoms of mental illness as well as the side effects of treatments including Electroconvulsive Therapy (ECT). Medications are the main treatment approach for mental health conditions, and many have unwanted effects, some of which are common while others differ from person to person. Unwanted effects can also be caused by the interaction between different medications a person is taking. Some directly relate to cognitive function, for example drowsiness or confusion, whereas others are not directly related, but will have some influence on overall cognitive capacity, such as nausea, twitching or akathisia (inner restlessness) (Sane Australia 2016).

Trauma is widespread in our society and is known to be a common experience for individuals with mental health conditions. It is very likely that trauma, especially that which was experienced in childhood, will have impacted on cognitive development.

*'Mental illness and trauma, especially when they co-exist, may and often contribute to and exacerbate difficulties'*  
(Nikulina & Widom 2013).

The long-term effects of alcohol and other substances, including prescription medication can also cause problems with cognition. Likewise, individuals can experience cognitive difficulties due to an acquired brain injury (ABI) for example, which may be the result of a stroke or a traumatic head injury such as a severe blow to the head (Langolis et al. 2006).

Despite thoughts to the contrary, research has shown that it is relatively uncommon for older people to experience cognitive difficulties, although the risk of having mild cognitive difficulty or dementia increases with age (Deloitte Access Economics

& Alzheimer's Australia 2011). Urinary tract infections (UTIs) are types of infection that are common among older people which can cause 'delirium'. Awareness of the presence of UTI in the elderly, especially when pre-existing cognitive difficulty is present, is important for early recognition and treatment. Similarly individuals with eating disorders experience significant difficulties that may be related to cognitive changes that occur as a consequence of starvation, fixed thinking patterns and altered body image (Tchanturia et al. 2012).

Unsurprisingly physical health issues (especially related to blood circulation) can negatively impact cognition. However, it is possible for some people to improve their cognitive ability by looking at aspects of their everyday life. By making changes in some areas, such as physical activity and brain training, improved sleep and nutrition, evidence shows that such changes can contribute to improved cognitive capacity and the ability to make decisions.

### Applying the decision-making process

A key aspect of recovery oriented practice is to work collaboratively with a person to identify their personal hopes, dreams and aspirations or 'goals for recovery'. The process of thinking through goals and ways to achieve them can be a complex task for many of us. MHCC's course assists participants to consider a number of factors that can influence a person's ability to identify the decision by utilising the supported decision-making process.

This can help navigate the steps toward successfully supporting the person to achieve aspirations, through consideration of the following:

1. Identify the decision: From the person's perspective, what is important in this situation?
2. Involve other people in the process: Who might also be affected, who can assist and who may the person wish to involve?
3. Gather information: How would you assist the person to be informed in their decision? What people, services or resources might be relevant?
4. Identify a range of options: Address concerns and see all possible options.
5. Consider the consequences of options and prioritise: What duty of care, privacy and confidentiality, and ethical concerns need to be considered? How would you help a person explore the pros and cons and prioritise options?

6. Make and carry out the decision: From the person's perspective, imagine what they consider as the best option? What resources/supports would you recommend? Who else might you involve in carrying it out?
7. Reflect and review the decision: What questions would be important to ask to review the effectiveness of the process and build on the person's confidence to make further decisions?

(Adapted from Gooding 2016; NSW Public Guardian 2016)

### Transitioning towards supported decision-making

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has been the driving force behind moves towards supported decision-making around the world. The right to decision-making autonomy, and the importance of supported decision-making, appears in the UNCRPD General Principles as: 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'.

Supported decision-making represents the transition towards a social and human rights approach to empowering people to make and communicate decisions about their lives. It upholds a person's right to make decisions and to be supported in doing so, and assumes that all people have preferences, wants and needs that can be built upon to support decision-making.

Rather than assessing a person's capacity for decision-making, focus centres on what the person can do and identifies the supports they might need. Emphasis has shifted from people with disabilities being passive service recipients to being supported as active members of the community. This shift will gain further momentum when reform to relevant legislation is achieved (Advocacy for Inclusion 2012).

### Embedding learning into practice

*Supporting choice and control: skills for mental health and psychosocial support workers* is a course designed to embed learning into practice. It is relevant to anyone who works with people living with mental health conditions. The course enhances knowledge and skills and provides focused strategies aimed at improving a person's daily functioning in alignment with their recovery goals. It asks participants to reflect on the potential opportunities for growth and utilise the process as part of their own skill enhancement alongside those of the person they are supporting.

Further information about the course is available from this link: [Supporting choice and control](#)

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The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has been the driving force behind moves towards supported decision-making around the world.

Figure 1: Decision making principles

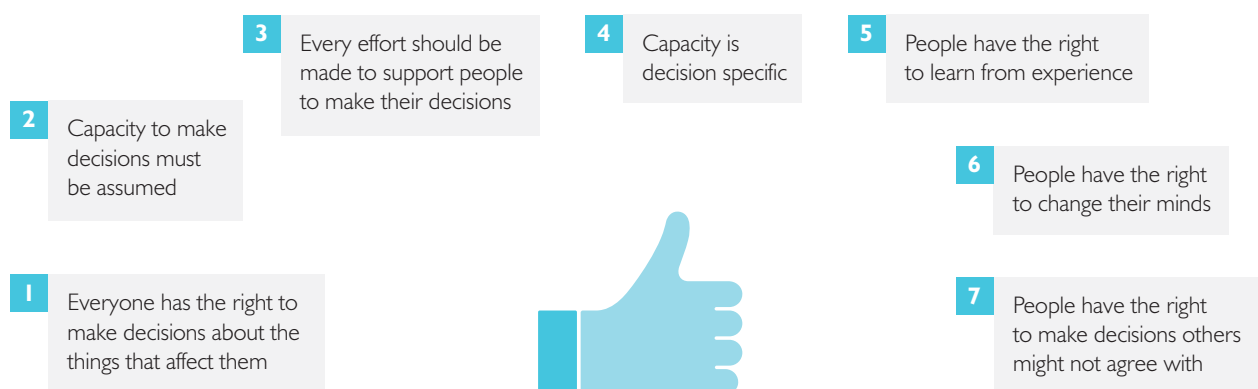
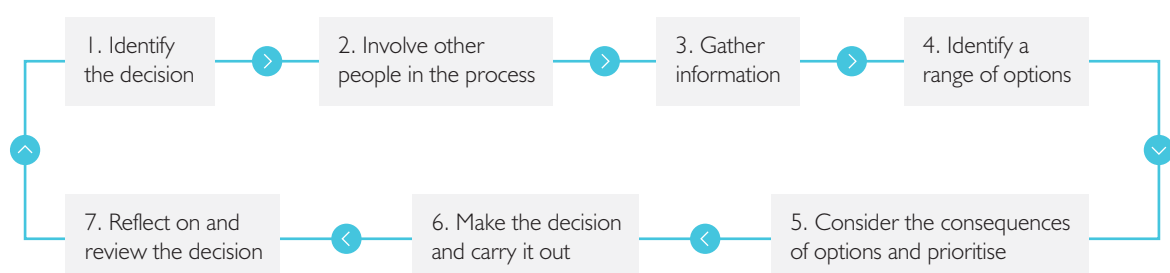


Figure 2: Decision-making process



# Occupational therapy for mental health in an NDIS framework: Exploring the evidence



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A key issue identified by OTA members working in the NDIS is the lack of understanding and recognition of the role of occupational therapists as service providers.

## The role of occupational therapists

The World Federation of Occupational Therapists (2012 p.1) defines occupational therapy as 'a client-centred health profession concerned with promoting health and wellbeing through occupation'. It also notes that 'the primary goal of occupational therapy is to enable people to participate in the activities of everyday life'.

So, the role of occupational therapy in health care and service provision is broad in scope, with occupational therapists providing therapeutic interventions to improve both mental and physical health. In the field of mental health they provide services to people of all ages, playing a role in the assessment, support, treatment, rehabilitation, skill development and recovery of clients.

They employ a person-centred approach to support work which includes:

- exploring consumers' occupational histories, life roles and goals
- working in a holistic manner and as part of multidisciplinary teams, often supporting people with more than one diagnosis
- designing a range of individual and group programs and activities that are tailored to specific cultural, developmental, occupational and social needs
- developing strategies to assist consumers to better manage or overcome their mental health issues
- improving consumers' participation in social, relationship, employment and educational contexts

- providing therapeutic interventions to guide, coach and motivate consumers with mental health issues to achieve their stated activity and participation goals
- maximising opportunities for social inclusion by facilitating occupational engagement in personally meaningful activities, and therefore mitigating the risk of occupational deprivation.

Following reforms to mental health services announced in November 2015, the Australian Government committed to a 'stepped care' model reflecting the different levels of care required by consumers. Occupational Therapy Australia (OTA) believes that the provision of National Disability Insurance Scheme (NDIS) services to people with psychosocial disabilities should reflect this needs-based approach, allowing people to access the services they need when they need them.

## Evidence for occupational therapy in mental health support

Occupational therapists are well established mental health practitioners (Paterson 2014). In a research synthesis of 22 qualitative articles examining occupational therapy intervention in mental health, Wimpenny et al (2014) found that the use of occupationally-based interventions, such as horticultural therapies (Clatworthy et al. 2013), groups which meet in the community around a shared activity (Horghagen et al. 2014), the arts (Webster 2016) and music (Macdonald et al. 2013) resulted in a sense of healing, self-rediscovery, identity formation and community participation in consumers. These interventions were more valued by consumers than short-term, psychologically based interventions (Wimpenny et al. 2014).

## OTA believes that principles of recovery oriented mental health practice should be used to guide the delivery of the NDIS for people with psychosocial disability.

A range of articles also point to occupational therapy's consumer-centred core philosophy (Whalley-Hammell 2015; Ribiero et al. 2017) and its ability to incorporate counselling techniques (Chan et al. 2015) into occupation-focused practice; this is identified as being particularly effective and beneficial. Since 2000, more than 1,700 research studies have been published in peer reviewed literature about the use of occupational therapy for people experiencing mental illness, suggesting the evidence base for this therapy is growing and diverse (Hitch et al. 2015).

### **The NDIS and psychosocial disability**

There is ongoing confusion around the eligibility criteria for people with psychosocial disability to access NDIS supports. Indeed, there is confusion around the very term 'psychosocial disability' in the context of the NDIS (Lester & Jacobs 2016). Those people with psychosocial disability ultimately deemed eligible for the scheme have experienced poorer outcomes than other NDIS participants (Mavromaras et al. 2016).

Based on the evidence of lived experience, it is apparent that NDIS Planner inconsistency is a significant problem nationwide. The quality of NDIS plans varies considerably from person to person, and depends to an extent on the Planner's experience and understanding of the breadth of services available to participants. A key issue identified by OTA members working in the NDIS is the lack of understanding and recognition of the role of occupational therapists as service providers.

While OTA acknowledges that some Planners have an allied health background and have developed plans that adequately reflect the complexities of a participant's needs, occupational therapists have reported that NDIS Planners frequently underestimate the hours of therapy required for a participant to achieve their goals. Additionally, Planners often do not recognise that NDIS participants with psychosocial disabilities can be effectively supported by an occupational therapist to meet their goals.

Occupational therapy is particularly beneficial when the participant's goal is to increase participation in everyday life and activities, and when there is a co-existing physical disability, as occupational therapists employ a holistic approach to practice which takes into account the needs of the whole person. These holistic needs should be reflected in the person's plan.

NDIS plans should facilitate integrated, multidisciplinary care with a greater emphasis on goal setting. Training provided to NDIS Planners should ensure the development of comprehensive participant plans in order to reduce the frequency of plan reviews. Planners should be required to have a deeper understanding of therapeutic supports and their value in assisting participants to achieve functional outcomes.

While there is strong evidence of the value of occupational therapy in mental health care, this is not reflected in the information provided by the National Disability Insurance Agency (NDIA). Accordingly, OTA supports the development of practice based evidence, incorporating expert professional input and the perspectives of consumers and carers.

Knowledge gained from each practitioner's professional experience contributes to the knowledge base of professions, thereby enhancing service delivery. Given that analysis of practice knowledge has been identified as a key activity for practitioners and educators, as well as for researchers and scholars (Higgs & Titchen, 2001), therapists are concerned that the NDIS may not foster the development of practice knowledge and service improvement.

This potential lack of practice knowledge is particularly worrying, given the incidence of mental illness. There is strong evidence (Australian Bureau of Statistics 2015) of the prevalence of mental health issues within society, and of their compounding effects when occurring as a comorbidity. Complex challenges require a complex and systematic approach, and the evidence is mounting that NDIS planning does not incorporate these elements well.

As more people with psychosocial disability become NDIS participants, a number of other issues have arisen including:

- Concerns that the NDIS does not take into account the episodic nature of mental illness.
- Lack of clarity around support for people with disability who are not eligible for the NDIS, particularly as governments begin dismantling existing services in preparation for the NDIS roll out.
- Multiple reports of people with mental health conditions having their NDIS applications rejected, despite evidence of significant functional impairment.
- Challenges associated with producing evidence to demonstrate one's need for support, as this often requires specialised assessments and reports.

## Emerging concerns

OTA has informally surveyed a number of mental health consumers and carers on their experiences of the NDIS. A number of common themes emerged, including a lack of easily accessible information about how the scheme can assist people with psychosocial disability, a lack of understanding of mental health conditions among NDIS Planners, and a perception that occupational therapists only provide physical therapy.

Whiteford (2017 p.487), in an editorial examining the increase in disability support packages being allocated to people with psychosocial disability in Australia, states that:

'the challenges posed by the introduction of the National Disability Insurance Scheme (NDIS) for people with psychiatric disability are significant, and...clarifying the threshold for the allocation of DSPs [disability support packages] and the type of support needed by those with psychiatric disability must be a priority'.

Similarly, Brophy, Bruxner and Wilson (2014) commented that, at that time, the implications for people with psychosocial disability being included in the NDIS were not fully understood and, despite the projected numbers (57,000 people were thought to be eligible through the scheme), there were then few studies exploring their perspectives. Barton et al. (2015) concur, expressing particular concern about consumers from rural and remote locations, especially those from Aboriginal and Torres Strait Islander backgrounds, whose perspectives are rarely, if ever, expressed in the literature (Townsend et al. 2017).

Williams and Smith (2014) express concern that the NDIS, which is tailored to meet the needs of the specialist disability sector, may therefore not meet the needs of people with psychosocial disability, and they comment that the scheme's worldview may not fit well with a recovery paradigm. Ennals et al. (2017), whilst acknowledging the scheme's potential benefits and its potential to improve the lives of people with psychosocial disability, express concern that those with psychosocial disability who are homeless will have difficulty accessing the scheme. They also question its fitness for purpose for those with psychosocial disability, commenting that the scheme was never designed to replace all community supports.

## Maximising NDIS potential

One obvious step to reducing uncertainty for mental health consumers and carers is to ensure information about accessing the scheme is readily available. Creating jargon-free versions of webpages and documents in a number of languages as required would also greatly assist those who are unable to navigate complex guidelines. The high incidence of unaddressed challenges in respect to literacy and numeracy clearly impacts people's ability to participate and reach their potential.

The need for a condition to be permanent seems to conflict with principles of recovery oriented mental health practice, which underpin the provision of mental health services by clinicians such as occupational therapists. These principles have been adopted by numerous federal and state government departments and agencies, and are used to guide the implementation of the National Standards for Mental Health Services (Department of Health 2010). OTA believes that principles of recovery oriented mental health practice should be used to guide the delivery of the NDIS for people with psychosocial disability.

The Joint Standing Committee on the NDIS released its final report from the inquiry into the provision of services under the NDIS for people with psychosocial disabilities in August 2017. The Committee (2017 p.xiii) recommended that the NDIS Act be reviewed 'to assess the permanency provisions in Section 24 (1) (b) and the appropriateness of the reference to 'psychiatric condition' in 24 (1) (a)', although OTA notes that the Productivity Commission (2017 p. 24) 'does not support changing the eligibility criteria to relax the definition of permanency and how it relates to psychosocial disability'.

OTA supports the Productivity Commission's recommendation (2017 p.24) that 'a psychosocial gateway, involving specialised staff, designed in consultation with experts in mental health' be created. Such a gateway would represent an acknowledgement that there are fundamental differences between the support needs of people with physical and psychosocial disability, and would allow for a more streamlined process.

When people experience both mental health and substance abuse issues, or mental health and physical disabilities, particular attention is required. A more holistic approach would enable integrated access to services, rather than requiring people to apply for, and access, several agencies for funding.

Occupational therapists are well placed to provide such holistic assessment and intervention in these instances, as they are trained to work with people with both physical and mental health conditions. Enhanced access to suitably trained NDIS Local Area Coordinators (LACs) would assist consumers to access information about supports that are available in their community. The Productivity Commission (2017 p.52) has recommended that LACs be 'on the ground six months before the scheme is rolled out in an area and...engaging in pre-planning with participants'.

Ensuring adequate support for people who are not eligible for the NDIS is also paramount. The 2017 Federal Budget included \$80 million over four years for psychosocial support services for people with severe mental health conditions who do not qualify for the NDIS, however exact details of this support are yet to be provided.

### Conclusion and future directions

People with psychosocial disability who seek to enhance their mental wellbeing face a number of barriers to accessing services through the NDIS. However, there does appear to be growing recognition of the extent of this problem, and steps are being taken to reduce uncertainty for mental health consumers, their family members and carers.

As the professional association for occupational therapists in Australia, OTA is constantly striving to raise the profile of occupational therapists working in mental health. This primarily involves developing resources for anyone involved in the referral process, as well as for consumers and carers. By way of example, during Occupational Therapy Week 2017, OTA launched a new website for consumers ([www.aboutoccupationaltherapy.com.au](http://www.aboutoccupationaltherapy.com.au)) which provides information about the different areas that occupational therapists work in and the services they provide.

As the NDIS becomes the foremost means of delivering disability services in Australia, it is vital the scheme recognise the valuable role occupational therapists can play in the support of those experiencing mental health conditions.

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The need for a condition to be permanent seems to conflict with principles of recovery oriented mental health practice, which underpin the provision of mental health services by clinicians such as occupational therapists.



## The *Reasons For Use Package*: how mentoring aids implementation of dual diagnosis practice



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Implementing a consumer-focussed dual diagnosis tool through a mentoring process creates sustainable practice culture that is reflective of the consumer experience.

A research collaboration between Nexus, Neami National and Monash University, commencing in 2013, has resulted in a new approach to dual diagnosis capacity building. During 2015, more than 100 Neami National staff across New South Wales and Victoria participated in a case-comparison trial as to the efficacy of training and mentoring to change dual diagnosis practice in mental health community support.

The *Reasons for Use Package* (RFUP) – a dual diagnosis package with an embedded mentoring component – assists workers to successfully create an atmosphere where consumers can explore the interaction between their mental health and substance use.

This therapeutic conversation is in itself a useful process for building rapport however it is also an essential precursor to collaborative treatment when and if the consumer wishes to take the discussion to potential strategies.

This article explores the RFUP mentoring model, which is an integral and evolving part of the RFUP and indeed, the pilot suggests, is the key ingredient to embedding practice change.

### Policy environment

Victorian and federal policies over the past decade (Department of Human Services 2009; Council of Australian Governments 2012) have stressed the need for improved service response to consumers with dual diagnosis issues – one or more diagnosed mental health problems occurring at the same time as problematic drug and alcohol use.

This has led to services engaging in a multitude of dual diagnosis professional development activities such as consultation, training and resource development. Despite the number and type of activities being undertaken in this area, there was still an apparent lack of knowledge and confidence in engaging consumers in order to structure

appropriate interventions in the Victorian Dual Diagnosis Initiative evaluation (Australian Healthcare Associates 2011) and the Commonwealth Improved Services Initiative evaluation (McDonald 2015).

Pockets of confident dual diagnosis practice existed within organisations, usually residing with individual staff rather than service wide, and organisational capacity fluctuated as a result (Mental Health Commission 2013). This had the potential to undermine consistent, hopeful, recovery orientated practice and could lead to reduced growth of practice wisdom, potentially weakening future efforts to build capacity (Roberts 2013).

### Background to Reasons for Use Package

The *Reasons For Use Package* (RFUP), a dual diagnosis resource, was developed by Nexus, a Melbourne dual diagnosis service, in consultation with consumers, carers and staff. The RFUP consists of the Reasons for Use Scale (Castle et al. 2006), and a number of potential follow-up strategies to explore with the consumer (Figure 1).

The package includes a specific “spirit” guiding the desired approach. This entails a collaborative and supportive process between staff and the consumer using the RFUP as a doorway to conversation about dual diagnosis. Staff receive training and, importantly, mentoring in how to use the RFUP which reinforces this “spirit.”

The consumer is supported to actively explore their dual diagnosis issues. This deliberately shifts the power balance to the consumer rather than the more passive approach whereby the staff member “assesses” the consumer and decides on treatment options. The consumer and the staff member gain a shared understanding and, importantly, the consumer is actively involved in negotiating their treatment plan.

### Mentoring as a part of the RFUP

*“Mentoring is a developmental relationship and, like education and training, the primary objective is learning.”* (McDonald J 2002, p. 11)

The RFUP mentoring process has a number of purposes. Firstly to facilitate reflection on initial use of the RFUP. Secondly, to generate a potential source of new mentors who then sustain the use of the RFUP practice, as individual staff articulate and discuss their thoughts around its use. Staff who are involved are then more able to facilitate mentoring of colleagues in their own engagement with and use of the package.

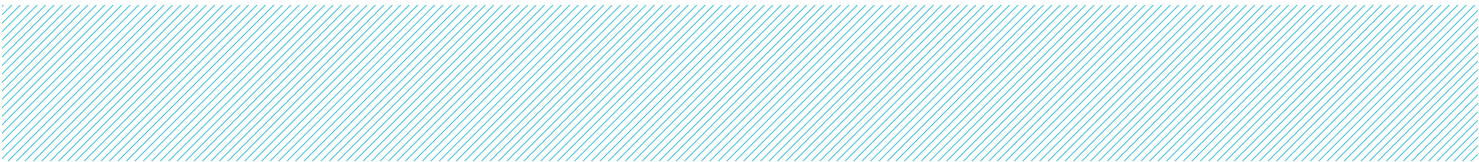
The mentoring model is outlined in separate guides for the organisation, mentor, and mentee. These have been developed and refined in response to feedback from various inputs and serve as a useful starting point when implementing RFUP mentoring.

The model was designed to mirror the spirit of the RFUP so that mentoring sessions reflected the desired collaborative explorative style of the consumer and staff interaction. Individual staff feel supported in exploring their practice and are thus able to move into mentoring their colleagues by following a structure based on facilitation rather than the perceived need for expert knowledge.

Mentoring helps externalise practice so it can be explored and change can occur (Scott & Spouse 2013). The two-part mentoring process reflects the two-part consumer process. Exploration prior to, or as part of, intervention in an environment of trust means that if the consumer or staff member wishes to make a change they do so with insights and energy from the process.

Figure 1 Components of the Reasons For Use Package





Staff need to feel that they can explore the use of the RFUP at different levels according to their experience. A staff member's initial use should not be judged based on the consumer outcome alone, as this will vary according to the consumer's circumstances.

In practice, staff confidence in their use of the RFUP often reflects the consumer's experience. Thus an organisational approach which aggregates various experiences is more likely to build practice wisdom. Implementation appears to work best when the RFUP process is completed within teams and organisations rather than to a group of disparate attendees from various services coming together.

At the first meeting with the creators of the package, the mentoring model is explained so that the organisation gains a clear understanding of the model and its benefits and issues to consider.

Importantly, at this stage, the organisation agrees to fully support the process, which includes freeing up staff to attend mentoring sessions. The creators of the RFUP suggest the allocation of a coordinator type role to assist with this process. Management identify staff who they think would be effective mentors; usually these are experienced staff who are seen as *practice leaders*. This organisational endorsement of engaging in the full RFUP rather than just training alone contributes to capacity building and culture change. Practice wisdom on both the use and impact of the RFUP for consumers is given support and conveyed through mentoring. Positive experiences can multiply over time rather than being lost as one-off events.

### Method

A case comparison evaluation of the RFUP was completed with Neami National, a large national mental health community support service. Two groups of staff were recruited in New South Wales and Victoria; control and intervention groups respectively. The groups were matched for similar service types and staff make-up. In the evaluation both control and intervention groups had a 12 question survey of knowledge and confidence of dual diagnosis intervention, based on the domains of the RFUP, delivered at three time points. The intervention group received training and mentoring in the RFUP.

### Results

The national evaluation trial held in 2015 found that the RFUP has several benefits including that it:

- increased staff confidence and knowledge around dual diagnosis interventions in a straightforward manner
- aligned with current State and National mental health and alcohol and other drugs strategies

- was recovery based and consumer friendly, user friendly for a range of health and welfare staff, and highly cost effective.

Data consistently found that mentoring assisted in maintaining gains in confidence and knowledge following training (See Figures 2 and 3 as examples). This evaluation provided valuable evidence of the utility of mentoring and informed the Australia-wide implementation across Neami National that is currently occurring.

Figure 2 shows that confidence and knowledge increased during the mentoring stage.

Figure 2: "I am confident/knowledgeable about dual diagnosis strategies for how to manage medication side effects."

1 (Strongly Disagree) to 6 (Strongly Agree)

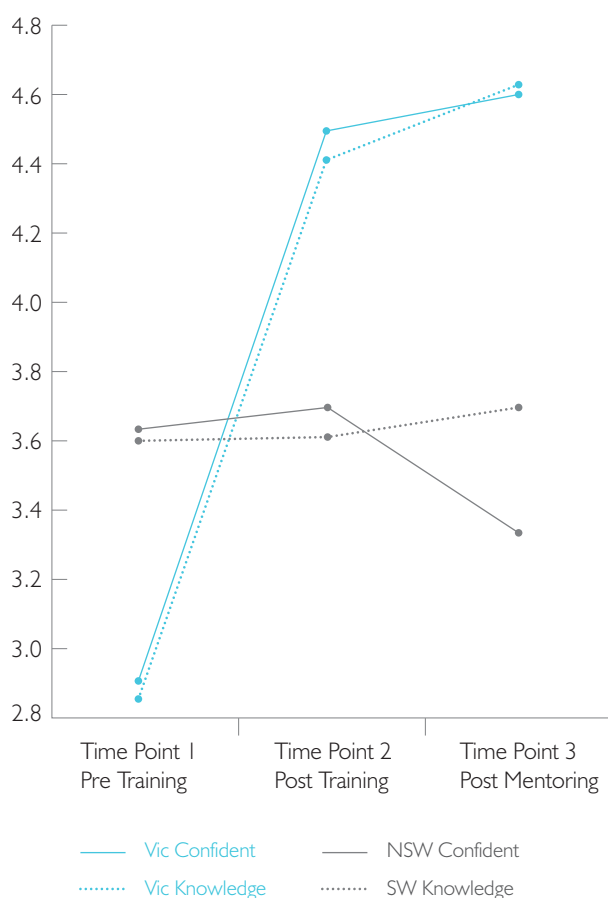


Figure 3: "I am confident/knowledgeable about dual diagnosis strategies for coping with unpleasant effects, including low mood, distress, anxiety."

1 (Strongly Disagree) to 6 (Strongly Agree)

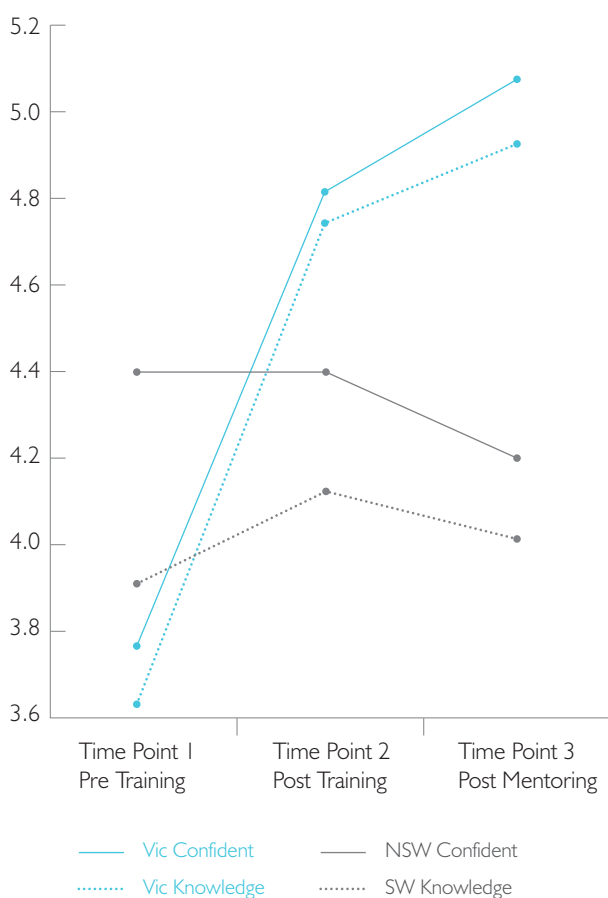


Figure 3 shows that confidence and knowledge increased during the mentoring stage.

Evidence from staff feedback focus groups indicated that the mentoring process is valuable in supporting a deeper exploration of dual diagnosis issues than would have occurred through training alone. Additionally staff provided qualitative feedback that the mentoring process has helped them to internalise the concepts of, and more effectively implement, the RFUP at their workplace (Myers, O'Connor, Petrakis & Kroes 2017). Staff reported that they could draw on thoughts and ideas in mentoring. This was similar to the discussion between staff and consumer.

Feedback from workers who have used the RFUP:

*"Simple, meaningful and related to work practice."*

*"Good for building dual diagnosis into core practice."*

*"...very personal approach to their (the consumer's) situation."*

### Discussion

In less than two years Neami National, a large national mental health community support service (MHCSS), went from having a handful of individuals who had been trained and mentored by Nexus, a Melbourne dual diagnosis capacity building service, to being able to implement a nationwide rollout reliant on internal MHCSS staff holding and developing their RFUP practice wisdom and being able to train and mentor their colleagues.

Nexus developed and implemented a collaborative process of consulting to Neami National and building on its existing infrastructure to drive this capacity building project.

This type of collaboration is a model for other organisations and is currently being followed in a number of other settings. That Neami National staff felt confident in providing mentoring to colleagues without a large degree of extra training and support is critical. This is possible because of the mentoring structure that emphasises facilitation rather than being reliant solely on expert knowledge.

### Limitations

It is possible there could be some over-statement of the impact of training, due to the self-reported data measures used in this study. The present study indicates that further research on the role of training, and particularly of mentoring, in implementing dual diagnosis tools is warranted. Overall however the gains achieved by mentored staff through training and mentoring, and reported benefits experienced by consumers through enhanced trust in the therapeutic relationship, suggest this package has much to offer the field.

### Conclusion

The authors have found the RFUP mentoring model to be a crucial aspect in assisting the development of individual staff and organisational dual diagnosis capacity. It is vital that mentoring be congruent with the desired approach of the RFUP for sustained practice change. Training in the RFUP is also greatly enhanced when combined with this particular approach to mentoring.

For a moderate investment in time, mentoring produces the clinically and personally meaningful results of enhanced knowledge and confidence with which to engage in dual diagnosis practice. Structured, supported and evidence-informed mentoring should be considered an integral part of relevant training in the health and welfare fields.

## Partners

### Nexus

Auspiced by St Vincent's Hospital (Melbourne), Nexus is part of the Victorian Dual Diagnosis Initiative (VDDI). It is one of four Melbourne metropolitan teams with rural partners established in 2001 to assist dual diagnosis capacity building in clinical mental health, mental health community support services and alcohol and other drug services. Nexus works across local government areas including Banyule, Boroondara, Nillumbik, Yarra, Darebin, and alongside rural VDDI colleagues in regional Bendigo and Mildura.

### Neami National

Neami National is a community mental health service supporting people living with mental illness to improve their health, live independently and pursue a life based on their own strengths, values and goals. It provides services from over 60 sites in diverse metropolitan, regional and remote communities in Western Australia, Queensland, South Australia, Victoria and New South Wales.

### Monash University

Monash University is ranked in the top one per cent of world universities according to the Times Higher Education World University Rankings (2013-2014). It is a member of the Group of Eight, an alliance of leading Australian universities recognised for excellence in teaching and research.

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## Cultural humility training in mental health service provision



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This article outlines the delivery of a workshop in Victoria that introduced mental health practitioners and providers to the concept of 'cultural humility', promoting and encouraging critical self-reflection around their own values, attitudes and behaviours in clinical practice with culturally diverse consumers, carers and families.

The 'Cultural humility training in mental health service provision' workshop was delivered by the first author at the invitation of the North East Victoria Innovative Learning, Training and Professional Cluster (NEVIL) in 2017.

Other workshop goals were to: define 'cultural humility' and apply it to clinical practice; outline key concepts regarding race and its relevance to mental health service provision; and promote the process of critical self-reflection, in order to enhance engagement and treatment outcomes for culturally diverse communities.

As well as outlining the workshop content, and the theory behind it, this article will consider the outcomes of an evaluation showing that participants had developed a sound understanding and application of 'cultural humility' principles, at both an individual, clinical and organisational level.

Participants developed a heightened awareness and sensitivity to how issues of race, bias and negative cultural stereotypes contribute to inequalities in mental health service provision. Further, they achieved an overall appreciation regarding key concepts of critical self-reflection and self-awareness, as significant tools towards culturally sound clinical practice.

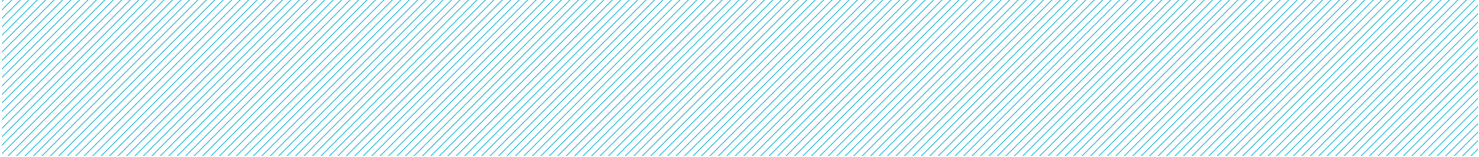
### Introduction

The concept of cultural humility and promoting cultural dialogue is gradually gaining attention within the Australian mental health context.

This constitutes a shift – from traditional aspirations towards cultural competence to a more challenging approach aimed at encouraging practitioners to reflect on their own cultural biases and stereotypes, and there are implications for treatment outcomes in service provision.

The concept of cultural humility originated almost two decades ago in the United States within the paediatric medical field, shaped by practitioners Dr Melanie Tervalon and Jan Murray Garcia (Tervalon & Murray-Garcia 1998). It emphasised the importance of health practitioners being mindful and committed to self-awareness around the values and judgments they brought to health service provision for African American people and those from other cultural backgrounds.

In the mental health field, the literature that has inspired the cultural humility training discussed in this paper is drawn from research investigating underlying issues of racial bias and negative stereotypes. This international literature draws



## Participants developed a heightened awareness and sensitivity to how issues of race, bias and negative cultural stereotypes contribute to inequalities in mental health service provision

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attention to higher rates of psychiatric admissions for African Caribbean immigrants in the United Kingdom and African Americans in the US, in comparison to their white native counterparts (Ellis 2012).

Similarly, for culturally diverse communities, the literature highlights the covert barriers they face in accessing mental health services. This often relates to being misunderstood, due to cultural differences and nuances, resulting in negative encounters with the service system (Weich et al. 2012). Although such research in Australia has been limited to date, much is learned from related research within the Aboriginal and Torres Strait Islander mental health literature; in terms of the importance of health service provision being challenged to address racial bias in order to optimise health and recovery outcomes (Konidaris 2016).

### **The concept of cultural humility and its origins**

Conversations around the relevance of a cultural humility approach in mental health practice arose from efforts to steer away from imposing stereotypes and from aligning with superficial cultural knowledge-building.

The growing recognition of barriers in practice with culturally and linguistically diverse (CALD) communities is not merely about addressing language barriers and issues of trust. It also relates to obstacles intrinsic within the therapeutic dynamic at both an individual and organisational level.

Deconstructing clinical issues of how fear and mistrust contribute to service barriers for CALD communities is very important to reflect covert and deeper layers regarding negative cultural stereotypes and racial bias. These biases are unfortunately still today reflected in mental health service provision and the notion of *cultural humility* has only in recent times surfaced in Australia.

### **Moving from cultural competency to cultural humility**

Globally, the plethora of literature in the transcultural mental health field has predominantly focused on cultural competence as a key outcome in working effectively with culturally diverse populations. According to Cross, Bazron, Dennis and Isaacs (1989), a comprehensive understanding of *cultural competence* involves working effectively with cultural minorities, prioritising

culturally specific assessments, formulations, and cultural strengths within diverse communities, but also a cultural self-analysis. The latter resonates with principles of cultural humility, given its focus on an internal process of self-reflection regarding bias and stereotypes.

In the Australian context cultural competence continues to be used synonymously with notions of *cultural humility*, *cultural responsiveness* and *cultural safety*. The latter concept originated from service provision with Maori populations in New Zealand and has also been embraced in the Australian context, recognising its relevance to Aboriginal and Torres Strait Islander populations.

As already mentioned, the research efforts of Indigenous colleagues with regards to the inequities and significant poor health outcomes for Aboriginal people are slowly being addressed in service development reform and programs, and health sciences curriculum pedagogy (McDermott 2012; Paradies & Cunningham 2013; Pedersen, Paradies, Hartley & Dunn 2011). Efforts to improve training for health and mental health service workers in their engagement and responsiveness to CALD consumers, families and communities sit within this collection of advocacy, scholarship, education and reform.

The transition towards an effective cultural approach in service provision, addressing values and beliefs of the practitioner and within the organisation, is not merely a shift in semantics. Instead, systems managers and the practitioners within them are encouraged to consider training that promotes an inward focus and greater self-awareness; this is to enable a mutual process of cultural dialogue, rather than aligning with a dominant paradigm of merely acquiring cultural knowledge.

### **A cultural humility training pilot**

The North East Victoria Innovative Learning, Training and Professional Cluster (NEVIL) is a funded initiative of the Victorian Department of Health and Human Services (DHHS). It is a collaborative partnership of a consortium of large health service networks in Melbourne and regional Victoria, including Forensicare. One of its aims is to enhance the delivery of mental health services in Melbourne's eastern metropolitan area and the northeastern region of Victoria.

It is a training unit offering ongoing professional education for mental health practitioners from diverse disciplines and for those with lived experience in consumer and carer consultant roles (North East Victoria Innovative Learning 2017). NEVIL aims to provide a range of professional development learning opportunities for mental health practitioners who are working across the broad developmental age spectrum, and working with consumers, carers and families.

The opportunity to pilot the cultural humility training initiative was well positioned within the Nevil Training Calendar, given its focus on training and skill development for mental health professionals across Melbourne and regional Victoria, working with consumers and families who are living with mental illness across the developmental age spectrum.

The one day workshop was divided into four sections and, as a pilot, aimed to:

- introduce and define cultural humility and related key principles, drawing upon diverse teachings
- outline the relevance of cultural humility to mental health service provision
- outline and apply cultural humility principles and practitioners' self-awareness and reflective processes at both an individual and broader service level.

The workshop introduction aimed to be mostly *experiential* and encouraged participants to reflect on their cultural heritage and identity, hence the importance of drawing upon the self and self-reflection in relation to participants' experiences around the key concepts of *race* and *culture*.

Emotional safety and robustness were also promoted as important qualities, given that some of the content may have presented as challenging. Integral to the workshop was

messaging on 'digging a little deeper' and the importance of self-awareness when dealing with difference, of being the 'other' and cultural diversity. Videos illustrated the risks around the single story and the transition from *cultural competence* to *cultural safety*.

Workshop participants were also informed that the training curriculum would demonstrate a shift from *cultural safety* concepts, such as from the commonly understood *cultural competence* and *cultural responsiveness*, to the significance of adopting principles of *cultural humility*.

Furthermore, participants were encouraged to consider concepts of *Whiteness*, attending to contexts of colonisation and white privilege and their own experience of *race* and how identities are *racialised*. Practical case examples were drawn upon to illustrate some of these key points, including a clinical video of a practice situation. Finally, given the evaluative aspect of the workshop, time was spent encouraging participants to summarise their reflections from the training in written form, to consolidate learning and make commitments toward enacting changes in their future work.

#### Initial outcomes: learning from the pilot

Fourteen mental health practitioners were registered to attend the workshop, with strong engagement from eight participants. Participants represented all parts of the mental health service system, including child and adolescent, adult and aged mental health services. As a self-selected purposive sample, the broad cross section of the workshop group was somewhat fortuitous, given that the training was not aimed at practitioners working with a particular cohort or age group. A mixed methodological approach was utilised, gathering pre- and post- quantitative survey data alongside qualitative reflective feedback from workshop participants.

Figure 1: Workshop outline:

Session 1	Session 2	Session 3	Session 4
<p>Introduction: background facilitator's personal acculturation journey; dealing with difference and being 'the other.'</p> <p>Professional – discuss barriers to engagement.</p> <p>Family therapy research influences.</p>	<p>Use of videos</p> <p>Defining key concepts:</p> <ul style="list-style-type: none"> <li>• race</li> <li>• 'racialised'</li> <li>• Whiteness</li> <li>• microaggressions</li> <li>• cultural competence</li> <li>• cultural responsiveness</li> <li>• cultural safety</li> <li>• ethnocentrism</li> <li>• <i>cultural humility</i>.</li> </ul>	<p>Practical and Applied: use of cultural humility principles and framework, utilising case scenarios and videos.</p>	<p>Reflective summary evaluations: NEVIL and post-workshop survey.</p>



The initial outcomes and learning from participants are outlined below. They highlight a positive response towards the principles of cultural humility in relation to their own development and in their practice.

#### **Outcome 1: Developing a sound understanding and application of 'cultural humility' principles at an individual clinical level:**

*Even though I have developed some skills in exploring and understanding worldviews for people from CALD background, I still have some biases to non-white men as there are very few (CALD people) in my friendship circle. It also made me reflect on the teams I have been a part of in the mental health field, as there has only been one Croatian and one Indian in these teams.*

*I liked the title alternative from 'cultural competency' to 'cultural humility' – it indicates a continuous learning, open mindedness to others and their life experiences/her/his stories. I shouldn't assume I know it all if am 'competent'!*

#### **Outcome 2: Developing a sound understanding and application of 'cultural humility' principles at an organisational level:**

*... why aren't there mandatory requirements for cultural diversity in teams and more safeguards to ensure staff are applying cultural humility principles to practice. I found this training helpful and (it) gave me a framework to consider the importance of culture.*

*Not knowing but being open to 'life-long learning' is key! To ask the questions and co-produce treatment/service/organisations (communities) and accountability that respond to all needs in all persons (as unique individuals who are deserving) and that it's just as important (if not more) to understand yourself and what you bring into these relationships.*

#### **Outcome 3: A heightened awareness and sensitivity to how issues of race, bias and negative cultural stereotypes contribute to inequalities in mental health service provision:**

*It reiterated the importance of checking in to my own beliefs/ self-awareness of life experiences/baggage I bring and how this*

*can affect those I have contact with, to practice what has been presented today.*

*This cultural humility is not an endpoint rather it is a 'lifelong learning process'. Many of us are blind to our biases and do not question their existence and influence. It is always worth doing so to ensure that we are culturally sensitive, both as individuals, teams and organisations. I'm looking forward to being open about my own culture and assumptions, and to keep asking questions that help me and my colleagues to serve our diverse populations.*

#### **Outcome 4: Appreciation of key concepts of critical self-reflection and self-awareness for participants, as significant tools towards culturally sound clinical practice:**

*That knowledge about cultures (ie competence) is useful, but not an assurance that one will have a culturally sensitive/attuned experience with a consumer. More useful is a humble approach, whereby clinicians are open to learning about each client's culture and their own sub-conscious biases.*

*Single story – explore to find more stories to create balance; we don't know that is ok; check in on yourself; what buttons are being pressed for yourself; what does the client want to achieve; what am I focusing on?; white privilege (explore your own understanding/stance on that).*

#### **Conclusion**

The challenges for the mental health field are ongoing and restrained by resource limitations, often resulting in fatigued clinicians and service systems.

This impacts negatively on service provision, with the added layers of complexity for CALD communities. Given this, it is important that the *cultural humility* approach in service provision demonstrates kindness toward such challenges, gently challenging bias and stereotypes in a non-threatening and inclusive manner. Fostering and promoting cultural humility principles in training and service provision will assist to reduce feelings of fear and mistrust, being the 'other'. It will better support those working to address issues of access and equity, and enhancements in assessment and in recovery outcomes for culturally diverse communities.

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## Recovery co-design and peer workforce development in the acute inpatient setting



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A pioneering program at a Melbourne hospital set out to reduce restrictive interventions in the acute inpatient unit. It set up a new team, led by a peer worker, to provide information and support to people in the Emergency Department while they were waiting for admission into the unit. This report explores and analyses consumer perspectives about the intervention.

For many people suffering from acute mental health episodes, the Emergency Department (ED) is not only a space for crisis assessments and support but also often the main access point for various clinical services including mental health in-patient units (Jelink & Andrew-Starkey 2015; Hamilton & Love 2010).

A key priority of Victoria's Department of Health and Human Services is to improve patient care, wait times and experiences within EDs (2009). This priority recognises that the ED can be a very stressful environment for those who work in it and those who access it, which is intensified by people presenting with mental health issues. For those who present with these issues in an already distressed state, the ED can be a traumatising experience (Hamilton & Love 2010). Although there have been significant studies focused on changes that can be made within mental health wards to reduce seclusion rates, many people are regarded to require seclusion as they arrive (Trauer, Hamilton, Rogers & Castle 2010).

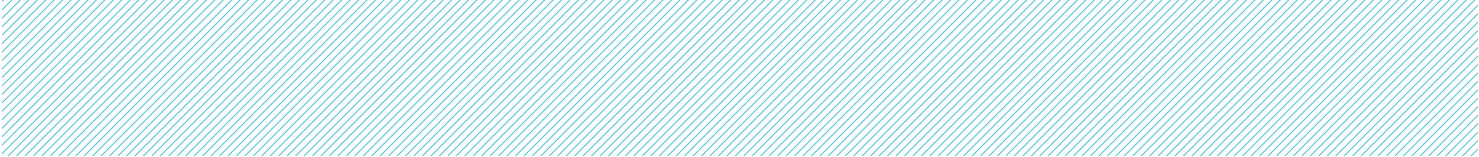
### Background to the study

Consumers who have experienced restrictive interventions, such as seclusion, have reported feeling punished, abandoned, frightened and re-traumatised (Holmes, Kennedy & Peron

2004; Cleary, Hunt & Walter 2010; Kontio, Valimaki, Putkonen, Kuosmanen, Scott & Grigori 2010; Ross, Campbell & Dyer 2014; Hamilton & Love 2010). Humanistic ideology underpinning interventions that are focused on developing trust and rapport have been shown to reduce restrictive interventions in other mental health settings (Safewards 2015; Bowers 2014; Kontio et al 2010).

Informed by Victorian Department of Health and Human Services policy '*Providing a safe environment for all: Framework for reducing restrictive interventions*' (2013), Victorian hospitals were funded to develop strategies and interventions which aimed to reduce restrictive interventions. Recovery-orientated practice underpins this framework. This utilises lived experience and aspirations of consumers to inform best practice and aims to support individuals to live an automatic and meaningful life (Bland, Renouf, & Tullgren 2009; Department of Health and Human Services 2011; Commonwealth of Australia 2013)

The *National Standards for Mental Health Services* highlights that delivery of care should take an overall recovery-oriented approach and include the involvement of consumers in development, delivery and evaluation of services. Practices



and principles for specialist mental health services have been further defined by the Department of Health in the *Framework for recovery-oriented practice*, identifying the importance of incorporating recovery values and a peer support workforce.

In this context, St Vincent's Hospital, in inner city Melbourne, set about implementing recovery-oriented practice from 2004 onwards and development of a peer workforce from 2014. In 2013 preparations were made in the acute inpatient hospital context to reduce seclusion rates utilising a pilot study, looking at admission data and seclusion rates. This paper sets out to discuss this intervention: *Reducing restrictive interventions using the Pre-Admission Liaison (PAL) program*, using a peer worker role as central to the innovation.

A descriptive study was undertaken to explore data relating to circumstances surrounding restrictive interventions within one in-patient service in Melbourne (Chavulak & Petrakis 2017). Focusing on the link between the ED and restrictive interventions, it was found that half of the number of people who were admitted via the ED were first time admissions and half of those people experienced seclusion. For many people their seclusion episode occurred within the first four hours of admission.

### **Providing support, information & 'familiar faces'**

Peer worker roles within the mental health system are newly emerging in Australia.

Worldwide people with lived experience are being increasingly employed in paid peer worker roles. This work is achieving positive consumer outcomes (Campbell 2005; Chinman, Young, Hassel, Davidson 2006; Gray 2014). Research has found that a peer worker can offer a sense of hope to those experiencing a 'patient role' and can supplement care in a different way than traditional clinical systems can (Austin, Ramakrishnan & Hopper 2014).

Informed by this evidence, the Pre Admission Liaison (PAL) Team was developed at St Vincent's to support people who had been assessed within the ED as requiring an in-patient admission. The team was led by a peer worker, accompanied by a nurse from the Acute In-Patient Service (AIS), and tasked with visiting people in the ED following assessment, to:

- explain the process of transferring to the AIS
- provide an introduction so the person would have familiar faces in the unit
- offer sensory modulation to make them more comfortable and more connected to reality
- have a conversation to help the person feel safe and supported.

It was suggested that by the time the person did come to the ward they would be less agitated and hopefully would not require seclusion.

These visits aimed to facilitate information sharing of processes and create a space whereby the person could voice any concerns or queries they had regarding their experience and the process; with a key focus on utilising the lived experience of the peer worker. Once on the ward, the person would have follow-up access to the peer worker alongside their nursing care and prior introduction was aimed to develop early rapport.

It was hoped this intervention would alleviate some concerns early on, with the goal of reducing agitation levels during and post transfer process, so that restrictive interventions methods would not be used as often.

The views of those who experienced this intervention were regarded to be of critical importance to understand the impact of such changes.

### **Research Question**

What is the feedback from consumers regarding the Pre-Admission Liaison team and support received during transfer from the Emergency Department to the Acute Inpatient Service (AIS) at a Melbourne hospital?

### **Method**

#### **Research design**

This project utilised a peer worker part-time to be available to liaise with consumers waiting in the ED for admission to the AIS during the hours of 12pm-4pm Monday-Thursday. It was a one year project. This was based on funding availability and the times allocated had the highest rates for admissions to AIS. Following a six month establishment phase in the project, a mixed-methods research design was added to allow for both quantitative and qualitative data to be collected; being a descriptive study of who the service was able to engage with PAL visits, and their opinions and feedback.

#### **Data collection**

A survey tool comprising of both measurement (Likert scale) and text responses was designed to collect detailed data from consumers regarding their access (or lack of access) to the PAL Team. This also collected demographics of participants. Admission records were accessed to compare demographics of those who were surveyed to the general cohort who were admitted to the AIS via the ED.

The survey was designed to be completed either online via SurveyMonkey or on paper, to increase the accessibility for consumers on the ward. Where possible the peer worker member of the PAL team assisted consumers to complete the survey. This approach was in line with that used successfully in the National Consumer Experience of Care survey, and was intended to increase consumer confidence regarding providing feedback. In a few instances a PAL team clinician provided this facilitation.

### Data analysis

The quantitative survey responses were analysed descriptively and the qualitative responses were analysed thematically.

### Ethical considerations

The hospital Human Research Ethics Committee deemed this research a quality assurance activity and it was approved under the 'Recovery-Oriented Practice and Peer Workforce Development' project. A second ethics process was undertaken and approval was gained from the university Human Research Ethics Committee to involve academic and student researchers.

As this research occurred within an inpatient setting, effort was made to ensure that participants were asked at appropriate times and participants could give informed consent to participate. All participants were given the options to have assistance or to complete the survey confidentially.

### Recruitment

Although the project was funded for one year, it took some months to establish a peer worker in the AIS setting. Once that was achieved, data was then collected and surveys conducted. During this time there were 194 people admitted to the in-patient unit, with 40 of those receiving a PAL visit (20 per cent or 1 in 5 people). The PAL surveys were conducted for approximately six months of this year. There were also four extra PAL visits completed, however these people were discharged from the ED.

There were 35 surveys collected, however five people specifically stated they did not want their results reported on, and three more did not give their consent, therefore this report only includes those who did consent. The purpose of this survey was to engage and report feedback from people who came via the ED; two of the remaining 27 respondents were not admitted via the ED, therefore this report will only focus on the 25 who did come via the ED.

### Results

#### Demographics

With regard to gender, nine (36 per cent) identified as female, 15 (60 per cent) as male and 1 as neither. For the general cohort during the time of data collection, 52 per cent identified as male and 48 per cent as female, so there are fewer female voices represented by the surveys than the general cohort. The same person who did not specify their gender did not specify their age, however of the remaining 24: four were 18-25 years old, four were 26-35, eight were 36-45, four were 46-55 and four were 56-65 years old.

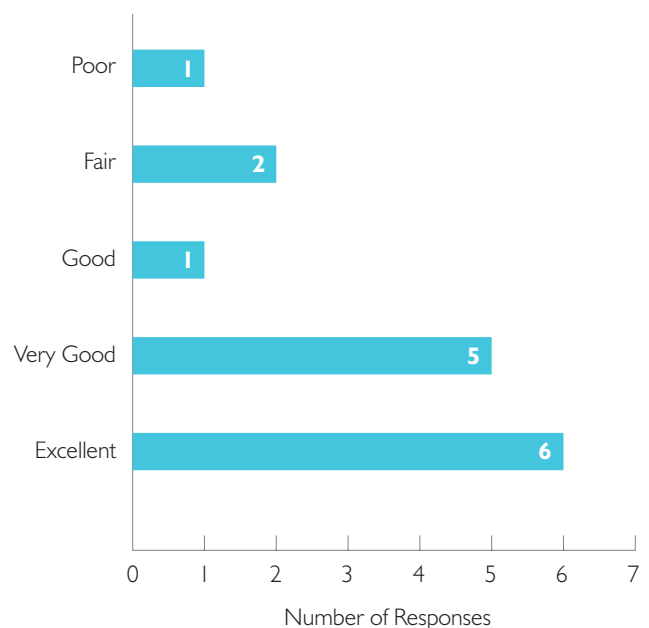
This is a very even spread across all ages and was reflective of ages of people within the in-patient unit at the time. Data from patient records during the time period of this survey indicates a similar curve in ages. The mean, median and mode age group was between 36 and 45.

Only three participants stated their preferred language was not English, the rest identified English as their preferred language. Fourteen people – over half – had the assistance of the peer worker from the PAL team fill the survey out; seven people (less than a third) opted to fill the survey out on their own.

#### Experience with PAL Team in ED

Overall 15 out of 25 people surveyed (60 per cent) reported seeing the PAL team in the ED. See Figure 1 below for their ratings of the intervention.

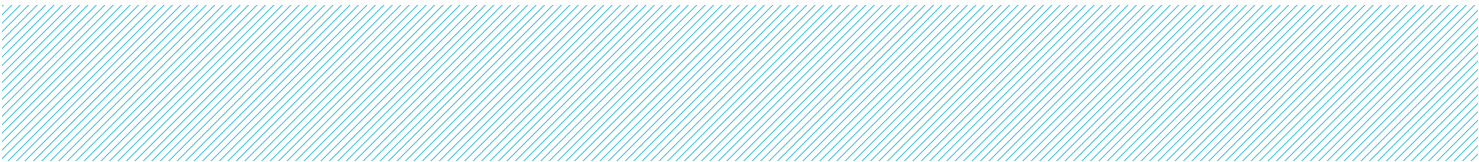
Figure 1: Responses to PAL team interventions



One comment of note in this section was from someone who did not have access to the PAL team. They stated they only saw:

*"Just the other staff, security, nurses. No one could tell me why [I was going to go to the AIS], or say 'you are going through an episode'. I was intense, but no one told me my rights. [The] police laughed at me [in the] divvie van".*

This experience will be explored further in the discussion.

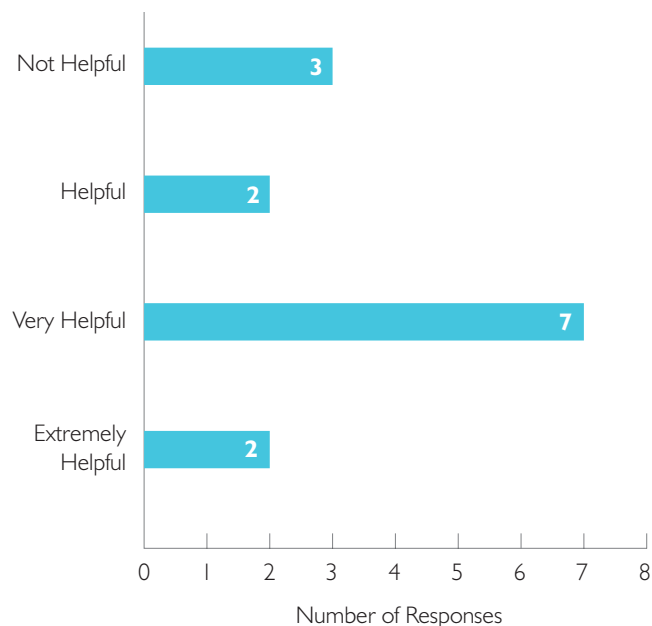


Overall 7 out of the 15 who had access to PAL elected to provide comment, and all were positive. One comment in particular raises questions as to where the PAL team could be improved, in saying “Friendly enough but didn’t really have anything specific that I personally found to be of use.” This too will be explored in the discussion. The remaining comments involved respondents’ feelings of being calmed and relaxed before their transfer, and being generally happy with the interaction.

**Experience with peer worker (specifically) in ED**

There were 14 people who also explicitly remembered meeting the peer worker (who is present on every PAL visit). One person, who stated they had seen the PAL team, said they had not seen the peer worker. Participants were asked how helpful they found the peer worker’s intervention during the PAL visit. Below are the results (Figure 2).

Figure 2: Peer worker rating



One participant who did not have access to the PAL team intervention stated they would have liked to have met such a person during their ED stay.

One of the ‘not helpful’ responses explains: “I wanted a mental health advocate.”

The other two ‘not helpful’ responses did not comment.

Four responses were relevant to the peer worker role, with statements such as that it was:

*“Good to talk to someone with shared experience.”*

*“Nice to have a welcoming committee.”*

**In the AIS: Post Contact with Peer Worker**

Overall 16 people (64 per cent) reported interacting with the peer worker once they were in the AIS. One stated he was unhelpful, 6 stated he was helpful, 6 stated he was very helpful and three stated he was extremely helpful. Not many people gave additional feedback (6 people who had access and 2 who did not have access to peer worker), but all feedback given was positive.

One suggested they would like the peer worker to take on more of an advocate role. The participants who did not meet with the peer worker in the AIS said that would have been good, and one stated they had asked for one but the request had not been met (possibly this was outside the hours of the pilot role). Other feedback included that it was useful to have someone to explain things for them, and overall being “helpful”.

**Discussion**

**Achievements**

Although there were a few missed opportunities and limitations regarding the times where people are admitted to the AIS, one in five people were able to have access to a PAL visit. This is commendable for a new program with restricted hours due to being a pilot with a limited budget, in a busy environment, with diverse staff input, whereby the program required inter-disciplinary communication across different services.

The age demographic of the sample collected was reflective of the population studied, however males were overrepresented in the gender of participants.

Overall most of the feedback was positive and reflected that participants valued being informed, having contact with people who have shared experience, and creating safe and positive links in the ward.

The qualitative component of this study allowed for consumers to voice their experiences in their own words. This allowed the service to gain insight into the experiences of participants in relation to the PAL Team interventions but also their experience more broadly.

Worthy insight was gathered from a participant who did not have access to the PAL team in the ED. As shown in the results, they stated they would like to have access to the PAL team; that they had had a negative experience of being in the ward and their experience of being brought in by police had been quite distressing.

## Consumers who have experienced restrictive interventions, such as seclusion, have reported feeling punished, abandoned, frightened and re-traumatised.

Another participant commented that they would have liked the peer worker to play more of an advocacy role, which highlights a possible area of service improvement to potentially provide greater access to mental health advocates during this process.

A key achievement of this project was the introduction of a peer worker within an acute inpatient service. Although the peer work role has been growing within the mental health community support sector, this was truly a pioneering project in a clinical setting.

### Challenges

A key focus of this study was to capture the voices of people who are experiencing an acute episode, however this posed a variety of challenges for the study. There were some questions regarding the ability for participants to give genuine informed consent due to their mental state. During acute episodes or traumatic experiences cognitive functioning may be impaired, such as memory, which made it difficult for participants to remember the intervention of the PAL Team even if it was documented that it occurred. There were those who were too distressed to complete a survey during their stay; and with the aim of being least restrictive as possible in a time where people are vulnerable it was important for participants not to feel pressured or approached too many times to complete the survey. This contributed to the smaller than hoped for sample size of the study.

The peer worker role was integral to this intervention and was aimed to be utilised in a variety of different ways, including collecting the data. This helped develop the relationships between participants and the peer worker; however it also meant that participants were answering questioning pertaining to the evaluation of a person's intervention to the person. This may have had an impact in the responses collected.

The timing that the peer worker was available to carry out the PAL Team intervention was also limited due to funding for 16 hours of weekly peer work being provided for the project. In order to determine the times the peer worker would be available to intervene the times for admission to the AIS were explored; explaining the choice for afternoon shifts. During the project this rationale was questioned due to long wait times in the ED. Rather than being present at the times people were admitted, joining people in the mornings when most people were waiting in ED to be admitted into the AIS could have increased support to people during the time of the pilot on reflection. This could have also increased the sample size of the study.

As previously and importantly reflected as an achievement, the introduction of the role of a peer worker into an acute setting was not without its challenges. There was some difficulty initially in terms of maintaining someone in the role of peer worker, due to the complex nature of the role. Important changes were made, such as increased supervision and support, and employing someone who had a long history of working within the peer workforce and was already known within, and familiar with, the specific service setting.

The nursing staff in the AIS were often extremely busy and at times agency nursing staff were utilised, which had implications for the PAL team interventions, both practically and ideologically. It was difficult for nurses to find time to accompany the peer worker to the ED. This was identified early on and nursing staff were given information and a consistent message from management about the intervention which assisted with nurses becoming available. Agency nursing staff were not privy to this training and consistency of message so at times this message was lost.

Overall most of the feedback of this new program was positive and reflected that participants valued being informed, having contact with people who have lived experience, and creating safe and positive links in the ward.

The busy ED environment also was often not conducive to a therapeutic intervention, and many of the ED staff were not aware of the purpose of the intervention. Many efforts were made to inform and provide a consistent message to this area of the hospital; however this was very challenging due to the high paced environment; the sheer volume of staff and that the primary purpose of the ED was to assess emergency medical conditions rather than as a waiting area for people with acute mental health issues.

## Conclusion

This report aimed to explore consumer perspectives utilising a survey within an acute in-patient service. The surveys collected to evaluate the Pre Admission Liaison Team's interventions showed to be overall positive. The aim of these interventions was to utilise a peer worker to provide information and support to people waiting for admission into the Acute In-Patient Service who were experiencing an acute episode. More broadly, this project aimed to broadly assist with hospital flow and reducing restrictive interventions. Although this was only a small sample,

it does raise and confirm themes which are important to consumers; such as being informed and working with people who have shared experiences. This pioneering intervention had its challenges however much was learned in regards to introducing peer work in an acute setting and ensuring the voices of consumers are heard within this space.

## Acknowledgements

This study was made possible through the support of Jayne Lewis, Service Development Manager, St Vincent's Hospital Melbourne; Merv Love, Acute Inpatient Service (AIS) Manager (and Project Lead, Reducing Restrictive Interventions project), and the nursing, allied health and medical staff in the Acute Inpatient Service; the consumers who participated, their families and friends.

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## Using consumer engaged evaluation to support service innovation



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In 2015 and 2016 a group of University of Melbourne researchers, including consumer researchers, were asked by Mind Australia Limited (Mind) to assess how well Mind's Peer Recovery Communities (PRCs) were working to support residents' mental health recovery.

This followed Mind changing the model of service delivery in what had previously been adult residential rehabilitation services to PRCs. As the name suggests, Mind wanted to achieve a more positive culture of mutual support, community and focus on recovery in these services.

The evaluation found strong support for peer recovery communities and the value of having peers involved in research activity as well as the model under investigation.

The study included multiple types of data collection including a document review, a survey, individual interviews and focus groups. The intention of this mixed methods approach was to provide a comprehensive picture of the implementation of the PRCs.

The subsequent report made some recommendations regarding the role and function of peer support workers in the PRCs and also the implementation of the models peer learning workshops. This paper explains the background to these recommendations and how they have influenced innovation in the PRCs.

Despite these best efforts to engage in participatory evaluation and service reform the PRCs face a somewhat uncertain future in the context of the roll out of the National Disability Insurance

Scheme (NDIS). This paper describes how managing these transitions have been enhanced by valuing lived experience expertise and ensuring that principles of consumer empowerment and choice and control have remained central to innovation.

### Background

#### The history of PRCs

In 1977 the first residents were accepted at Edith Pardy House, what was then an innovative adult residential rehabilitation (ARR) service. The situation was then fairly consistent as more ARR services opened across Victoria. However the situation began to then change as follows:

- 2011: Mind identified the need to reform and modernise ARR
- 2012: a state government funded evaluation questioned the future value of ARR
- 2014: a new service innovation was implemented – Peer Recovery Communities (PRC)
- 2014-2017: consolidation of Peer Learning Workshops (PLW) within PRC
- 2017: transition from PRC to Supported Independent Living (SIL) in response to NDIS reforms.





“We all want to be peer workers now. It’s a great place to live and experience the reward of providing peer support.”

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### **Drivers for change**

In 2011, Mind Australia prepared a position paper regarding its residential services identifying the need to reform and modernise these services to provide clarity regarding the target population, promote consistency of intake practices, and identify objectives and desired service outcomes (Grigg 2013). The urgency of reform increased following the 2012 Nous review of psychiatric disability rehabilitation and support services (PDRSS) Day Programs, ARR, and Youth Residential Rehabilitation Services (Victorian Department of Health 2012) which made recommendations about the future of these services. The review questioned whether ARRs were necessary and suggested these services be closed in favour of other models of care, in particular Housing First models.

The 2013 recommissioning process of PDRSS services also signalled significant change in the sector and increased emphasis on the need for reform and innovation (Victorian Department of Health 2013). The launch of the National Disability Insurance Scheme (NDIS) also posed opportunities and risks to the future of Mind Australia’s ARR services (Grigg 2013).

### **The Recovery paradigm**

In recent decades the Recovery paradigm has had an important influence on policy, practice and service reform in Australia and internationally. The aim of a recovery-oriented approach to mental health service delivery is to support people to build and maintain a (self-defined and self-determined) meaningful and satisfying life and personal identity, regardless of whether or not there are ongoing symptoms of mental illness (Shepherd, Boardman & Slade 2008). Thus a recovery-oriented approach represents a movement away from a primarily biomedical view of mental illness to a holistic approach to wellbeing that builds on individual strengths (Davidson 2008).

The Recovery paradigm became an important driver for reform in all of Victoria’s mental health services (Victorian Government 2011) and at Mind.

### **Peer support**

Peer support workers have been an important emerging workforce in mental health internationally (Stratford et al. 2017) and Mind has invested in developing its peer support workforce who are seen as making a highly valued contribution to service innovation and recovery oriented practice.

### **The Recovery College Model**

The expansion of the Mind Recovery College™ has provided new ways of thinking about group work, learning and skill development. This innovative service delivery model provides an alternative approach to mental health service delivery based on a co-production and education-based approach (Hall et al. 2017).

### **The Mind Peer Recovery Communities (PRCs)**

In response to the need for innovation, Mind developed a new service model, Peer Recovery Communities (PRC). Mind operates six PRCs across Melbourne providing a service to a total of 76 residents and each PRC is included in one of three service clusters. The model has a focus on supporting personal recovery and promoting wellbeing over a 12 month stay (with some flexibility according to need). The objectives of the PRC include enhancing clients’ choice and supporting clients to exercise control, improving participation and inclusion, and assisting clients to live an autonomous life through short term group living and separate individualised support. The PRC also encompasses the values of improved access and entry processes, increased support for families and carers, a flexible workforce, financial sustainability and the development of routine and rigorous evaluation processes to maintain quality and performance as well as consistency across services.

Peer Learning Workshops (PLWs) are provided as a key aspect of the model. Designed to teach participants skills that are needed to live a satisfying life, their content is based on what people who have experienced mental ill-health have said is important to them. The facilitators workshop manual outlines the modules, units and specific content of each workshop. The workshops content were co-produced with peer educators from Mind’s recovery college and designed to be delivered by Mind staff facilitators and trainers, including those with a lived experience of mental ill-health and recovery.

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Residents report that their relationship with the peer workers is unique, respectful and full of hope.

## The implementation evaluation

The aim of this evaluation was to investigate this process of change, and the satisfaction and experience of clients, their families and carers.

The methodology was developed using advice from a consultative process with both Mind staff and a consumer reference group (CRG). The consumer researcher (Catherine Roper) and Mind's consumer consultant (Nadine Cocks) and the consumer reference group provided valuable insights into the research at all stages including data collection, analysis and reporting. The consumer researcher also actively participated in all aspects of recruitment, including visiting the PRCs to discuss the study with potential participants, and she conducted four of the individual interviews with consumers.

## Mixed methods

The evaluation included the following methods of data gathering:

- desktop documentation review
- routinely collected Mind data
- survey
- interviews and focus groups.

## Implementation evaluation findings

The findings from the implementation evaluation confirmed that PRCs represent a highly valued service option that challenges the Nous group review that these residential services should be substituted with a Housing First model (Victorian Department of Health 2012).

As summarised by one external service provider, PRCs are considered by many stakeholders to be "a precious resource". The implementation evaluation suggested that, overall, the implementation of the new model has achieved many benefits, including early indications of improved recovery outcomes for clients and enhanced engagement of carers and families. The evaluation found strong support for value of having a stronger peer support component in the PRC model (Brophy et al. 2015).

## Recommendations

There were 13 recommendations made as a result of the evaluation and they have subsequently guided a range of activities that are monitored by the Mind PRC governance group to facilitate service improvement.

Two key recommendations regarding peer support were as follows:

- Undertake more planning regarding how to introduce the purpose and rationale of Peer Learning Workshops (PLWs) and ensure that co-production principles are extended to PRC clients to enable more participation, engagement and leadership of PLWs and other activities in the PRCs.

- Develop more clarity regarding the role of peer support workers in the PRCs and how employing staff because of their lived experience contributes to the PRC model.

As one participant described:

"We all want to be peer workers now. It's a great place to live and experience the reward of providing peer support." (Resident)

## Utilising lived experience in practice in the PRC

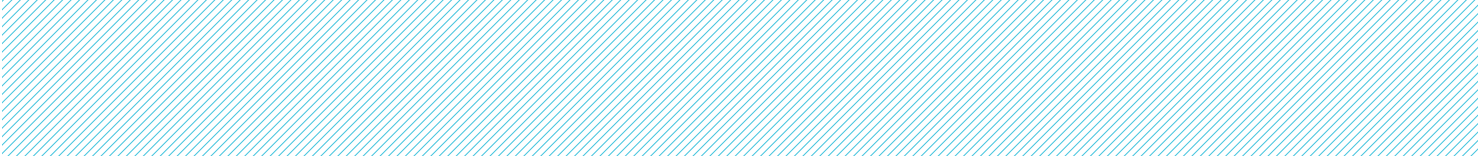
One of this paper's authors, CP, is a Community Mental Health Practitioner – Peer Practitioner at one of the PRC sites. She has undertaken this role for almost two years. This followed her own journey of mental ill health and recovery and her interest in utilising this lived experience in a practical way to help others.

There are three Peer Practitioners in the PRC cluster and they work closely together to ensure a consistent approach across the sites. The flexibility of the Peer Practitioner role allows CP to utilise her lived experience in her practice in a way that is individual to each resident's needs. Residents report that their relationship with the peer workers is unique, respectful and full of hope. The shared experience creates an implicit space of understanding and empathy which has the ability to bridge the gap between worker and consumer. The role of a peer worker extends to providing unique and effective expertise to support PRCs in their practice, and when advocating for clients with external services.

One of the projects in the Peer Practitioners portfolio is the Peer Learning Workshops (PLWs). When the concept of the PLWs was initially implemented into the PRC's curriculum, the objectives were for individuals to:

- improve their health and wellbeing
- find the words to articulate their life experiences in a way that is meaningful to them
- understand recovery and wellbeing and what those concepts mean for them
- identify and build on personal preferences, strengths and aspirations
- make choices about other learning opportunities
- contribute to the daily functions of the PRC, promoting self-care, mutual support and responsibility
- identify and build community connections and broader social circles.

As the recommendation from the University of Melbourne's research indicated, there were problems in implementing the PLWs related to both consumer and staff engagement. In reviewing the situation, Mind's values of hope, creativity and innovation, consumer focus and integrity were applied and it became clear that best practice would be to really hear what the residents were saying, and to provide opportunities for them to co-facilitate content that they wanted to see.



As a result, the new curriculum comes from a stronger standpoint of self-direction and control, allowing residents to determine content they want to share, see and learn. It also provides consumers greater opportunity to work on their goals and support their peers in achieving their own goals in a safe and supportive community setting.

Since the inception of this new model the PRCs have seen consumers facilitate workshops on a range of activities of interest to them including skills such as knitting, photography and yoga, and social skills, including assertiveness, as well as mental health interventions like mindfulness and sensory modulation.

Responding to the recommendations has generated a real shift in the energy and enthusiasm of both consumers and staff. Residents have been observed to, with encouragement, co-facilitate workshops, share their skill set, and subsequently develop new confidence and improved relationships with other residents. Peer Practitioners have heard residents say that involvement in creating and co-facilitating workshops has opened new possibilities, including increased interest in becoming a peer worker themselves. The value of peer support is hard to quantify, but every day there are examples in the PRCs of the power of the shared experience and its ability to encourage and inspire hope in the face of adversity.

### **Ongoing organisational change and innovation**

The new model demonstrates the value of embedding peer support workers in services and having more opportunities for co-production of activities focused on social inclusion. The PRCs have created new opportunities for people with psychosocial disability and demonstrate the importance of services shifting more clearly to new models of care that are focused on social inclusion and community participation. The PLWs provide opportunities for peers to model and observe the benefits of courage and perseverance on their recovery journey, providing hope for their own future.

The activities that have followed the implementation evaluation have demonstrated the value of research findings being integrated into service improvement and practice at the PRCs. The 2016 Mind Australia Satisfaction Survey (MASS) found that 93 per cent of clients surveyed (895 respondents, including residents of the PRCs) feel positive about the services they receive from Mind.

Even so, the future of the PRCs in the context of the NDIS and the transition to Supported Independent Living (SIL) and Specialist Disability Accommodation (SDA) is an important area of focus. Six per cent of NDIS participants nationally will receive SDA within their plan (*Disability Services Consulting – SDA Checklist* May 2017).

Ensuring individuals receive adequate levels of Core support within their NDIS plan will be crucial for continuity of support; this in turn would be SIL. Additionally, securing appropriate accommodation, post legacy stock, to provide SIL to individuals with a psychosocial disability is a new challenge.

### **Peer Recovery Communities and the NDIS**

As defined by the NDIS, Supported Independent Living (SIL) is assistance with and/or supervising tasks of daily life to develop the skills of individuals to live as autonomously as possible. SIL is costed on a weekly basis and is reviewed at scheduled planning meetings annually. NDIA planners and delegates are required by legislation to make funding decisions that are deemed to be reasonable and necessary (NDIS Provider SIL Pack Training Guide 2017). Once the NDIA planner has determined SIL is reasonable and necessary to be in a participant's plan, the agency offering the SIL place will then generate a quote that will then be submitted to the NDIA for review.

The change – from block funding to the service provider to billing participants individually for the services provided – introduces economic and transactional dimensions to the relationship between participant and service provider. This also creates significant opportunity for participants to be able to flexibly choose how their funds are spent. They will be able to access supports that will be provided to assist with independently living even while living in a shared environment.

Although there is greater opportunity for current residents of the PRC to be able to flexibly use their funding, there is concern for new participants with a significant psychosocial disability entering the scheme and receiving SIL funding within their plan.

A report by the Independent Advisory Committee on implementing the NDIS for people with mental health issues (2014) has shown individuals with a psychosocial disability are much less likely to be approved for NDIS than those with an intellectual disability. Trial sites indicated that one in four applications for mental health support was deemed ineligible, compared with one in nine for the rest of the scheme. Furthermore, the COAG Disability Reform Council Performance Report from June (2017) reports that 33 per cent of participants entering in that quarter had a primary disability group of Intellectual Disability compared to eight per cent with a psychosocial disability. In this context, NDIA assessments on SIL may require more specialised understanding of the needs of people with psychosocial disability and advocacy. It appears that the NDIS planners need to develop skills in the assessment of the person's level of need and the proper understanding of the person's functional level that ensures the appropriate allocation of funds in a package.

As the move from the PRC model into SIL takes place there will be an even greater focus on the very important human right of each individual to have choice and control over their recovery journey. This is the right to participation, which is part of the right to health.

As a result the PRCs have incorporated regular feedback events into the program, where residents are encouraged to give their honest opinions on the service and how it can continue to grow and improve. The creation of a resident advisory committee provides another platform for consumers to be the drivers for change not only within their community but within Mind Australia as a whole. There have been interesting reflections from current participants who have transitioned from the MHCSS – Adult Residential Rehabilitation funding to receiving NDIS – Supported Independent Living in their plans.

Peer learning workshops are still seen to be a highly valued part of the SIL group supports on offer. As evidenced at a PRC consumer feedback day held in August 2017, co-designed and peer led activities are seen to enhance and create a strong sense of community. As part of the individual supports a resident receives via SIL, having a consistent key worker and building a trusting and supportive relationship is paramount. As continually fed back within MASS surveys, individual relationships have a profound positive impact on recovery and wellbeing.

However, having enough skilled workers to provide the level of support required may be a challenge in future. As the Productivity Commission's report found, the disability sector workforce "will not be sufficient" to meet demand and this is a future challenge for the wider disability sector.

Mind is aware of this challenge and is committed to ensuring our current workforce within our SIL services have a minimum qualification of Cert IV in Community Services and staff continually receive training and development. In return, NDIS participants will be able to rely on being able to access high quality psychosocial supports to assist with living independently in a residential setting.

## Conclusion

After a history of fairly static service delivery dating back to 1977 in Victoria, in less than seven years adult residential rehabilitation in Victoria has experienced dramatic organisational change in response to the recovery paradigm and the introduction of the NDIS.

This paper described how managing these transitions has been enhanced by valuing lived experience expertise and ensuring that principles of consumer empowerment and choice and control have remained central to innovation. Our focus for the future needs to be on the power of choice and control to build confidence and self-worth, develop skills, achieve ambitions and create community.

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## Somewhere to be safe: women's experiences of a women-only Prevention and Recovery Care (PARC) service



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**Alys Boase** is interim CEO, Ermha Inc

**Professor Ellie Fossey** is Head of Occupational Therapy, School of Primary and Allied Health Care, Monash University

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In response to concerns that not enough was being done to protect women's safety whilst recovering from mental health issues, Victoria's first women-only Prevention and Recovery Care (PARC) service was begun in February 2014. The authors have collected and analysed feedback from the women who accessed the service in its first years to inform the further development of the program and other future service provision.

### Background

Articles and guidelines have been published in Australia on the need for gender sensitive practices in mental health, including: *Nowhere to be safe: Women's experiences of mixed sex psychiatric wards* (Clarke 2007) and *Service guidelines on gender sensitivity and safety* (Department of Health 2011). They clearly document the need for women to feel safe when recovering from mental health episodes in mental health programs and provide guidelines for mental health services staff to promote care that is sensitive to gender-related issues.

Guidelines include considering gender in planning around service design and professional development activities to ensure current knowledge of best practice and ensure that practice is tailored to gender differences and individual needs (Department of Health 2011).

The Victorian Government made a commitment to trialling a Prevention and Recovery Care service (PARC) as a women-specific unit to enable female patients to access gender-sensitive treatment, free from victimisation or stigma.

This was in response to Department of Health (2011) Service guideline on gender sensitivity and authors such as Clarke (2007) who found that 67 per cent of female patients reported experiencing sexual or other forms of harassment during their acute psychiatric hospital stay.

### Service context

Springvale Prevention and Recovery Care service has been in operation for more than 11 years and was one of the first PARC programs in Victoria. It is a 9 bed residential program in a subacute residential setting in suburban Springvale, providing assistance to women recovering from mental health issues. Springvale PARC is collaboratively run between Ermha and Monash Health and funded by the Department of Health and Human Services (DHHS).

To help meet the government's commitment to a Women's PARC (WPARC), the Ermha Monash Health Springvale WPARC began trialling the WPARC model from 3 February 2014.

The Ermha and Monash Health Springvale WPARC steering group looked to the then Victorian Department of Health for guidance in developing a model of care. The Adult Prevention and Recovery Care (PARC) services framework and operational guidelines, 2010, state:

*Providers working with persons in a PARC service must recognise, respect and respond to the diverse needs, values and circumstances of each person, such as their gender,*

*family circumstances, culture, language, religion, sexual and gender identity, age and disability. Through inclusive professional practice at PARC services every reasonable effort is made to accommodate people's cultural, religious, racial or linguistic backgrounds or other needs.*

The department's service guideline on gender sensitivity and safety (Department of Health 2011) includes:

- 'gender sensitive care recognises that women and men may experience mental health issues differently' (page 2)
- 'organisations must review existing policies, procedures and practices using a gender-sensitive lens' (page 3)
- 'policy which addresses bed based services, referring to mixed-sex bed based environments' (page 17).

There are no guidelines from the Department of Health and Human Services, however, that provide direction on translating gender-sensitive policies into single gender bed based programs. With the absence of a more comprehensive gender sensitive lens in federal and state mental health policy, there are challenges for providing gender specific programs. The writers, therefore, set about collecting information about the experiences of women who have accessed the WPARC with the intention of using this information to inform the further development of the program.

## Becoming an accidental researcher

### Reflections from Karen Dixon, formerly Practice Leader, Ermha, Springvale WPARC

Shortly after the busy-ness of the Christmas/New Year period in 2014, the whispers that we had heard at the Springvale Prevention and Recovery Care service (PARC) were confirmed: we were about to become the first women only service of its kind in Victoria, starting in two weeks!

Our team looked to our managers and our managers looked to the Department of Health for guidance on how to translate theory into practice and a program that would support women with mental health issues and their families and allies. There were guidelines and policies but nothing specific enough to answer all our questions – after all, we were going to be the first service of its kind in Victoria.

Starting February 2014, we quietly changed from a mixed gender service to single gender by simply accepting only female consumer referrals. Our program was a collaboration between Monash Health and Ermha Inc. and we were guided by the Collaborative Recovery

Model, and trauma informed care and family sensitive practices. We were satisfied that our model of care was person-centred, so wouldn't that translate to being women-centred?

As Ermha Practice Leader of the service, I was responsible for the quality of the program and, therefore, needed to deliver an evidence-based practice. But where was the evidence? It did not exist, so with a joint effort from all the staff, two wonderful Monash University Masters of Occupational Therapy students and the consumers, we made a plan to collect feedback from the women who stayed at Springvale WPARC during 2015 and 2016. We would use this feedback to shape the program's development and contribute to the body of knowledge on women's mental health. In order to share our findings with all interested stakeholders, we would need to conduct the evaluation safely, ethically and professionally so that the findings would be valid.

Before I knew it, I had become an accidental researcher, a practitioner researcher!

## What the evaluation involved

At Springvale WPARC, a Consumer Satisfaction survey is provided to each resident towards the end of their stay, as part of exit planning. This is voluntary and completed independently by the resident unless help is requested. It is collected prior to departure, and the de-identified data is entered into a data base. See Figure 1 for the questions asked in the survey.

The study method for this project involved analysing 115 Consumer Satisfaction surveys and the transcripts of four focus groups, which are held onsite every six months and include 7-8 previous residents, to discover the experiences of women at a women-only PARC service. This data was collected during the period of 1 February 2015 to 31 December 2016 from clients of the service in that period. Over that time, 229 women stayed at WPARCS.

Of the 115 surveys collected and analysed:

- 53 per cent had been at home immediately before their entry into WPARC (known as 'step up')
- 47 per cent had been in an acute psychiatric inpatient unit immediately before their entry into WPARC (known as 'step down')
- 52 per cent of the participants had completed their first stay at WPARC.

Figure 1: Questions we asked the women

Q: Have you appreciated being in a female only PARC?  
If yes, please give more details.

Q: Has your stay at WPARC better prepared you for managing your mental health?

Q: Is there anything that could have improved your stay at WPARC?

Q: Any further comments?

## Results of the evaluation

The survey revealed striking levels of appreciation from the residents for being in a women-only PARC and overwhelmingly high satisfaction with their stay at Springvale WPARC:

- **"Overall how satisfied were you with your stay at PARC?"**  
91 per cent of residents rated their satisfaction overall at 7/10 or above, with 56 per cent rating their satisfaction at 10/10.
- **"Have you appreciated being in a female only PARC?"**  
96 per cent answered 'yes'.
- **"Has your stay at WPARC better prepared you for managing your mental health?"** 94 per cent answered 'yes'.

Forty one per cent reported that they would not have wanted to come to a PARC service if it was not women-only.

The themes that consistently emerged from the survey were around feeling comfortable, safe and relaxed in a women-only environment. The women reported that this led to more honest and in-depth discussions around their needs and contributed to positive peer support experiences during recovery.

## What the women said

Below are some of the survey responses grouped in emergent themes:

### Question: Have you appreciated being in a female only PARC?

Being with people like me

"Yes I like to stay in this PARC because I met a lot of people who have the same feelings like me."

"It was easier to communicate and to be open with each other as women."

"Comforting to know that other women struggle with similar problems."

Relaxed and safe environment

"Female only is fantastic. I felt safe and secure and able to discuss personal issues."

"A safe and non-judgmental environment was there for my recovery at PARC."

No men

"As I feel nervous, easily taken advantage of, when around males. Also suffer from PTSD due to domestic violence."

"My stay was so much more relaxing – no men to be threatened by."

"I felt intimidated by the men in the hospital and it was nice to not feel that way during my recovery at PARC."

Comfortable

"I felt comfortable in an all-female environment. I could get into my night clothes early if I wanted to."

"Being all female just felt more comfortable."

### Question: Has your stay at WPARC better prepared you for managing your mental health?

Relapse prevention plan

"Helped with early warning signs and how to seek help."

"The relapse prevention plan and early warning signs were very helpful."

Strategies

"Routine, felt safe, managing my outbursts of anger."

"Yes, given me strategies to help with overwhelming feelings."

**Question: Is there anything that could have improved your stay at WPARC?**

More individual support

- "I would have liked greater contact with my key worker."
- "More one on one counselling."

Facilities

- "Fix your washing machine."
- "Internet connection (Wi-Fi)."
- "I needed an area to be alone besides the bedroom – like a timeout room."
- "More arts and crafts."

Physical activities

- "More physical activity."
- "Yoga."
- "Exercise class."

**Question: Any additional comments?**

Thank you

- "The staff are incredibly dedicated and caring. Even at my lowest, I was always treated with dignity and respect and never felt like I was a mental patient."
- "The support staff are the most understanding of any group of people in mental health I've encountered."
- "I feel privileged to have been in this PARC. It had a real homely feel about it, not clinical at all. The staff were amazing and made my stay enjoyable every day."

**Enablers for recovery**

The residents who completed the survey and attended the focus groups reported that the most helpful aspects of Springvale WPARC, other than the women-only environment, were the supportive interactions with staff, both one-on-one and in groups, the support from their peers and engagement in the daily routine and meaningful activities at WPARC.

**Suggestions for improvements**

The suggestions for improvement were small in number but included requests for more time with support staff on an individual basis and improvement to the physical environment.

**Recommendations**

As residents have found it overwhelmingly positive to participate in a women-only PARC program, it would be preferable to have more than one gender-specific program of this kind in Victoria. The learnings from the first years of operation of Victoria's first gender-specific PARC could be transferred to similar programs to enable larger numbers of women with mental health issues to benefit.

More rich and valuable data about what contributes to the comfortable environment at Springvale WPARC could be obtained by individual interviews with former participants. In particular, it would be interesting to do an evaluation of the Recovery Group program, which is a group program held twice per week and facilitated by support workers, in order to determine if more gender specific content would be appreciated.

It would also be of interest to evaluate the responses of the residents to the increased involvement in the program of the WPARC consumer representative which has been a change to the program since the data has been collected.

**Implications**

The findings of this project will be used to inform the future planning of Springvale WPARC and may inform other gender specific mental health programs.

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## Creating an environment that cultivates meaningful consumer-led or co-produced research. Are we there yet?



**Dr Katherine H Gill** is Chair of the Consumer-Led Research Network

The phrase ‘*Nothing about us, without us*’ has long been proclaimed in the disability, psychiatric, consumer and survivor movement. It continues to ring true for many consumer advocates today, and is highly applicable in mental health research.

In Australia and internationally there is increasing recognition of the importance of active consumer involvement in research. In 2002, the National Health & Medical Research Council (NHMRC) and the Consumers’ Health Forum of Australia (CHF) released a Statement on Consumer and Community Participation in Health and Medical Research which acknowledges the benefit of and rights of consumers to participate in health research. This statement was updated in 2016 (National Health & Medical Research Council 2016) and highlighted why consumer and community involvement in research was so important.

The statement recognised that consumers offer unique and valuable insights as research is framed, conducted and translated and that consumers help to ensure research quality and relevance. It indicated that consumer involvement in research leads to increased public confidence in the relevance of the research, improved openness and transparency in the conduct of the research, and improved accountability for the use of public money, with communities being better informed and having a greater understanding of the research.

The NHMRC recognises that involving consumers adds value to health and medical research, and that consumers have a right as well as a responsibility to do so. The Australian Code for the

Responsible Conduct of Research (2007) states that ‘*appropriate consumer involvement in research should be encouraged and facilitated by research institutions and researchers*’ (NHMRC 2007).

Consumer expertise in research projects may add a different perspective to the research frame, making the research more relevant to the people who benefit from the end product. Consumers may facilitate dissemination and translation of the research through their peer networks, adding to the impact and value of the research.

Facilitating the consumer voice throughout the research provides consumers with a sense of ownership and helps to break down the barriers and divide of ‘us’ and ‘them’, whereby consumers are seen as the ‘*done to*’ not the ‘*done with*’. Working with consumers on a research project has the potential to break down stigma and discrimination, with consumers recognised and valued for the expertise the lived experience brings to the research table.

The NHMRC/CHF statement provides the key to developing stronger partnerships between researchers and consumers at all levels of health and medical research in Australia. Researchers are encouraged to foster partnerships with consumers and to actively involve consumers in their proposed research when they apply to NHMRC for research funding.

It provides information for research institutions to involve consumers in a meaningful and ethical manner. This includes:

- the development of policies that stipulate consumer involvement and partnership in all stages of research
- ensuring the consumer's time and expertise is valued and appropriately remunerated and acknowledged
- building capacity of researchers to involve consumers by providing training and recognising consumer involvement as good practice
- building the capacity of consumers through training, mentoring and support
- minimising barriers to meaningful consumer involvement.

The statement highlights that researchers should have planned and budgeted strategies to support, implement and acknowledge appropriate consumer involvement throughout the research process.

The Australian National Framework for Recovery Orientated Practice (Australian Health Ministers Advisory Council 2013) Domain Four identifies recovery orientated organisations as having an organisational commitment to acknowledging, valuing, respecting, drawing on, and learning from the lived experience. This includes [Domain 4B] providing opportunities for research and evaluation conducted by peers and people in recovery, and incorporating these findings into quality improvement initiatives and ongoing organisational change.

While policies, frameworks and guidelines dictate the involvement of consumers in research, what this looks like in practice can be vastly different across different services and organisations, with researchers having varying ideas and expectations of consumers and consumer capabilities in research.

### No or only tokenistic consumer involvement

Consumer involvement in research can be represented on a continuum, with four distinct levels of consumer involvement [Figure 1].

Level 0 represents no consumer involvement, with the research being done 'to', 'for' or 'about' consumers.

Level 1 is tokenistic consumer representation. This may include speaking to or consulting with consumers about the research. The consumer feedback may or may not be taken on board, and in this consultative process the balance of power lies with the researcher, with the consumer input having little or no real impact on the output of the research.

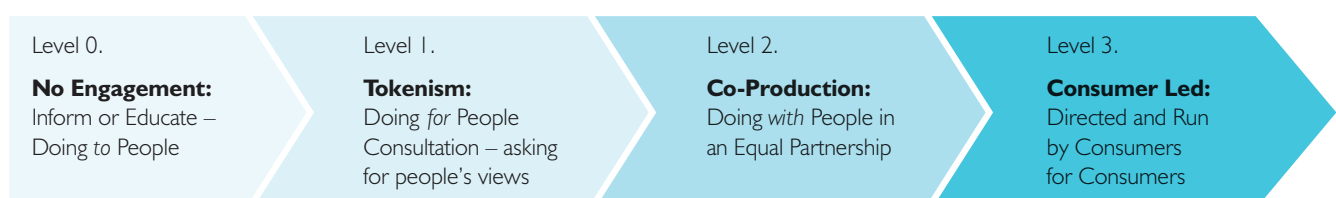
In such research, consumers may be invited on or recruited as a committee member in a research project but have no real say in the research project, design or research question/s. The researchers may have no expectations of the consumer to contribute as an active team member, and should the consumer/s challenge the status quo or the prevailing dominant view, the consumer input may be invalidated and/or seen as less relevant than the input of the other researchers.

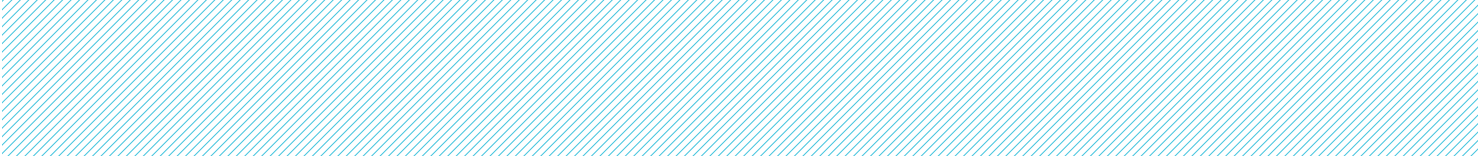
At Level 1 the consumer researcher is not expected to bring any more than their lived experience. The consumer is not expected to have any real research skills or experience and may not be remunerated for the time they contribute to the research, or remuneration may be at a basic rate with the assumption that the consumer researcher has no real research skills or experience.

Between Level 1 and 2 of consumer involvement in research, a consumer may be supported to be involved in the research, but still have no real say in the research design or questions. For example a consumer may be recruited to do a specific task, such as interview other consumers or support consumers to fill in questionnaires. This type of consumer involvement may see the lead researcher dictate what a consumer researcher does and says as part of the research. At this level of consumer involvement it may be assumed that consumer researchers do not have the skills or capability to contribute to the research design, research questions and data analysis.

The participation of consumer researchers at Level 1 is often enacted simply to 'tick the box' of consumer involvement. There may be potentially immutable power differences between the consumer researcher and the rest of the team, which gives the consumer researcher no real say, so that the involvement of consumer researchers can only be regarded as tokenistic. While the consumer voice may not be heard with this type of research partnership, this does provide an

Figure 1: Consumer involvement in research: a continuum.





opportunity for junior consumer researchers to build skills and experience within research projects, as a pathway to consumer-led or co-produced research projects.

With the lifetime prevalence of mental illness and mental distress in society identified as almost one in two (ABS 2008) it is highly likely that a large percentage of people involved in research may have been touched by mental illness or mental distress at some point in their lifetime. With the prevalent stigma and discrimination that exists in society and particularly in the workplace setting about mental illness, people with lived experience are less likely to disclose experiences of mental ill health for fear of recrimination and having a negative impact on their career and how they are seen in the workplace. When a person becomes skilled at hiding their lived experience of mental illness and/or mental distress they are unlikely to be skilled in using their lived experience purposely to inform service design, delivery, research and evaluation.

Consumer researchers are not just researchers with a lived experience of mental illness/mental distress, but researchers who are skilled at harnessing their lived experience purposefully, alongside their professional training, experience and qualifications, to contribute to the research, at all stages throughout the research processes.

When opportunities present that respect consumer researchers as valued members of a research team, including remunerating them at a rate equivalent to their skills, experience and qualifications, there is no shortage of qualified consumer researchers. However consumer researchers find there is a shortage of opportunities that enable them to be supported, included and respected as active members of research teams and to use their lived experience in a meaningful and authentic way that adds value to the research project.

### **Working in partnership**

Co-production, Level 2 on the continuum, involves consumer researchers working in partnership with other researchers in a collaborative, equal and reciprocal manner. In co-production, consumers and other researchers share power and contribute equally, recognising that all parties bring valued experience and valued perspectives. Co-production is more than consumer involvement, consumer engagement and/or consumer consultation. Co-production is about active engagement of consumer researchers that recognises they bring vital expertise and knowledge based on their lived experience, combined with their professional background, training and experience. As such, a consumer researcher would be remunerated appropriately based on their skills, experience and qualifications.

At its most effective, co-production has been recognised as having the potential to be transformative (Needham 2009). Co-production requires a redefining of the relationships between consumers and the traditional 'expert'. Co-production

may require a shift in organisational structure and culture (Gill 2014). Co-production requires staff and other researchers to respect and accept the expertise of the lived experience, to be able to share power and decision making, and to recognise that consumers have an additional asset of lived experience that can be harnessed in the design and implementation of research and evaluation.

Co-produced research requires the active involvement of the consumer researcher at all stages of the research. Working in partnership in a collaborative manner enables researchers to better understand consumer experiences. This lends itself to far stronger research with co-produced research projects having the potential to lead to innovative outcomes.

Working in equal partnership helps to break down barriers, stigma, and pre-conceived ideas about the potential of consumer researchers and the expertise consumer researchers can bring to the project, but co-production is not without challenges. In an ideal co-produced project, the consumer would be supported and empowered in the research process to contribute in an equal and reciprocal manner with others on the research team. However, frequently the consumer researcher may be a sole consumer voice on the research team and may feel disempowered and that their voice and opinion is not as equally valued as other team members. At times society's prevalent stigma and discrimination may lead to a process that becomes unsafe and potentially damaging to the consumer researcher.

Consumers experience many barriers to meaningful engagement in co-produced research projects. These may include:

- feeling powerless
- discriminatory attitudes of others
- use of disempowering language
- feeling isolated/siloed and/or treated differently to others without a lived experience, including having reduced access to resources.

Organisations with strong hierarchical structures and top-down processes may contribute to feelings of disempowerment; there may be poor human resource processes with a lack of flexibility and a lack of understanding of illness and the legal requirement for the use of reasonable accommodations in the workplace setting.

In order for research to be meaningful, authentic, safe and useful to consumers, some consumer researchers are opting for a consumer-led process [Level 3] whereby the balance of power and decision making process is shifted and lies with the consumer researcher. In consumer-led research the research is planned, directed and executed by consumers. Professionals may be involved in guiding, supporting and assisting the research process but in consumer-led research the balance of power lies with the consumer researcher.

## The NHMRC recognises that involving consumers adds value to health and medical research, and that they have a right and responsibility to do so.

### Recommendations to facilitate authentic and safe consumer involvement in research

1. Facilitate consumer ownership and leadership, involving and championing active consumer involvement from the start to finish.
2. Foster an attitude of innovation and curiosity, be open to learning from the lived experience expertise, and be willing to be challenged.
3. Create a culture of openness and honesty, with clear and transparent communication, and recognise that all opinions, perspectives and ideas have equal weight and are all respectfully considered.
4. Work in equal partnership, with equal and reciprocal collaborative relationships, and a commitment to sharing power and decision-making.
5. Create a culture that values and respects the consumer experiential knowledge base.
6. Facilitate adaptive, responsive and flexible leadership.
7. Have equality in numbers of consumer representation, to facilitate peer support and strengthen the consumer authentic voice.
8. Be willing to change and address negative organisational culture, misperceptions, negative assumptions, stigma and discrimination and be open to challenge the predominant mainstream and medical model belief system.
9. Facilitate safety and break down barriers to inclusion; consider resourcing flexible and accommodating work places, supervision, peer support and the impact of negative, stigmatising language.
10. Provide supportive, inclusive environments that foster teamwork, support empowerment of the consumer voice, and offer sensitivity and respect for the consumer voice with no divide of 'us' and 'them'.
11. Acknowledge and recognise the input and contribution of the lived experience expertise.
12. Recognise that co-production and consumer leadership can be challenging for the system, that it requires a redefining of the way 'experts' view consumers, a change in the language and nature of interactions, and a shift in organisational structure and culture.

Australian policies, frameworks and funding bodies mandate the active involvement of consumers in research, and consumer involvement in research is recognised as an ethical imperative. However the lack of clear frameworks, guidelines and funding structures leads to a haphazard and *ad hoc* process of consumer involvement.

While the input of consumers in a well-designed and supported co-produced or consumer-led project can lead to transformative outcomes, the lack of clear structures and processes to facilitate consumer involvement and to recognise consumer expertise can lead to a process that becomes disempowering and potentially harmful for the consumer.

The recommendations above can help to facilitate the safe inclusion of the authentic consumer voice in research projects so that consumer researchers add value to the research and improve outcomes for the community affected by the research.

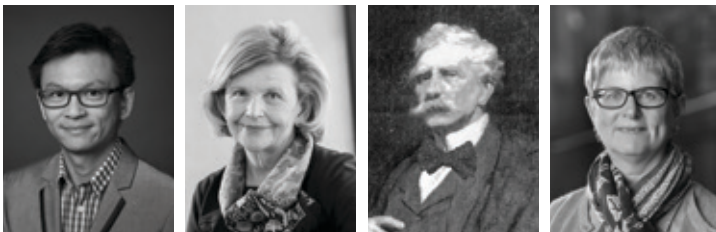
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**RESEARCH  
NEWS**

**RESEARCH NEWS**

# Changes in health and wellbeing of carers of people with psychosis over time



**Dr Abner Weng Cheong Poon** is Lecturer, School of Social Sciences, University of New South Wales

**Professor Lynette Joubert** is from the Department of Social Work, Melbourne School of Health Sciences, University of Melbourne

**Professor Andrew Mackinnon** is from the Centre for Mental Health, Melbourne School of Population and Global Health, Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne

**Professor Carol Harvey** is from the Psychosocial Research Centre, Department of Psychiatry, University of Melbourne & NorthWestern Mental Health

## Background

Studies of carers of people with severe mental illness show that carers often experience negative impacts such as care-giving burden, poor quality of life, psychological distress and social isolation (Awad and Voruganti 2008). However, most studies recruited carers from support groups and psychiatric clinics. Therefore, the results of most studies are likely not generalisable to other carers.

In addition, there is a lack of longitudinal findings regarding changes in carers' health and wellbeing over time. Together, these limit the understanding of the recovery process and changes in health and wellbeing of carers of people with psychosis over time.

## Methods

This caregiving study was conducted within the context of the second Australian prevalence study of psychosis which used a random sampling strategy in recruiting people with psychosis (Morgan et al. 2012). Ninety-eight carers of people with psychosis were recruited from two of the Australian prevalence study sites in Victoria. Standardised, validated questionnaires

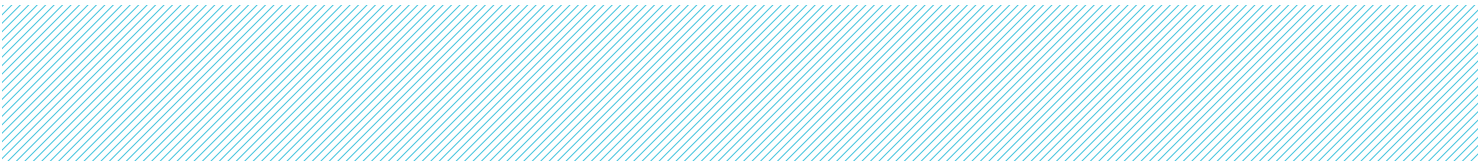
(Friendship Scale, Kessler-10 and WHOQOL-BREF) were administered to 98 carers, with 78 of them repeating the questionnaires one year later. Statistical tests were conducted to identify changes in carers' health and wellbeing over time.

## Findings

A considerable percentage (29 per cent) of carers were socially isolated at baseline and the same percentage experienced social isolation at follow-up. There was no statistically significant difference in average social isolation scores over time.

One in five of carers (20 per cent) experienced psychological distress at baseline and 23 per cent at follow-up. There was no statistically significant difference in average psychological distress scores over time.

Carers reported moderate quality of life. There was no statistically significant difference in their average quality of life scores over time except for a statistically significant and meaningful deterioration in carers' physical health over time. On average therefore, carers' health and wellbeing remained mostly stable over time.



Cross-lagged analysis suggested that poorer functioning of people with psychosis as perceived by carers had a small individual-change effect in influencing carers' social isolation and psychological distress over time. However, carers' perception of their own social isolation and psychological distress did not have an individual-change effect in influencing their perception of the functioning levels of people with psychosis over time.

## Discussion

It is well known that some carers experience negative impacts in care-giving. Our findings have shown that within the current mental health context, carers of people with psychosis experienced poor health and wellbeing, and their levels of health and wellbeing were stable over time.

This suggests that carers' needs are largely unaddressed by routine mental health service provision. In addition, our findings showed that carers perceived their physical health to worsen over time, indicating the need for services to consider physical health interventions and respite programs to support the physical health of carers (Thunyadee et al. 2015).

As the functioning of people with psychosis has a long-term effect on carers' health and wellbeing over time, services need to consider providing psychiatric rehabilitation interventions to support improved functioning of people with psychosis. Simultaneously providing such interventions to people with psychosis and reviewing services to respond to carers' needs will likely better support the recovery of people with psychosis, as well as their carers.

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## Acknowledgment

This report uses data from the 2010 Australian National Survey of High Impact Psychosis.

## RESEARCH UPDATE

# Gateways and gatekeepers: examining the experiences of people with episodic mental illness during transition to the NDIS



**Elizabeth Hudson** is a PhD candidate and recipient of an inaugural 2016 Future Social Service Institute PhD scholarship. If you are interested in following up this study, please contact Elizabeth at [elizabeth.hudson@rmit.edu.au](mailto:elizabeth.hudson@rmit.edu.au)

**Academic supervisors:** RMIT Associate Professors Martyn Jones and Paul Ramcharan

**Industry supervisor:** Mary Sayers, Deputy CEO VCOSS

### Overview

Self-directed funding and support is a key feature of social care reform in Australia, and the introduction of the National Disability Insurance Scheme (NDIS) in 2013 is arguably an exemplar of this model.

Lauded as one of the country's most notable social policy changes, support for the NDIS construct extends across stakeholder groups. However, there are concerns in some sectors of the disability communities about the application of specific eligibility criteria. That includes that restrictions to access may exclude those with fluctuating mental health conditions (episodic mental illness), who may face challenges in demonstrating the permanence of their disability, which is a precondition for access to the Scheme. Furthermore, as resources are diverted away from existing services toward the NDIS, it is unclear to what extent community supports will be available for those who are ineligible.

As the NDIS design premise is based on entitlement to support and located in aspirational concepts of choice and control and social inclusion and recovery, this study seeks to examine the consequences of eligibility determinations for people with psychosocial disability. An analysis of NDIS policy, and the

findings from first-hand accounts with people with episodic mental illness and NDIS industry professionals, will aim to reveal how social fields of power (Bourdieu 1984) lead to differential pathways and raise issues around notions of social justice and fairness in the system.

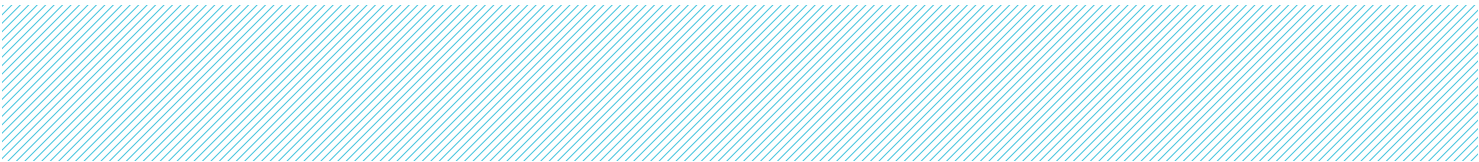
### Aim

The research project aims are to examine:

- how people who experience episodic mental illness are affected by the transition to an emerging and evolving NDIS
- the Scheme's eligibility rules and the interface between policy and practice
- whether there is evidence of gaps in service delivery as a result of the introduction of the NDIS.

The project will examine the experiences of people with episodic mental illness during transition to the NDIS. It will explore the perceptions of both people with episodic mental illness and industry sector professionals to determine how access to the scheme is negotiated and understood.





### Research question

What are the first encounter experiences of the NDIS for people with episodic mental illness?

Sub questions:

- What are the enablers and barriers to choice and control, recovery and inclusion?
- How is access negotiated and understood?
- Are there emergent service gaps?
- What is the wellbeing impact?

### Approach

#### Qualitative study

The aim of this research is to examine the issues regarding NDIS accessibility, suitability and eligibility for people with episodic disability from a variety of perspectives. The project will examine the perceptions and experiences of people with episodic mental illness as well as industry practitioners (Local Area Co-ordinators & planners) as they engage with the NDIS.

The perceptions of both industry practitioners and people with psychosocial disability will be explored through semi-structured interviews. As such, interview questions are structured to include both open-ended and closed questions to elicit in-depth responses. The interview content is informed by insights derived from the Research Advisory Panel (see below).

The National Disability Insurance Agency has endorsed the research and is assisting in the recruitment of 14 NDIS industry professionals.

#### Recruitment

Participants (people with episodic mental illness who are registered consumers of mental health services) are recruited from two Victorian mental health organisations (NEAMI National and Mind Australia).

#### Semi-structured Interviews with people with episodic mental illness:

North East Melbourne Area – (n= 10-13)

Regional Victoria (Bendigo/Ballarat) = (n= 10-13)

#### Semi-structured Interviews with specialist NDIS industry professionals:

NDIA Planners (n=6)

Local Area Co-ordinators (LACs) North East Melbourne Area (n=4)

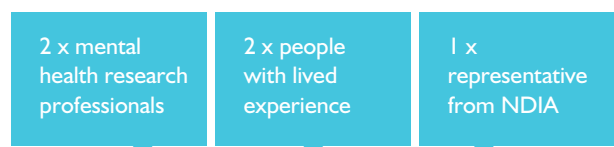
LACs Regional Victoria; Ballarat and Bendigo (n=4)

#### Investing in the value of lived experience

Acknowledging the valuable contribution of those with lived experience of mental illness and the expertise of industry, a research advisory panel for my research project has been established. The panel consists of five specialists and includes two lived experience experts: Ebonyrose Lyons and Judith Drake. Funding for their participation is provided by the Future Social Services Institute. The panel will meet regularly over the lifetime of the PhD project and provide input into the research design and implementation.

*The Future Social Service Institute is a collaboration between the Victorian Government, RMIT and the Victorian Council of Social Service (VCOSS).*

#### Research advisory panel



**RESEARCH UPDATE**

# Exploring the experiences of people in supported residential services through the NDIS roll-out



**Liz Dearn** is a PhD candidate and recipient of one of the inaugural 2016 Future Social Service Institute PhD scholarships

**Overview**

My PhD will explore the experience of people with mental illness and complex needs living in supported residential services (SRS) in the context of the roll out of the National Disability Insurance Scheme (NDIS) in Victoria.

SRS are privatised congregate care facilities that provide accommodation and support for large numbers of people with mental illness and complex needs. Concerns have been raised over the past two decades about gaps in funding and support for people living in SRS environments.

**Aim**

The aim of the study is to explore how residents experience choice and control over their goals and lives as they come into contact with the NDIS. The research is exploratory and will employ a critical ethnographic approach, involving observation and interviews with residents living in two SRS. The study will look at change over time by examining the lives of 12 residents over a 12 month period.

While choice and control are key concepts underpinning the NDIS, people living in institutional settings like SRS often experience little choice and control in their lives. What constrains or limits choice and what facilitates or enhances choice for people with disabilities has been a subject of research in Australia (for example, Laragy, Fisher & Purcal 2015) and overseas. Similarly, the right of people with disabilities to the support they need to exercise their capacity to make decisions about their lives has been the subject of much research (see Browning, Bigby & Douglas 2014).

There is evidence from the UK that there is a higher uptake of individualised funding for people who are younger, educated and middle class, and for people who have the benefits of networks of support and individual agency. Accordingly, concerns have been raised in Australia that people with disabilities and mental illness at risk of disengagement from support systems and social exclusion, risk further marginalisation from the service system in the NDIS context (Dowse and Dew 2016).

This study examines a significant gap in the NDIS policy context as the voice of residents living in institutional settings has not been heard. The research will increase understanding of how the NDIS is implemented and is expected to produce new evidence that will inform policy and planning and practice.

Liz Dearn has worked in the area of policy and social equity for over 20 years, in local and state government and not for profit organisations. Liz has taken three years leave as coordinator of the Policy and Research Unit at the Office of the Public Advocate (OPA) to undertake this PhD.

At OPA, Liz had portfolio responsibility in the mental health area which entailed systemic advocacy relating to mental health policy and legislative reform. Liz's research and analysis were instrumental in the Long Stay Patient Project, a Community Visitor initiative that raised concerns about the indefinite detention of many consumers in secure extended care units.

Liz will commence data collection in November 2017 and will have some preliminary findings in mid-2019. If you are interested in following up this study, Liz can be contacted at: [lizdearn@yahoo.com](mailto:lizdearn@yahoo.com)

*The Future Social Service Institute is a collaboration between the Victorian Government, RMIT and the Victorian Council of Social Service (VCOSS).*

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## RESEARCH NEWS

# Exploring the impacts of the NDIS on mental health carers



**Amaya Alvarez** is the recipient of one of the inaugural 2016 Future Social Service Institute PhD scholarships

### Overview

My PhD will explore the experience for mental health carers of the National Disability Insurance Scheme (NDIS): how it impacts on their lives, the care work they do, the ways in which their work is supported, and on the sustainability of their work in the context of their own ability to live ordinary lives.

### Aims and approach

The aim of the study is to:

- examine how mental health carers feel the NDIS impacts on their care work, and their own needs and rights
- explore the gaps between the policy frame of the NDIS and the lived experience of mental health carers
- identify what supports are available and needed for mental health carers in this new marketised system.

The research is qualitative and designed in two phases. The first phase involves interviewing mental health carer support and advocacy staff to identify key challenges, issues and concerns from a service perspective. The second phase involves listening to mental health carers in guided discussions regarding their experience of the NDIS, drawing on key issues identified in the first phase of the study to generate discussion. It is anticipated participants for the second phase will be sourced through informal mental health carer support groups in different locations across Victoria.

### Rationale

Although support for the NDIS is widespread in principle, concerns have been expressed about the experiences of carers in the Scheme, and the lack of a separate assessment to ensure that their choices, needs and wellbeing are not compromised by the Scheme's design and implementation.

Emerging evidence suggests that transition to the NDIS reduces carer support services, and can increase carer burden (Kemp et al. 2016). Mental health carers are particularly concerned about what happens to individuals they support who are not eligible for the Scheme, what this will mean for the supports available for the person they care for, and consequently for their care work.

Some research on the impact on carers of the NDIS is emerging (Sheen et al. 2017), however there is little literature on the experience of mental health carers of the NDIS. It is important to capture this evidence as the scheme unfolds particularly in a context where mental health carers are already undertaking high levels of support work often at the expense of their own health and wellbeing (Diminic et al. 2017).

Peak carer organisations and mental health carer advocates are keen to see research in this area to assist in developing their own policy responses and carer supports into the future (Carers Victoria 2017).

**Amaya Alvarez has worked as an educator, researcher, and project officer across a wide range of areas from rural sustainability and regional community engagement, to healthy ageing and the social dimensions of peri-urban planning.**

**Her work in applied research has always been motivated by a commitment to facilitating more equitable and just social change. As well as her professional experience, Amaya brings to her research lived experience as a mental health carer.**

**Please don't hesitate to contact Amaya if you would like further information on her research, or if you are interested in following up this study.**  
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