new**paradigm**

BUILDING THE KNOWLEDGE
MENTAL HEALTH RESEARCH AND ENQUIRY

CONTENTS

new**paradigm**

EDITORIAL

Welcome to the Summer 2015 edition of new**paradigm**.

Debra Parnell, VICSERV

In the context of so much change occurring in mental health and across the community sector in 2014, it seemed timely to take a step back and consider the knowledge base that is being explored and developed for the improved delivery of mental health supports and for better outcomes for consumers and carers.

We are pleased to be able to present articles on a number of diverse mental health research projects underway in Victoria and to report on projects that present the voices of consumers and carers on current issues.

The scene is set by an overview of current directions in mental health research by Dr Lisa Brophy and Dr Margaret Grigg from Mind Australia, who highlight emerging trends not only in the research that our sector initiates but how it engages in that research with consumers.

As might be expected in the current environment there are a number of articles related to the implementation of the National Disability Insurance Scheme (NDIS):

- Indigo Daya from the Mental Illness Fellowship met with consumers, carers and workers in the Barwon NDIS trial area to ensure that the voices of people living with mental illness are being heard. The result provides great insight into the perspective of consumers and carers on the Scheme.

- Also looking at consumer perspectives, Dr Lisa Brophy and her colleagues provide an update on their project that asked: 'When given a choice, what supports do people with a psychosocial disability think they need to have a good life?'

- Brooke Baxter from Pathways Rehabilitation and Support Services brings us the views of Mental Health Community Support Services workers involved in the Barwon trial, in an effort to understand the impacts of the change and pressures of the reform process on staff, and how they can be supported by their organisations.

The introduction of *Victoria's Mental Health Act 2014* under the former Coalition State Government has been another significant recent development, along with the anticipated launch of the state's first Mental Health Advocacy Service in 2015. In a special feature article, experienced consultant Allan Pinches has brought together a 'virtual panel' of consumers and consumer consultants to consider what a consumer-oriented, fair and better-resourced mental health advocacy system might look like. His paper provides a stimulating discussion of models, and the potential of consumer advocacy under the new service.
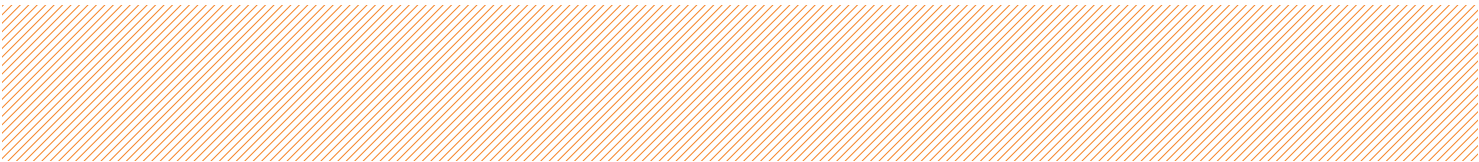
We are pleased also to provide overviews of a number of other important mental health research projects now underway:

- Kate Higgins from Mental Illness Fellowship reviews the implementation of the Individual Placement and Support (IPS) model, finding that while there has been some progress on employment outcomes for people with mental illnesses, social exclusion remains the norm.
- In 2012 Peninsula Support Services (PSS) identified the need to adopt a new model of care, and an Outcome Measurement (OM) tool to meet its aims for recovery-oriented, person-centred, family-inclusive service delivery. Finding that there was no suitable tool available, they set about to develop their own. Cindy Keys from PSS and Jane Howard from Frankston-Mornington Peninsula Medicare Local report on the development, trial and evaluation of the Person Outcome Measurement Tool (PROMT).
- Innovative research from the Psychosocial Research Centre at Melbourne University has provided new evidence of the impact of adverse events in childhood. Suzanne Turner and her colleagues conclude that this has important implications for the sector and for more and better trauma-informed models of care.
- PULSAR (Principles Unite Local Services Assisting Recovery) is a four-year project funded by Victoria's Mental Illness Research Fund (MIRF). The PULSAR team describes its work on developing an approach to recovery-oriented practice that is comprehensive, locally tailored, clearly operationalised, thoroughly documented and robustly evaluated.

- With consumer engagement becoming a central tenet in the design and delivery of health services, it is timely to examine the benefits on recovery outcomes of this approach. Dr Victoria Palmer outlines the three year CORE study, which will test an experience-based co-design technique in improving psychosocial recovery outcomes for people affected by mental illness in the community mental health setting.

Finally, in our *vox pop* feature, we ask consumers and carers for their views on the opportunities and risks that are emerging under the new and changing mental health support services, and the areas in which they would like to see more research.

I would like to thank the contributors who have made this a very interesting and stimulating edition of *new**paradigm*** and to the VICSERV team for their valuable assistance in the production process.

I hope you enjoy reading this edition and that it contributes to the knowledge and practice focussed on improving outcomes for people living with mental illness and their families.

BUILDING THE KNOWLEDGE

Mental Health
Research and Enquiry

Trends in research and the Mental Health Sector

Dr Lisa Brophy is Director of Research at Mind Australia and Senior Research Fellow at the Centre for Mental Health at the University of Melbourne
Dr Margaret Grigg is Deputy Chief Executive at Mind Australia

One of the characteristics of a maturing system is that it is less the object of research and more the generator of its own knowledge and meaning. This edition of new*paradigm* showcases some of the research being conducted across the community mental health sector in Victoria. The range of topics and methodologies indicates how the sector and individual organisations are becoming more strategic in initiating and engaging with research activity, and in developing their own research and evaluation frameworks.

There are not only trends in *what* is being investigated but also *how* that research is conducted. As this edition indicates, the sector is shaping and influencing mental health research, in particular research into recovery and well-being. It also features examples of efforts to embed principles of recovery and the value of lived experience in research by improving access to and engagement with consumers (Ramon, Healy & Renouf, 2007; Rethink, 2010). Recovery oriented systems not only need to be informed by lived experience: lived experience is being called upon to both define and answer critical research questions. Thus more interpretive inquiry into the complexities of service users' and service providers' experiences is encouraged.

While it is commonplace to both seek the views of and employ consumers in mental health service development, this engagement is an emerging area within the research field. However, overall trends in mental health research now are seeing greater recognition of people being experts through lived experience and increased employment on projects of consumer researchers. This reflects growing recognition that consumer researchers can enhance research in many ways including through improved design and safety for participants and enabling more honest responses and improved engagement (Goodson & Phillimore, 2012).

The introduction of the National Disability Insurance Scheme (NDIS) is the most significant change to the service delivery system in Australia since deinstitutionalisation in the mid 1990s. The Barwon trial in Victoria is an important opportunity to learn about the impact of the system and the shift to individualised funding packages, not only on the clients who will be eligible, but also for those people who will not be supported through the scheme.

Individualised funding in a mental health context is a highly contested concept. While there are many who have high hopes for its potential for individual recovery there are concerns that this shift requires careful investigation, especially regarding unintended consequences. It has been suggested that personal budgets can be powerful in changing people's lives; however, budget-holders need supportive infrastructure to have real choice and control, and providers themselves need support to deliver personalised, recovery oriented services (Williams and Smith, 2014). It is likely that over the next few years, the NDIS will stimulate substantial research. It will be essential that the community managed mental health sector become active participants in this research effort.

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of Victoria (VICSERV)

Trends in research and
the Mental Health Sector
by Dr Lisa Brophy and Dr Margarett Grigg

It is likely that over the next few years, the NDIS will stimulate substantial research. It will be essential that the community managed mental health sector become active participants in this research effort.

The Victorian Mental Illness Research Fund has provided significant research funding to explore innovative ways to improve service delivery in mental health (Department of Health, 2014). The projects have been based on strong partnerships between universities, clinical services, community managed mental health services and consumer and carer representatives. It could be argued that these projects are setting a standard for mental health research in Victoria, both in the quality of their research and level of collaboration and engagement of consumers and carers and other key stakeholders.

Following the recommissioning of Victoria's community mental health services, the Department of Health and Human Services has released a performance framework with an emphasis on services demonstrating outcomes. Few people would disagree that services have an obligation to make a difference in the lives of people to whom they provide services; consequently there has been considerable research effort directed towards the measurement of outcomes. The Personal Measurement Outcome Tool (PROMT) developed by Peninsula Support Services is another example of the plethora of tools that have been developed or are in development to measure outcomes.

Central to the dilemma of choosing an outcome measure is the question of 'which outcome for whom'? The growing focus on measuring outcomes that are meaningful to the people who use our services is an important direction that is also being taken up nationally by the National Community Managed Organisation (CMO) Outcome Measurement Project being conducted by Australian Mental Health Outcomes and Classification Network and Community Mental Health Australia. These initiatives will build the capacity in future for the sector to demonstrate meaningful outcomes.

There are current opportunities to engage in and encourage non-clinical mental health research that is focussed on recovery, wellbeing and social inclusion such as many of the projects described in this edition of new**paradigm**. There is also the ongoing challenge of integrating this knowledge into policy and service development. In a tightening financial environment, both in the research and community mental health sector, the investment of organisations such as Mind Australia in a Director of Research will become more important. The sector needs to consider how to position itself in an ongoing way to ensure that research is focussed on the expressed needs and priorities of people with mental ill health and their families. Also, as services look to ensure their financial sustainability, investment in knowledge generation and dissemination will become even more important.

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Raising Our Voices: Emerging consumer and carer stories from the NDIS Barwon trial

Indigo Daya is General Manager, Consumer and Carer Advocacy and Leadership at Mental Illness Fellowship Victoria

Sometimes it seems that everyone has something positive to say about the National Disability Insurance Scheme (NDIS). 'It's going to be the saviour of community services.' 'It's filling gaps.' 'It's bringing amazing new choices and opportunities.' Is this really the case? What do consumers and carers have to say about it, and what does our sector really need to know?

It is indeed true that there are some extraordinarily positive stories from the NDIS trial sites. These are to be congratulated and continued. As consumers we want choice and control. We want new paradigms. We want our lives back. But we are also somewhat suspicious of new systems that offer us these things. We have heard these promises before, and have often experienced little real change. Our lives exist in a context of involuntary treatment, profound distress, extreme disadvantage, stigma, exclusion, trauma and violence, so you must allow us space if we are a little slow to trust. This is just a realistic adaptation to our history. Human rights and advocacy work is as vital to the mental health system as service delivery and treatment.

Those of us who work in mental health advocacy have been hearing increasingly of issues emerging out of the NDIS trial. This is to be expected in a trial of any kind, and I cannot conceive of an initiative even half as significant as the NDIS that wouldn't have wrinkles to iron out. Thankfully none of these issues are beyond our capacity to solve, given the right will by the right people, sustained effort and a commitment to engage transparently and constructively.

A need to look and listen more deeply

Last year it was clear from a series of consumer and carer issues emerging out of the NDIS Barwon trial site that we needed to find out more. While we knew that the NDIS was reporting 94 per cent participant satisfaction, we realised that this data was not telling the whole story for the people in our sector. This is because the reports:

- amalgamate all participants – there was no report specifically for mental health
- did not include participants from our sector who were not part of the scheme but may have been affected by it
- included a cohort of new people entering the mental health part of the scheme who were not previously participants in our sector.

Anecdotal evidence was telling us that consumers who were found *not* eligible for NDIS funded support may be missing out on critical support services. A number of other concerns had been raised by consumers and carers who were not necessarily in the scheme.

The National Disability Insurance Scheme (NDIS) has been trialled within community-managed mental health services in the Barwon region since July 2013. In Victoria the intent is for NDIS funding to eventually replace all previously block-funded community-managed mental health support services.

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by Indigo Daya

Our aim was to hold a community advocacy event to find out the real stories from the people who use our sector and who felt they weren't being heard, and to address that need. Our focus was on those people and our sector rather than the scheme itself.

We knew that the National Disability Insurance Agency (NDIA- the body that administers the NDIS) was funding consumer feedback forums, however we also knew that these forums were not picking up the full story because:

- consumers who had been found ineligible for the scheme could not attend
- some consumers reported feeling uncomfortable attending or sharing at the forums because of feared repercussions (we are not aware of any repercussions, but we understand this fear)
- other consumers would be excluded because some had chosen not to apply for the scheme or found it too difficult to apply for the scheme.

Further, we were concerned that there was not an adequate space to hear the stories of carers and workers.

In response to these issues, Mental Illness Fellowship's consumer and carer advocacy portfolio led an initiative to form an alliance in Barwon of service providers and peak bodies which included Victorian Mental Illness Awareness Council (VMIAC), Psychiatric Disability Service of Victoria (VICSERV), Tandem, Pathways, Mood Support, Karingal and Salvos Connect.

Our aim was to hold a community advocacy event to find out the real stories from the people who use our sector and who felt they weren't being heard, and to address that need. Our focus was on those people and our sector rather than the scheme itself.

The advocacy event was called 'Raise Your Voice, Barwon', and was held during October 2014 at the Simmonds Stadium. Around 60 people attended the event, including consumers, carers and workers, and 50 responses/stories were shared. Given some of the fears and discomfort that we knew existed, we offered people the chance to share their stories in different ways, including surveys, interviews, audio or video recordings and unstructured written feedback.

What people told us at the event

Many stories emerged out of the event, and these included both positive and negative experiences.[1] Looking at those people who completed the structured survey (n=27), the first finding was that consumers, carers and workers all have different perspectives. Table 2 amalgamates different questions about overall improvements to service and experience as a result of the NDIS in these four domains:

1. Improved mental health.
2. More choices.
3. Better support.
4. Increased control.

Respondents	Positive responses 'Better'	Neutral responses 'About the same'	Negative responses 'Worse'	Unsure 'I don't know'
Consumers (n=12)	**55%**	9%	**23%**	13%
Carers (n=5)	26%	**32%**	11%	**32%**
Workers (n=10)	**30%**	5%	**53%**	13%
Weighted Average	41%	11%	32%	16%

Table 2: Collated survey responses for 'improved mental health, more choice, increased control and better support' for consumers, carers and workers. Text in bold indicates top two response categories.

[1] A detailed report of findings is available online at http://mifellowship.org/node/476

Assessing a person's mental health needs and goals in a 1-2 hour session, with a complete stranger, once a year, is almost diametrically opposed to recovery-oriented practice in mental health.

While a majority of consumers at the event reported positive experiences with the trial (55 per cent), a substantial proportion reported worsened experiences (23 per cent). For carers the top responses were different: split between 'I don't know' (32 per cent) and 'About the same' (32 per cent). Workers had the most negative experiences, and many said they were speaking on behalf of participants who wouldn't or couldn't come to the event. Their primary response was negative (53 per cent) with a secondary response of positive (30 per cent).

Another 23 responses at the event were delivered through unstructured mechanisms – mainly audio interviews and handwritten stories. These have also been thematically analysed.

In general, consumers with positive experiences of the NDIS:

- had a support worker, advocate or carer/family member to support them through the application process
- reported interactions with the NDIA as friendly, timely and responsive
- were granted funded support packages which met their needs
- received detailed and supportive referrals from GPs or psychiatrists
- found that speaking about their needs with a deficit focus helped to get a better package.

In general, consumers with negative experiences of the NDIS:

- had been found ineligible for support and many had to appeal this decision
- found the process difficult, frightening and/or disheartening
- took offence to language such as 'permanence of impairment'
- experienced long delays, often many months
- felt that NDIA did not understand mental health
- had difficulties getting medical referrals and/or having these accepted
- had not used a support worker, advocate or carer
- reported a worsening of their mental health
- found that speaking about recovery or focussing on strengths meant they were less likely to get support.

Many participants spoke about feeling that no-one would listen to their concerns. As a result we produced a short film of people's stories and promoted this on *YouTube* during the 2014 state election campaign. Anecdotal feedback from both consumers and carers was exceptionally positive as people felt that their voices had truly been magnified.[2]

So, what do we need to do?

The implications of the event demonstrate issues in six distinct domains, each requiring a different set of actions.

Issue 1: More consistent quality and process

Quality and process issues with the scheme and NDIA included staff skills and knowledge, process improvement to address delays, communication, streamlined accessibility, and building more clarity amongst referring specialists. We note that experiences of many of these issues were highly variable in that sometimes they were positive and sometimes extremely negative.

There are issues here that require more complex thinking. These include:

- Consumers requiring a support person, advocate or carer to assist with the application process. Currently this is unfunded and widely variable. We found that having this in place made a substantial difference to the consumer experience and package outcomes. A solution is required which allows access to this support during the application process.

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[2] The film can be viewed online at: https://www.youtube.com/watch?v=qjaxfFxux5w

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- An appreciation that assessing a person's mental health needs and goals in a 1-2 hour session, with a complete stranger, once a year, is almost diametrically opposed to recovery-oriented practice in mental health. In fact, this process is often the core work of recovery and rehabilitation programs, not what happens at the entry point. It requires a relationship built on trust and rapport, an exploration of personal values, strengths and dreams, and opportunities to explore different ways of thinking about mental health. Our mental health problems often lead to low self-esteem, concentration problems, hopelessness and low confidence. We need support to grow in these spaces in order to think differently about needs and goals. Substantial thinking is required to adapt the NDIS to allow space for these processes to occur.

Issue 2: Need for recovery-oriented NDIS support clusters and processes

The current version of the scheme shows little relevance to contemporary best practice in community mental health. It assumes people's needs remain static. It focusses on deficits, not strengths. It is about disability, not health. It is modelled far more on physical impairments than mental health. It is about maintenance rather than growth. It needs substantial rethinking by both the NDIA and the federal government, and we urgently require mental health specific and recovery-oriented clusters of support.

Issue 3: Using the NDIS to replace community-managed specialist mental health services

This strategy is failing. The NDIS was never meant as a replacement for state-funded specialist community managed mental health, and it isn't working that way. Attempting to do so is leaving increasing numbers of people without critical support services, will cause huge impacts for clinical services as people's mental health is impacted and have broad socioeconomic consequences. Most other issues are significantly compounded by this. Being found not eligible is obviously very significant if the NDIS becomes the only available support system. If we change direction and continue to block fund the community managed mental health sector, the whole picture changes dramatically. We need to retain a separately funded community-managed mental health sector. This is clearly a major decision requiring review by the Victorian government.

Issue 4: Labelling people as 'permanently impaired'

The *National Disability Insurance Scheme Act 2013* states under eligibility criteria that 'the impairment or impairments are, or are likely to be, permanent' (2013, p. 27). This concept of permanence in mental health lacks evidence, is disrespectful and may cause harm.

There is no such thing as a mental illness that is permanent, and many consumers report feeling hopeless and despairing as a result of having to subscribe to this type of thinking.

The inbuilt rationale for this language is most likely to keep down the numbers of people who can access the scheme. And of course, there is only so much money available. However it is possible to maintain reasonable limitations on the scheme while also using criteria which are evidence-based and helpful. For example, we could assess people's needs based on their actual history and current situation, rather than on speculative predictions about the future.

The issues raised with the concept of 'permanent impairment' include:

1. Damaging, rather than building, hope

Hall (2014) states:

'Enduring is a statement of fact, "permanent" is a prediction of the future that, in the light of personal testimony and decades of recovery research, cannot be an honest appraisal of the diversity of psychosocial disability, and, as folks are noting, can become a prescription of hopelessness for some.'

2. Misaligned with best practice in recovery

The language of permanence permeates every aspect of the scheme. While this language continues, it will be difficult to develop recovery-oriented practice into services. As stated in the National Framework for Recovery-Oriented Mental Health Service, '*Promoting a culture and language of hope and optimism is the overarching domain and is integral to the other domains*' (Australian Health Ministers Advisory Council, 2013, p. 29).

3. Contrary to evidence

O'Hagan (2014) states:

'There's a very simple reason permanence is a problematic concept in mental health and not so much in other areas of disability. If I snap my spinal cord or am born without a functioning optic nerve it is easy to predict an outcome of permanence. If I am diagnosed with schizophrenia or bipolar at 20 no-one can reliably predict the outcome 5, 10 or 40 years later. I was labeled 'chronic' in my hospital notes three months before my last admission.'

4. Creates barriers to service entry

A number of consumers at the forum told us that they would not apply for a scheme that uses this language. One event respondent stated:

'To be eligible for NDIS funding, one has to sign an agreement that one is permanently disabled. It's a major moral dilemma. They don't know what

NDIS funding will reposition our workforce at a Certificate II or III level of funding which will substantially reduce the skilled services we are able to offer. Ultimately it will lead to reduced standards of mental health care, worsened recovery outcomes and higher costs in clinical systems and other social services

they're asking us to sign really. It's like signing yourself to a doom, of sorts. It's saying 'I give up, I'm not ever going to recover', and a lot of us do, like it or not.' (Respondent).

5. Reduces choice and control

We need to allow people to make sense of their experience and direct their recovery in their own way.

This issue sits squarely with the federal government and Council of Australian Governments and must be addressed as part of the major review of the NDIS legislation which is scheduled for mid-2015.

Issue 5: Reduced access and support for carers

This issue was only just emerging at our advocacy event, because funding of services for carers is still being transitioned into the scheme and most people were still able to access support through other funded programs. This will not remain the case as other carer support funding streams are redirected towards the NDIS.

Unlike current carer support services, carers will not be able to independently apply for support under the NDIS, or access the same types of support as before, such as carer respite. This will cause widespread and major issues for carers who will be less able to perform their role as carers. It will increase the likelihood of mental health issues for carers, and lead to greater demand on services.

We see this issue – which also has been flagged by Carers NSW in a recent report on the NDIS Hunter trial in NSW (Carers NSW, 2014) – as a major emerging concern.

Issue 6: Service standards and quality outcomes at risk

This issue was reported more by workers and organisations, although it was flagged by some consumers and carers and we expect it to emerge in the future as a stronger issue.

The NDIS pays organisations less than half the amount they are normally paid in the community managed mental health sector to provide a similar service. This creates risks of service failure and a

major deskilling of the community mental health workforce. Previously our sector has tended to employ staff at Certificate IV, diploma and degree levels. NDIS funding will reposition our workforce at a Certificate II or III level of funding which will substantially reduce the skilled services we are able to offer. Ultimately it will lead to reduced standards of mental health care, worsened recovery outcomes and higher costs in clinical systems and other social services.

Summary

Our consultations with consumers, carers and workers from the Barwon NDIS trial site reveal six major emerging issues. Some sit squarely with the Victorian government to address and resolve, others relate to the federal government or with state or national offices of the NDIA. It is neither unexpected nor a failure that these issues exist – it is simply the nature of major change. What matters now is that all parties commit to deep learning from the trial, and to working collaboratively with consumers, carers and the community sector to adapt funding, legislation, processes and structures to meet the needs of people who need support.

Transparency and fast adaptation are both essential as we move forward. Consumers said they want to hear more than just good news stories – they also want to hear about the real problems and what's happening to fix them.

We must remember that this trial is different to any other in terms of ethical considerations. No participant had a choice about whether or not to participate in this trial, and if participants choose to opt out, there is no ongoing alternative to choose. We are conducting a trial on real people, with real vulnerabilities, without much of a safety net. Given this reality, we must continue to work together, and to address issues with the scheme as soon as they emerge.

Just as every person has the potential to recover, so too does the NDIS have the potential to be a scheme which enhances mental health and life outcomes for people in our community.

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People making choices: The support needs and preferences of people with psychosocial disability – Project summary

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The aim of this project was to improve understanding of the choices that people with psychosocial disability would make about support for priority life goals if they were offered individualised funding packages. This was timely given the inclusion of psychosocial disability in the National Disability Insurance Scheme (NDIS), which has been designed to enable Australians with disability the opportunity to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports (Commonwealth of Australia, 2013b).

In the *People making choices: The support needs and preferences of people with psychosocial disability* project, sponsored by Mind Australia, 41 people who self-identified as having a psychosocial disability as a result of mental ill-health participated in individual interviews. All of the participants were currently accessing specialist mental health services in the Barwon region.

It was intended that the project would:

• Assist people with psychosocial disability to influence the development of current service systems through improved understanding of their preferences for support.
• Provide the community mental health sector with information about how self-directed funding may impact on service delivery and the types of changes needed to develop more responsive services in the transition to an individualised service delivery environment.

The overall research question was:

When given a choice, and based on their personal preferences, what supports do people with psychosocial disability think they need to have a good life?

The concept of good life (Felder, 2013) was used to guide the research. A good life discussion is consistent with the overall goals

of the NDIS and the United Nations (UN) Convention on the Rights of Persons with Disabilities (United Nations, 2006), which focus on improving social and economic participation, supporting people's independence and maximising opportunities for full inclusion in the community.

In both, the discourse is one of self-determination, autonomy, and self-directed supports for inclusion. Two of the authors were peer researchers on the project and every effort was made to take a recovery oriented approach to the research activity. More detail about the interview questions and how they were developed is provided in the project report (Brophy et al., 2014a) and in a previous article in new**paradigm** (Brophy et al., 2014b).

Findings

Overall, participants in this project broadly reflected many of the common characteristics of people living with psychosocial disability. A large proportion lived alone or in supported residential services, in poverty and experienced social isolation. Around half had been excluded from completing high school. Although around one-third had a post-school certificate or diploma, many participants reported that they had completed this higher training through supported employment agencies. Not all were using these skills. The vast majority were reliant on the Disability Support Pension as their main source of income. Most reported the expectation of a continuing and fluctuating

impact of their psychosocial disability over time, and reported significant impacts on a range of life activity areas including lifelong learning activities, social interaction, and employment.

The good life goals that participants prioritised as their 'top five' were:

1. *Health* (68 per cent of participants) – focussing on both their physical and mental health needs and recognising the connection between the two for their wellbeing. As explained by one participant:

So I can't run. There is no physical possible way I am healthy, I am not. I'd like to lose a stack of weight. I have diabetes and a whole lot of other health-related issues that come along with mental illness. You don't feel like going for a walk but you know you should.

2. *Economic* (61 per cent) – to assist them to achieve economic stability and increase their incomes through assistance with training and education, employment and financial security. Help with achieving greater economic security was described by one participant as follows:

I was thinking of getting a mentor and support worker but that was more for the economic sort of thing to help me… I was thinking of getting them to help with budgeting, getting budgeting up to scratch so I can save money and actually pay off my debts and such.

those that were about more intimate or family relationships. Many had lost contact with their families and did not have an intimate partner but could see value in support to work towards building or rebuilding these relationships. For example:

'Personal life' because getting married is important to me and having a partner and things like that, it will bring me lots of happiness in life; also, it's shown that people with a permanent relationship or a marriage partner are known to live longer and happier than those who don't.

Experiences of stigma and discrimination and living in poverty emerged as key barriers for the participants in relation to working towards their good life goals.

Having a support person was something many participants prioritised and identified as a key enabler to meeting their life goals. Participants had preferences about the characteristics of the support workers they would purchase with individualised funding, including:

• being respectful and compassionate
• having a good knowledge of the mental health system
• understanding the impact of mental ill health and psychosocial disability
• being able to take up multiple roles
• having good communication skills.

Having a support person was something many participants prioritised and identified as a key enabler to meeting their life goals.

3. *Social Connection* (58 per cent) – to connect them with potential friends and other individuals and/or with social groups and the community. Loneliness and isolation was one of the common experiences for people interviewed. For example:

Someone to talk to. I mean when I don't go anywhere for a couple of days, you know, I think who's around to talk to? I don't speak for a couple of days because there's no one around to talk to you know.

4. *Housing* (34 per cent) – to enable more stability, safety and independence in their housing. Many people were aware that disruptions associated with unstable or insecure housing made it hard to achieve a better life and wanted support around housing. For example:

Actually that would be a good thing to have support with, if you need to move, because that's huge and not just mentally or physically but both.

5. *Personal Relationships* (32 per cent) – to help them to meet people and therefore have opportunities to develop intimate relationships. This goal was also linked to that of Family which focussed on assisting people to repair, sustain or improve their relationships with their families. Participants made important distinctions between relationships related to those that assisted with social connection and

This data enhances understanding of what is a 'good' support worker. This is particularly important in the community mental health sector where currently so many of the resources available are allocated to the employment of support workers. The findings offer an opportunity to hear directly from participants about the characteristics, values, skills and knowledge they value in a support worker.

Discussion

The 41 people with psychosocial disability interviewed in this study live the reality of health inequality in Australia. Hence, to make the most of individualised funding packages they require skilled assessments that begin an iterative process that encourages hope and enables recognition of positive outcomes, stumbling blocks and changing needs and goals over time.

Participants were able to identify their life goals and forecast how they would allocate funds from personal budgets to achieve these. They also identified a large proportion of supports that arguably are the responsibility of other jurisdictions or providers and hence not eligible for individual funding via the NDIS (Commonwealth of Australia, 2013a).

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Psychiatric Disability Services
of Victoria (VICSERV)

People making choices: The support
needs and preferences of people
with psychosocial disability –
Project summary

Lack of appropriate housing is a substantial issue. Assistance may be required with a wide range of housing costs such as mortgage and rent assistance, housing relocation, house and home maintenance and housekeeping.

This is problematic as they also identify the significant level of under-resourcing and unmet need from these 'provided' services, where services are either not available, or not available in a way or to the extent required for the person to achieve outcomes/goals. Most, if not all of these services, are seen to address critical underpinning needs, where lack of services and supports will significantly hamper or deny the achievement of other goals. This is a significant issue for the NDIS and the mental health sector.

People with psychosocial disability are likely to have fluctuating needs which will make initial assessment complex and require an ability to constantly adjust plans and provision. In terms of initial assessment, there is a significant risk that some people may not be deemed eligible simply because the fluctuations in their condition are not understood and they are judged as 'too well', to use a concept from one of the participants, to be eligible.

Lack of appropriate housing is a substantial issue. Assistance may be required with a wide range of housing costs such as mortgage and rent assistance, housing relocation, house and home maintenance and housekeeping.

Due to the critical lack of social and personal connection, people with psychosocial disability lack access to informal support networks (National Mental Health Consumer and Carer Forum, 2014). Support is needed to assist with initiating, developing, maintaining and repairing social and personal connections. This support might include family counselling, transport costs, activity costs, and costs related to community group and recreation participation.

Participants identified a key support to be that of a skilled support worker who can undertake a variety of roles. This is more than a 'personal assistant', though the roles of a personal assistant may be included. In addition, people want opportunities to purchase a range of specialised supports including support with finances, legal issues, and health.

There is substantial need for ongoing social change to reduce the stigma and discrimination faced by people with psychosocial disability. Also the financial strain that many people experience needs to be understood as a potential barrier to taking up any new opportunities for care and support.

Recommendations

The following is a summary of the suggestions made in the report for the community mental health sector based on what participants prioritised in this project:

- Assist people with psychosocial disability to achieve improved health.
- Further develop services designed to assist people to move out of poverty.
- Support people to deal with loneliness and isolation, and value interventions that help people connect with other people, including their families.
- Provide programs and services that address the significant problems people have because of unsafe, insecure or unaffordable housing.
- Ensure support workers employed in the sector have the characteristics, skills and knowledge that are in line with the preferences expressed by participants in this project.
- Find new and innovative ways to help people envisage a good life including through further developing opportunities for peer support.
- Enable opportunities for direct funding of formal and informal community-based resources, supports and activities.

▶ ▶ ▶ FIND OUT MORE: Please see **http://www.mindaustralia.org.au/about-mind/research.html** for a link to the full final report, presentations on this research and a summary document prepared for the Barwon community.

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NDIS reform: experiences of community mental health support workers

Brooke Baxter is Manager of Service Development at Pathways Rehabilitation and Support Services Ltd.

Unfortunately, following the aftermath of welfare reform, the impact on support workers is often overlooked and little examined.

'*The relationship between social policy and human services delivery has always been complex and riddled with contradiction*' (Abramovitz, 2005, p.1).

It is well documented in the human services literature that the sector has felt the pressures of welfare reform, managerialist functions, tighter regulations, budget cuts and the decrease in governmental responsibility of service delivery (Abramovitz, 2005; Lonne, 2003).

The intrusion and tightening of market forces create a service delivery environment where support workers experience philosophical practice issues, unethical practice situations and professional dissonance. These external market forces and increased managerialist functions have meant that front line workers are challenged in their role, by how they were trained to practice and how they are required to do so in a competitive market environment (Galliana, 2010; Lonne, 2003). Unfortunately, following the aftermath of welfare reform, the impact on support workers is often overlooked and little examined.

This study is a qualitative account of the lived experiences of seven community mental health support workers involved in the roll-out of the National Disability Insurance Scheme (NDIS) for mental health. Mental Health Community Support Services (MHCSS) need to understand what their workers are experiencing, the challenges faced, and the resources required to carry out their role effectively. It is important to hear the perspectives of support workers, describing their experiences of the NDIS transition process and to contribute to the learnings of the wider scheme roll out.

To uncover the experiences, the workers were asked:

'*What are the experiences of community mental health support workers during the roll-out of the NDIS reform?*'

Research Methodology

This research study is supported by interpretive phenomenology (IP). The study aims to highlight and describe the meaning and lived experiences of a group of support workers and how they make sense of the phenomenon (Creswell, 2006). IP gathers in depth, rich information to understand the context and its complexity (Smith, Jarman & Osborn, 1999). Phenomenology does not provide definite explanations or prove that something is occurring; it is to raise awareness and increase insight.

Research Design

The seven participants in the study were from three MHCSS from the Barwon region. The study was approved with a low ethics approval from the university and was conducted through two semi-structured mini focus groups.

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NDIS reform: experiences
of community mental
health support workers
by Brooke Baxter

Workers agreed that some NDIA staff did not understand the role of community mental health workers or the wider MHCSS sector, and feared being 'questioned' if they were found to be supporting clients outside of the funded supports.

The questions provided to the participants were:

- Has your role as a community mental health support worker changed under the NDIS?
- What are the challenges facing community mental health support workers?
- What are the priority areas you would like addressed in relation to the NDIS practice changes and outcomes for clients?
- What strategies do community mental health support workers use to maintain or strengthen their resilience during major organisational change?
- What recommendations do support workers have for management to prepare and support their staff for major change?

Findings

Role conflict and ambiguity

Role conflict and role ambiguity was highlighted in the sharing of stories, with role conflict reported more often. Workers agreed that changes to their role created conflict and they were challenged to keep within the parameters of the NDIS practice environment. The researcher heard many instances where workers believed they were being forced to practice in a way that was not recovery-focussed and holistic. In one particular discussion from Group A, workers discussed giving more in their role than was actually funded by the National Disability Insurance Agency (NDIA). Their comments included:

'It's compensating a poorly designed system.'
'It cheapens what we do'.

Workers from both focus groups raised role ambiguity in the context that outreach support – such as family and carer work, therapeutic responses, grief and loss, and shared care practice – would not be funded under the scheme. Workers were conflicted because they believed these services are recovery-focussed and required by MHCSS clients.

Workers agreed that some NDIA staff did not understand the role of community mental health workers or the wider MHCSS sector, and feared being 'questioned' if they were found to be supporting clients outside of the funded supports.

One worker discussed a situation where they were supporting their client to attend an NDIA planning meeting. The client informed the NDIA planner that their worker helped them address issues with their partner. The planner questioned the worker and accused them of blurring their role and acting as a family counsellor.

Work stress

The focus groups clearly demonstrated that the NDIA practice changes intensified the work environment, creating stress, ethical challenges and value conflict. All workers described a loss of control and practice constraints, and reported feeling 'anxious', 'overwhelmed', 'pressured', 'on edge' and 'ready to snap'.

Moral and ethical dilemmas were described consistently throughout the focus groups. The eligibility process left many workers ethically challenged because they disagreed with the principles that underpinned the NDIS eligibility. For the purpose of the NDIS transition, workers felt they needed to challenge their clients and focus on their deficits so they could 'look worse on paper' to keep receiving the same or increased supports.

A story was told by a worker whose client had been doing really well for some time. When the transition process started, the worker focussed on the times when the client was most unwell and areas for support, in order to meet eligibility requirements. The worker described being upset about the conversation and the client was distressed and asked, 'is this what you think of me?'

Worker challenges and practice demands

The lack of process and consistency from NDIA, loss of professional respect, language barriers and disjointed work practices were topics discussed across both groups. A common issue was the lack of collaborative practice between NDIA and MHCSS. Workers used phrases such as 'disrespected', 'minimised' and 'demoralised' in describing accounts where they felt isolated and professionally challenged. A worker described an incident where an NDIA staff member put their hand up to block them from the conversation. Another was told to 'be quiet' by a NDIA worker, who said 'we don't want to hear from you'. Workers felt this challenged their proper role of advocating for their clients.

Both groups discussed issues relating to disjointed practices. Workers described the NDIS supports as being 'disjointed' and trying 'to separate people into boxes'. One worker debated the NDIS support items, arguing that 'we are integrated beings' and we are being forced to 'treat people in a disintegrated way'.

A worker described an example where their client was facing a decrease in home help supports. The client appealed the decision and NDIA organised a functional assessment. The client explained to the worker that they felt stupid, because the occupational therapist kept asking them to demonstrate how they hold the broom. 'How do I explain to them that it's in my head, not how I hold the broom?', the client asked.

Management and workforce Issues

It became clear that the workers' stress was predominantly due to the reform and organisational changes and not a result of the client work. Group A worried about increased administration demands, particularly as it was unfunded. Some workers described the pressures of reaching their target hours at all times. This was further extended in the context of clients who cancel or miss appointments. A worker observed that they used to 'applaud our clients for not wanting to see us for one week' because this showed independence and self-mastery. Now they were worried about funding and targets.

The financial pressures and change in work practices identified many workforce issues. Workers argued that highly skilled staff will be forced out of the sector and the work would be offered to untrained or new graduates. There were concerns that NDIS funded mental health supports now represented the work of personal care attendants and not social work, psychology or peer work.

Workers who felt highly supported by their managers and reported effective change management had regular opportunities to discuss how they were feeling and felt informed. Others told of being encouraged to eat their lunch in the car or at the end of the day, and of extra work hours being the norm and expected. Workers who were frustrated with management wanted to talk about their concerns, but felt dismissed and/or encouraged to focus on the positives and to be more adaptable to change.

Positive outcomes and practices

Despite the challenges and dissatisfaction reported, each of the workers agreed that the NDIS reform process had united staff and promoted teamwork. Comments included:

'You can't own it all, be open to receive help'
'I have a fantastic team, I'm very lucky'.

Workers explained that a positive work environment, whilst hard to achieve in the current reform environment, is important for high work morale and good internal relationships. In both groups, humour or black humour went a long way and was highly regarded. All workers contended that they work in the sector because they believed their role made a difference in clients' lives. Focus groups argued that individuals with a mental illness should have access to a connected health and community services system where the philosophy and language of recovery is continued. As one said:

'Give mental health its own language and the respect it deserves'.

Discussion

This study confirmed similar findings to studies (Abramovitz, 2005; Jones, 2001; and Lonne, 2003) that concluded that welfare reform and external market forces can negatively impact on support workers. These adverse effects can create role conflict, role ambiguity, work stress and increased practice demands. Whilst this study did not prove that workers were experiencing distress or burnout, the stories shared by workers suggest that they are experiencing increased work stress, greater workload pressures and reduced decision making opportunities.

The personal impact on workers was not greatly explored in the focus groups due to the restrictions of the low ethics approval. Stress was considered more in the context of what was most challenging in their role and positive work strategies. Interestingly, the researcher observed that some workers minimised the personal impact and often redirected the conversation to the impact this had on clients. An extension of this study could be conducted through individual interviews with support workers.

The focus group discussions indicated many situations where workers were confronted with ethical dilemmas and role conflict. The dilemmas generally presented in the context of the eligibility requirements and being forced to transition clients through a system that focussed on permanency and functional impairment. This challenged workers as they believed that they had forced clients to go through a system which did not focus on their talents, strengths and achievements.

Conclusion

The study showed the MHCSS system and support workers are struggling with the NDIS transition process which was confrontational at many levels. Signs of stress, role conflict, role ambiguity, managerialist pressures, ethical dilemmas, practice demands, grief and loss, lack of professionalism, and workforce issues were raised as major concerns.

Human services must provide support structures to decrease the negative impacts associated with reform and business pressures. Collegial support, an open team approach, joint advocacy efforts and courageously advocating for change, are considered important strategies for workers and management to achieve change and build resilience in the workplace. Joint advocacy efforts need to be met at the worker, organisational and sector wide levels. The NDIA, state and federal departments, peak bodies, mental health advocates, MHCSS providers and clinical mental health services need to work collaboratively to address the issues facing the mental health system and ensure that the wellbeing of support workers is a central agenda item.

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Making Individual Placement and Support (IPS) more effective in Australia

Kate Higgins is Consultant of Quality and Service Development at Mental Illness Fellowship Victoria

The majority of people categorised as having a 'severe and persistent' mental illness continue to be excluded from employment supports or find themselves cycling through an employment service system which does not meet their needs.

In 2010, VICSERV released a series of papers on the unfinished business of deinstitutionalisation in relation to a range of social inclusion measures. In '*Unfinished Business: participation in employment and education*' Collister (2010) argued that psychosocial rehabilitation services must take the lead in integrating employment/education and mental health services to improve social inclusion outcomes. Four years on, this article reviews the implementation of the evidence-based Individual Placement and Support (IPS) model within Australia, assessing its successes and challenges, and argues that, despite some progress, social exclusion remains the norm.

A failure of our system

There is broad agreement at state and federal levels of the importance of employment to people affected by mental illness. It is widely recognised that employment has a significant impact on recovery, improving health and well-being, self-confidence, financial security and a sense of belonging in the community (Bond & Drake, 2014). Despite this being recognised within national and state mental health plans, government has largely failed to deliver the frameworks and resources needed to support people who experience mental illness into work. As a result, the majority of people categorised as having a 'severe and persistent' mental illness continue to be excluded from employment supports or find themselves cycling through an employment service system which does not meet their needs.
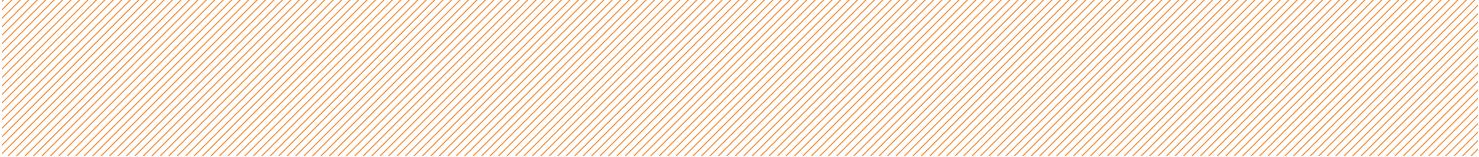
The unemployment rate for people who experience mental illness continues to be the highest of any other 'disability group'. The 2010 national survey of psychotic illness found that 85 per cent of those surveyed relied on government pensions as their main source of income, only 33 per cent had been in paid employment in the past year and only 22 per cent had worked in the past month, compared to 75 per cent of the general population (Department of Health, 2010). These figures are unchanged since the first survey in 1997 and people with mental illness remain the largest group in receipt of disability support payments (Killackey, 2014).

The current government funded employment service system has failed to address these inequities. An evaluation of the Disability Employment Service program found that for the nine month period from March 2010, only 24.5 per cent of program participants experiencing 'severe and persistent mental illness' gained employment (Department of Education, Employment and Workplace Relations, 2012). Despite reforms, this cohort continues to be disadvantaged by a system that has limited resources, is burdened by red tape and is driven by a performance framework that can perversely encourage providers to exclude those seen as 'too difficult to place' or not 'work ready'. As Lisa Fowkes, former CEO of Job Futures states: 'the high volume, low margin nature of the work means that [employment service providers] rely heavily on standardised approaches [and] enrolment in work preparation courses' (Fowkes, 2011).

These approaches are not in line with current evidence based practice and have continually failed people with a mental illness. Whilst government has invested in new initiatives such as the Personal Helpers and Mentors (PHaMs) Employment Services, these are not sufficient to address the underlying systemic issues. PHaMs Employment programs may enhance services through the provision of intensive support and collaboration with employment providers but do not have the capacity to affect major cultural change when constrained by the existing employment service system.

What works – the IPS model

Research shows us that Individual Placement and Support (IPS) continues to be the most effective model to support people categorised as having a 'severe and persistent mental illness' into competitive employment. This model has been evaluated in 19 randomised controlled trials in North America, Europe, Asia and Australia. IPS programs have achieved a competitive employment rate of 61 per cent compared to 23 per cent for those accessing traditional employment services (Killackey, 2014). When young people access IPS in the early stages of their illness and combine education as well as employment, outcomes rates of up to 85 per cent have been achieved (Killackey, 2014).

PHaMs Employment programs may enhance services through the provision of intensive support and collaboration with employment providers but do not have the capacity to affect major cultural change when constrained by the existing employment service system.

The IPS model is comprised of the following eight principles (Bond, 2004):

1. Every person with severe mental illness who wants to work is eligible.
2. Employment services are integrated with mental health treatment services.
3. Competitive employment is the goal – at award wages, not temporary jobs, piece work, voluntary work, unpaid work experience or jobs reserved for people with disabilities.
4. Clients receive personalised benefits counselling – ensuring they have an understanding of the impact of work on welfare benefits.
5. Rapid job search begins as soon as possible after a person expresses interest in working.
6. IPS specialists develop relationships with employers.
7. IPS specialists provide ongoing support, as needed.
8. Individual preferences are honoured – clients are assisted to get the jobs that interest them.

IPS in the Australian context

Currently in Australia, IPS is predominantly delivered through government funded employment service providers in partnership with state based community health services, with varying degrees of fidelity to the model. There are a small number of providers such as Orygen Youth Health who provide the IPS program through direct recruitment of an employment specialist within their service, without reliance on funding through the employment service system.

Research on the effectiveness of the IPS model in Australia clearly shows that people accessing IPS programs achieve better employment outcomes than those accessing non-integrated disability employment services. A recent study in regional Australia showed that those accessing the IPS program had a commencing competitive employment rate 2.8 times greater than the national non-IPS benchmark (Morris et al., 2014).

More recently, a four site randomised controlled trial was conducted comparing integration of government funded disability employment specialists with mental health services to local non-integrated disability employment service sites. The results showed that 42.5 per cent

of those accessing the integrated IPS model commenced employment within 12 months compared to 23.5 per cent of those accessing the non-integrated service (Waghorn et al., 2014). A retrospective study conducted by St Vincent's Health, Mental Illness (MI) Fellowship Victoria and Monash University, analysing seven years of IPS employment outcomes through government funded disability employment services, indicated an average commencing employment rate of 40.4 per cent (Stirling, 2014).[1]

Whilst these studies show that IPS can improve employment rates in Australia, the average outcomes achieved are well short of the average 60 per cent commencing employment rate in the US. We therefore need to ask whether IPS employment outcomes are being hampered by Australian Government funding requirements (Morris et al., 2014). It is also unclear how many people have been excluded from accessing IPS programs funded through the employment service system as a result of more stringent eligibility criteria. On this basis, more non-employment service funded IPS services are needed to compare the effectiveness of the models and to ensure people with a mental illness get access to IPS programs outside of the existing employment service system.

Enhancing IPS – including peers and families

In order to improve employment outcomes, the IPS model needs to be enhanced through the inclusion of lived experience expertise and the engagement of natural supports. A recent US study proposed that reliance on ongoing paid supports under IPS may actually inhibit job retention rates rather than improve them (Murphy, Mullen & Spagnolo 2005). The IPS model does not refer to the inclusion of families, carers and natural supports in the process of gaining and sustaining employment, yet these factors are often fundamental to successful employment outcomes.

Peer expertise has not been commonly utilised within Australian employment support models, yet evidence shows this is one of the most effective ways to support recovery. Peer support can play a powerful role in reclaiming aspects of self and enabling people experiencing mental illness to develop or restore confidence (Solomon, 2004). Peers can assist job seekers in unique ways to overcome stigma, understand rights, re-establish a sense of identity

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[1] 17.6% of these outcomes were unspecified in terms of competitive or non-competitive.

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Psychiatric Disability Services
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Making Individual Placement
and Support (IPS) more effective
in Australia

by Kate Higgins

When young people access IPS in the early stages of their illness and combine education as well as employment, outcomes rates of up to 85 per cent have been achieved (Killackey, 2014).

and explore motivations and goals. This is particularly important within a service system which has often disempowered people and engaged in a rhetoric of shaming and blaming the unemployed.

Peer education programs have been proven to support recovery and have great potential to improve employment outcomes. Evaluation of the Well Ways MI Recovery Program has shown statistically significant outcomes in relation to empowerment, illness management, stigma reduction and health status (Porter, 2011).
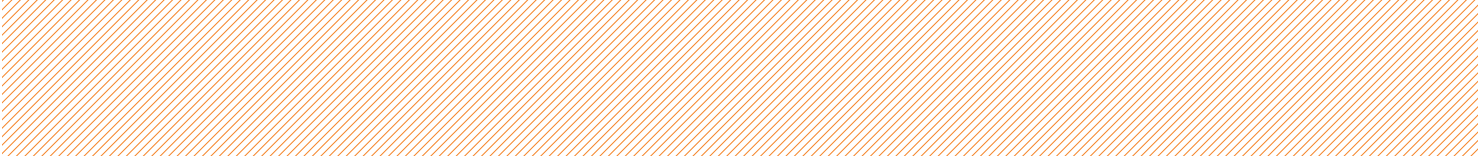
There is some initial evidence in Australia that peer education delivered to job seekers who experience mental illness has also been positive. An evaluation of Social Firms Australia's HOPE program, a 10 week program co-facilitated by peer educators, resulted in an increase of employment outcomes from 10.3 per cent at the beginning of the program to 26.1 per cent at the final session (Social Firms Australia, 2011). A survey of participants of MI Fellowship's Well Ways to Work program, a six session peer education program facilitated by PHaMs Employment peer educators, showed that 83 per cent felt more confident to find employment and all knew more about their rights. Participants indicated strongly that the program had supported them to overcome stigma, develop confidence, increase hope and imagine a more contributing life and that peer support was an integral factor in that (Higgins & Stanley, 2014).

In the US, the Dartmouth IPS Supported Employment Center has begun to incorporate peer support and family centered practice within its IPS services. The Centre has established a learning collaborative

which has adopted two key projects: the IPS Peer Advocate Project and the Family Advocacy Project. The Peer Advocate Project focusses on: sharing models for how peers enhance or deliver IPS services; strategies to make IPS supported employment more accessible to potential workers; and informing the IPS Learning Collaborative about the value of peer involvement in IPS. The Family Advocacy Project aims to advance family participation in three ways: family advocates provide education to IPS teams on the important roles that family can plan in the employment process; families educate other families and community members about the benefits of work and the IPS model; and family advocates support the development of IPS in their local communities and at a policy level (Dartmouth College, 2014). In undertaking these projects, Dartmouth recognises that addressing systemic discrimination and social exclusion of people who experience mental illness must involve the expertise of people with a lived experience.

Conclusion

If we are to begin to turn around the current inequities in education and employment faced by people with a mental illness in Australia, major reform is required. The National Disability Insurance Scheme (NDIS) is designed to improve productivity and inclusion of people with a disability. However in its current form it is unlikely to have any significant impact on the employment outcomes of people who experience mental illness. In fact, the possible inclusion of programs such as PHaMs into the NDIS may see a reduction in available employment supports.

Peers can assist job seekers in unique ways to overcome stigma, understand rights, re-establish a sense of identity and explore motivations and goals.

On this basis it is even more imperative that evidence based models such as IPS are made accessible across Australia and are not constrained by employment service systems. We must consider the potential of IPS specialists to be integrated not only with mental health services but also in other service sectors such as housing, and drug and alcohol services. The IPS model should also learn from the advances in the mental health system and IPS successes overseas by beginning to incorporate the expertise of people with a lived experience and families. The costs associated with this type of reform are far less than the current cost of administering an expensive system which continually fails to achieve employment outcomes for people with a mental illness.

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Better mental health advocacy: A 'virtual panel' of consumer thinkers explore some possibilities

Allan Pinches is a researcher and consumer consultant for mental health

What might a consumer-oriented, fair and better-resourced mental health advocacy system look like?

This new**paradigm** special feature article aims to develop an independent and constructive dialogue about how to build opportunities and resources for a range of consumer advocacy projects and programs in a changing mental health sector landscape in Victoria.

As well as providing background to those changes, it reports the insights of five well-regarded Victorian consumer thinkers who were interviewed by the author in separate interviews as part of a 'virtual panel' on recent developments and potential innovations in consumer advocacy.

1: Background and analysis

Consumer advocacy has long been under-resourced within Victoria's mental health sector, amid overstretched services, burgeoning demands for community backup facilities and other complexities which have come with deinstitutionalisation since the mid-1990s. But now, at least some partial solutions are on the way.

The proclamation of Victoria's *Mental Health Act 2014* promises less restrictive treatment options, more of a partnership relationship between service providers, consumers, carers, and community organisations, and more recovery oriented practices. Consumers can express needs and wishes, co-creating their treatment and support planning.

Under the new Act, the Victorian Government will launch the state's first Independent Mental Health Advocacy Service (IMHAS) in early 2015, to be provided by Victoria Legal Aid (VLA) as a complement to its existing Mental Health Legal Advocacy Service.

The Department of Health has said of the IMHAS: 'It will provide face-to-face, individual advocacy for patients subject to the Act…and also offer a telephone triage service. The focus of the advocacy will be mental health treatment, care, and recovery, not general advocacy, and the type of advocacy to be provided will be representational or instructed advocacy.'

Exploring ways to 'get the settings right'

Advocacy is a challenging issue in the mental health sector, with differing definitions of the term, many complex layers and often difficult and confusing pathways. Historically, there have been competing demands for funding dollars between individual advocacy and other forms of existing or potential systemic advocacy, particularly for consumer organisations.

An all-too-human tendency for something of an 'us versus them' mentality set in around socio-cultural systems and organisations generally, has also posed significant challenges to the progress of mental health consumer advocacy.

Some major barriers to consumer advocacy could be identified as:

- a lack of forums for discussion of key concepts and mutual learning;
- under-development of common language, effective conceptual models, and shared understandings about the nature of mental illness/ psychosocial disability and possible responses; and
- difficulty promoting 'new thinking' for a broad reform agenda, providing for new partnerships, shifts in power balances and greater understanding of consumers' 'lived experience'.

The Victorian Mental Illness Awareness Council (VMIAC) has provided individual advocacy for consumers for 32 years, with much of its work taking place at the 'hot end' of the system – advocating for consumers who request support with crisis situations during a stay at a Psychiatric Inpatient Unit. This focus was partly due to a lack of accessible other agencies – or at least a lack of *visible* access points – to handle such urgent and frequent advocacy requests.

This has impacted on time and resources that VMIAC, as the peak consumer body, has been able to dedicate to broader systemic advocacy projects. It has made heroic efforts, including an innovative Experience Based Design Project (Fairhurst & Weavell, 2011) in collaboration with Tandem (formerly Victorian Mental Health Carers Network) and major research into problems with women's safety on wards (Victorian Mental Illness Awareness Council, 2013), which has been followed up by Department of Health and local services. However, it will still be necessary for VMIAC to continue to play a significant role in individual advocacy, including on 'matters of principle' or service quality issues, because the new Independent Agency's brief rules out general advocacy and is bound to work with consumers subject to the provisions of the *Mental Health Act*. (In other words, not 'voluntary' or 'private patients').

Dedicating new resources for more systemic advocacy

Better resourcing and structuring for the provision of individual advocacy could well open up greater discussion space, opportunities, and resources, creating a 'new balance' with a greater variety of consumer-led systemic advocacy.

Systemic advocacy means many things to many people, and may include:

- highlighting consumer perspectives across many issues, drawing on the consumer movement's collective values, knowledge and experience
- supporting the development of the 'lived experience' workforce
- enabling and funding parts of a long-term '*wish list*' of consumer-led research and development projects
- growing numbers and networks of mental health consumer academic researchers carrying out consumer-perspective research into a wide range of innovative and practical topics

- consumer developed direct-service initiatives, such as peer support advocacy to support consumers to participate in life and in the wider community, including reducing barriers to housing, employment, education, or socialising opportunities
- experience-based co-design projects involving various services and organisations
- creating real partnerships between consumers, service providers, and policymakers and governments based on shared goals and respect
- supporting valued and appropriately resourced consumer participation in government and service committees and projects
- funding consumers to develop communications strategies linked with consumer projects
- promoting and teaching skills for self-advocacy.

Applying new advocacy models

In the interest of genuine progress, it is important to find new ways that governments, policymakers, mental health services, carers and community stakeholders can act on the evidence about the role and benefits of consumer advocacy for services, personal recovery, and the broader community.

A number of new and innovative models for consumer advocacy have been developed in Victoria in recent years. Among them:

- Consumer Advocates are 'embedded' within the new Mental Health Tribunal, including at high levels, and others are likely to be employed in the new Independent Advocacy Service and the new Mental Health Complaints Commission.
- Clinical Advocates or 'Experts by Experience' are now working in a few pilot peer support roles in Emergency Departments to assist patients who are being admitted for a psychiatric stay. Other consumer workers are facilitating peer support 'diversion' alternatives to seclusion or other restrictive practices.
- Consumer advocates/ facilitators are becoming involved with some peer education and support groups on wards, and at Community Care Units and Adult Prevention and Recovery Care (PARC) services.
- Community education and stigma-busting is a growing advocacy activity area for consumers, using music, art, drama, video, community radio and TV, and fun gatherings aimed at getting positive messages across.
- Growing numbers of general welfare agencies are getting involved with mental health advocacy.
- A number of Consumer Advocacy and Leadership roles have been set up at management level in several clinical and Mental Health Community Support Services, creating great potential.

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Better mental health advocacy:
A 'virtual panel' of consumer
thinkers explore some possibilities
By Allan Pinches

It will still be necessary for VMIAC to continue to play a significant role in individual advocacy

The Virtual Panel:

Wanda Bennetts is a longstanding Consumer Consultant with a Master of Education and a passion for consumers being involved in training and education of mental health workers and to have access to training and career development themselves. Wanda was principal researcher in a Department of Health fellowship grant funded research project, which produced the 2009 report '*Real Lives, Real Jobs…*' aimed at the advancement and better resourcing of the 'lived experience' workforce.

Leah Martin is a Consumer Peer Support worker/ project officer with a Mental Health Community Support Service. She is a qualified Creative Arts Therapist, has participated a number of service development projects and is driven by 'hope and new opportunities' for service users.

Neil Turton-Lane is the Team Leader of a combined mental health consumer participation workforce at an integrated Community Health and Mental Health Support Service. Neil has a Bachelor of Arts in Community Development and has active links to many consumer organisations. He has a strong belief in shared learning among all stakeholders.

Robyn Callaghan is a project officer with a Mental Health Community Support Service, with qualifications in Psychology and Theology and experience in the consumer world. Robyn's work combines peer support, education, and recovery oriented services. Her focus includes the rights of the person and the need for their own integrity of mind and soul.
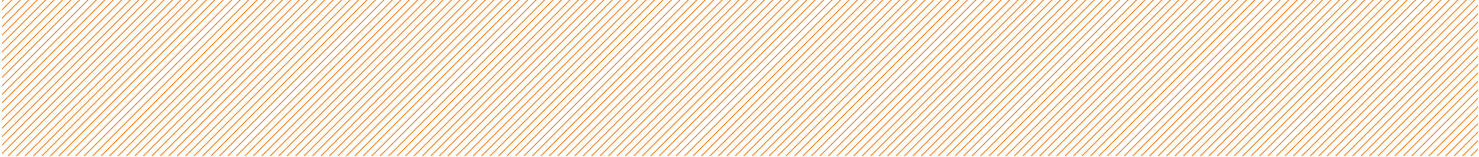
Jon Kroschel is an accomplished consumer movement thinker and educator, currently engaged in Canberra-based project work. Having worked in consumer consultancy and research projects for some 25 years, Jon is a critical thinker with a talent for seeing the big picture. He was a co-founder of Ourconsumerplace.com.au.

2: The Virtual Panel – emerging themes in consumer advocacy

Thanks are extended to our Virtual Panel. Selected comments from the interviews/discussion are grouped according to the seven themes that emerged from this process. These are intended to stimulate wider discussion in the consumer movement and Victorian mental health field.

1. **Defining advocacy:** Advocacy is a strong current in the consumer movement, but is not beyond having contested areas. Some aspects of consumer advocacy could be argued to be better defined in broader, more developmental terms such as consumer research, participating in learning events, or promoting discussion of issues – while other aspects of advocacy may benefit from a tighter-focussed definition, like speaking up for the rights of others, crisis intervention, or enlisting other supports.

2. **Balance and scope:** There is an often a stated need for a balance between the provision of individual advocacy and systemic advocacy. This question has often arisen due to funding necessity; better resourced and structured advocacy might look quite different.

3. **Crisis response:** Sometimes things do go wrong in frontline mental health services and consumers may need urgent 'personal-crisis' based advocacy – what are some ways to provide for this?

4. **Role of relationships:** Many benefits in consumer advocacy can be unlocked by promoting better relationships between services and consumers, both individually and collectively, across consumer and service provider organisations.

5. **Autonomy in recovery:** Self-advocacy is an important part of a consumer's recovery journey because two-way engagement between the person and service providers can encourage the person to speak for themselves more readily, set some personal goals, and participate with greater autonomy in the community.

6. **Structures and training:** For systemic advocacy to flourish, consumer organisations and service provider related organisations would need to work together to develop:

• improved structures and processes of organisation and communication
• opportunities for consumer trainers to educate consumers and service workers about potential innovation and change based on 'lived experience'

In my current service, we have a mandatory fortnightly reflective practices meeting where we talk about values and how things make us feel, without seeking solutions. That can be really fertile ground for learning. It helps people to realise that we are all humans and to realise the judgements we bring from our own situation.

- additional 'listening' forums of discussion
- space to engage in creative dialogue, including decision free sessions; greater formulation of shared understandings and values; and sometimes allowing friendship across the borders.

7. **Strategies and systems:** Funding opportunities for strategic and collaborative systemic advocacy could result if the new Independent Advocacy Service does free up potential for growth within consumer-led and partnership-based advocacy projects and programs. It would be important to have better information sharing and networking among consumer organisations and to build closer ties with the Department of Health and the wider mental health and community sectors.

1. Defining advocacy:
Wanda Bennetts

"One of the first things to recognise is that there are many roles that consumers can take on. They can be systemic or individual advocates, they can be educators of staff or other consumers, or researchers, or they can do peer support. There are project worker roles. There are many roles."

"To know what the issues are at a systemic level you need to have good mechanisms in place to hear those issues and be able to respond to them, through things like education, research, quality improvement meetings, consumer advisory groups and many others. There are many things we need to do, because they are all layered and intertwined, and impact on each other."

Leah Martin commented on ways to optimise communication and build trust between consumer workers, consumers and service delivery workers:

"I think the best way is to have 'disclosed lived experience' positions at all levels within organisations so there isn't that friction as well. In my current service, we have a mandatory fortnightly reflective practices meeting where we talk about values and how things make us feel, without seeking solutions. That can be really fertile ground for learning. It helps people to realise that we are all humans and to realise the judgements we bring from our own situation. I think that when

you work in mental health you have to realise that when something rubs you the wrong way, that's your own stuff."

Neil Turton-Lane favoured a wider interpretation of advocacy: "I think there's potential for a wider advocacy role for consumer consultants [whose current position descriptions typically exclude individual advocacy so as to not undermine the systemic work] and the VMIAC gets called in to do all sorts of advocacy, including individual advocacy."

"Could I suggest the reappraising of both consumer consultant and peer worker roles to include systemic advocacy as one of the core components of these disciplines? Also should we be pushing for Advocacy to be included as core content with the Certificate IV in Peer Support Work, seeing as the content for this course is being developed? Further training in negotiation and conflict resolution may enable other people within a service to carry out those roles."

Robyn Callaghan

"Advocacy doesn't need to be defined as narrow and adversarial. It can be developmental, educational, about services learning better ways, partnerships and better relationships among many interested parties in mental health, research, peer support – any part of the continuum can be a form of advocacy."

"Meaningful change does not always have to mean bigger, better, more… It can also be about being able to more clearly see what's happening on the ground and to conceptualise about ways that a wider range of advocacy related activities could be brought into action, in a more collaborative way. Consumers often have different, distinct and valuable ways of looking at the service."

Jon Kroschel said there was a need for a rethink about definitions and the imputed roles of advocacy:

"Over the years there seems to have been a blurring of consumer consultants doing systemic advocacy, compared to what individual advocacy is, compared to peer support workers presuming and advertising that they do individual advocacy. And I don't believe that they do. There is systemic advocacy. There is peer support and there is individual advocacy… and it shouldn't be assumed that we are only

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I think that when you've got a few runs on the board or achieve something the organisation sees as beneficial to consumers and the service… that provides a really good foundational platform for it to grow, and it can grow rapidly if you've had a really good success. Particularly if it's an 'everyone wins' outcome for consumers and the service.

talking about advocacy in acute inpatient units. A new advocacy agency should provide advocacy not only in acute inpatient units, but also in community clinics and the private system. The private system gets left behind so many times, and I've seen breaches of human rights happen there too."

"An advocate can also help explain stuff to you in plain English. They don't just give a chart with the minimal information about medication. An advocate will find the best information so you can make informed decisions about 'do you want to take this medication,' or support you in saying 'Dr Psychiatrist, these are my symptoms, aren't there five medications designed for these, why can't I try one of the others?' The person could be involved in decision making about medications, perhaps trying a range of medications, over certain intervals, with agreement to adhering to the plan."

"This type of approach could greatly reduce the need for Community Treatment Orders (CTOs) and involuntary hospital stays, and all the adversarial stuff that goes with it. An advocate can help a person work through all that enforcement stuff. And that's not what a consumer consultant does, and not what a peer support worker does."

2. Balance and scope:

Neil Turton-Lane

"At some stage the system has to do a better job of advocating for the rights of people. If we are to have diverse and multi-skilled services we need opportunities for knowledge and roles and expertise in areas to be shared around, and it's really about developing clearer understandings… and being more relationships-based."

"It's good to have a consumer voice that could bring discussion within services around from not just opinions of what would be good for the person, but what that person wants and what could be good for them as well. The idea of what the clinician feels is right for a person and what the person wants can be very different. Consumers may have very different ideas about what is progress and what would help."

"There's also much potential in internet-based activism such as www.change.org and greater formulation of shared understandings and values; and ideas like 'warm lines' (phone support lines that provide assistance for people whose need is not urgent), peer

oriented services, and advocacy information services which might be funded and supported by volunteers."

Working in an Area Mental Health Service, **Wanda Bennetts** has observed "a steady improvement in communication, respect for consumer knowledge, active support for consumer research and development, willingness to grow the consumer and carer lived experience workforce, and consistent support from the senior management and staff for consumer systemic knowledge."

"I think that when you've got a few runs on the board or achieve something the organisation sees as beneficial to consumers and the service… that provides a really good foundational platform for it to grow, and it can grow rapidly if you've had a really good success. Particularly if it's an 'everyone wins' outcome for consumers and the service."

3. Crisis response:

Leah Martin
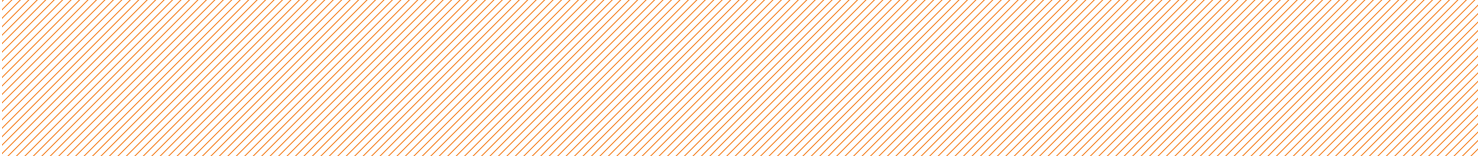
"I think it's really important that consumer advocates in agencies are not seen as the 'bad guys' so mental health services aren't scared of them and it's not 'Oh my God, the advocates are coming and they are going to tell me my practices are all wrong!' And the advocates need to be seen as part of the [extended] treating team, and everyone will have to do a lot of work on communication, a lot of looking at language too, to not put anyone offside, I guess."

"Ideally a consumer should have the right to an automatic meeting with an advocate, immediately they are brought within any form of involuntary treatment… rather than 'oh, here's a pamphlet with a number you can ring if you want.' And perhaps having an extra layer of accountability might discourage people handing out Community Treatment Orders 'willy nilly' as well."

4. Role of Relationships:

Robyn Callaghan

"Consumers and carers, people and their friends… there are natural relationships between people. If I need an advocate, I know who I want as my advocate. They would need to know me well. It may be that a carer also needs someone to advocate for them.

In talking about empowerment of individuals, people can be given training in communicating and putting their wishes across... Secondly, you can put in training and education for the clinicians to be able to hear and respond to and respect the individual's wishes. What happens is there's less argy bargy across difference and less reliance on CTOs and enforced treatment.

"People's natural relationships need to be more respected and those natural relationships who people choose to be their advocates need to be supported, by people who might have greater skills, resources and knowledge about how services work."

Neil Turton-Lane said that a blended advocacy approach allowed a more nuanced conversation with consumers. His current diverse work schedule includes talking with clients of a multiple and complex needs service.

"The service recognises it would be good for a consumer worker to have conversations with clients, who sometimes would just say what they want [the service provider] to hear. Some have been in prisons – and this consumer consultant work involves having discussions with people, giving information, encouragement, talking about their rights, drawing on lived experience, knowledge of the system, community resources and the consumer movement. This can really open out more options for people and the service sees the value of it."

5. Autonomy in recovery:
Leah Martin

"Self advocacy is very important, where a person has enough information and confidence to advocate for themselves. It is often important to have access to another person who is an advocate. Also the amount of information provided is very important… my experience was that the clinical staff didn't tell me much. I might have done more research into a type of medication, for example, than the doctor had."

Neil Turton-Lane

"Tools and resources are needed for self-advocacy and support. What I would propose would be for the government to provide funds including a start-up grant for a mutual support self-help-advocacy service. What do you need? You need an office, you need some phones. You can do the Ross House thing, or situate it within an organisation that's supportive of the idea and use methods of 'co-production' involving many partners."

"I think this type of initiative is something that is not necessarily going to come from 'the system' – some of that work has to come from the community."

Jon Kroschel

"In talking about empowerment of individuals, people can be given training in communicating and putting their wishes across… Secondly, you can put in training and education for the clinicians to be able to hear and respond to and respect the individual's wishes. What happens is there's less argy bargy across difference and less reliance on CTOs and enforced treatment. It's not just about the person trying to say what they are trying to say, it's also incumbent on the listener in being able to hear. Training in both realms is needed."

6. Structures and training:
Wanda Bennetts

"You've got to have a workforce that is responsive to the things that we need to do as advocates. You've got to have training and professional development; you've got to have career paths. If you don't have the foundations, you set it up to fail. I think that's a point that is often missed for consumer consultants, is that no other workforce is expected to just turn up and know the job."

Leah Martin

"Any education or training of mental health workers should include at least one unit involving lived experience of consumers. This also needs to take into account the variety of consumer views on many issues; say, on the issue of [funding cuts to] drop-in centres, where some consumers feel a sense of loss about their closures, but others wanted a diverse range of other services. It is important that the different range of views are brought together and discussed."

"There's a need to have lived experience consumer workers at all levels with the appropriate skills and knowledge – not just 'here's a consumer, let's just chuck them in'."

Jon Kroschel said that better information sharing and networking were necessary for real change to occur. Consumer consultants in Area Mental Health Services and other organisations tend to keep information gathered within their own areas. "There is a lack of structures and processes for bringing together such data about consumer experiences in a systematised way, and to be able to plan and act upon it."

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You've got to have a workforce that is responsive to the things that we need to do as advocates. You've got to have training and professional development; you've got to have career paths. If you don't have the foundations, you set it up to fail. I think that's a point that is often missed for consumer consultants, is that no other workforce is expected to just turn up and know the job.

7. Strategies and systems:

Jon Kroschel

"Many consumers can offer visions about what could be better, whereas bureaucrats say, 'we can't do that because of the money… etc.'. But even in the department there have been innovators, and people who would support consumer ideas and put money in… There is more commonality than difference. We need to get together and start from that basis… Many managers and staff really want that and will support it."

Neil Turton-Lane

"There might be some merit to having funding opportunities available for a variety of organisations to carry out various consumer-led projects, such as research and development, consumer or staff education projects – spreading the potential of advocacy but also going beyond it, and trying to operate within communities where broader mental health awareness and community access issues can be addressed."

Wanda Bennetts

"At the moment we have to find ways to do this that are not ad hoc. If these things are only theoretical they are less likely to work – we need to put them into practice. As consumers, working in a tiny miniscule way in big system, we can't respond to all of that – organisations need to take responsibility for embedding practices, and supporting practices that will enhance a range of activities that, taken together, will make a difference."

"If people can put their own words and wishes together into plans at a time when they are seen as having the credibility the service wants from them when they are well, then they are advocating for themselves on another layer as well, and this is also going to help get the lived experience of consumers to be embedded into another layer of the system. "

Allan Pinches has worked in mental health consumer participation roles for more than 22 years, including on the boards of the Richmond Fellowship of Victoria and Neami. Allan has worked as a Consumer Consultant within NorthWestern Mental Health services and the wider sector during the past 18 years. He has a Bachelor of Arts in Community Development (VU) and has contributed to many projects involving service improvement, research, writing, and education and training of service workers. He recently completed a research project funded by a Department of Health Fellowship Grant into a proposed Peer Support Program in Preston, which has generated wide interest in the sector.

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PROMT: Developing, testing and assessing a new Outcome Measurement tool

Cindy Keys is Director of Services at Peninsula Support Services
Jane Howard is Program Evaluation Officer at Frankston-Mornington Peninsula Medicare Local

In early 2012, Peninsular Support Services (PSS) began to review quality procedures, tools and other documentation to ensure these aligned with recovery-orientated person-centred, family-inclusive service delivery. Through this review PSS identified the need to adopt a new model of care, along with a complementary Outcome Measurement (OM) Tool.

Development phase

A comprehensive analysis of models and OM tools employed locally, in Australia and overseas showed that many OM tools appeared to have been developed without significant input from consumers or carers and, rather, utilised a top down process. One service acknowledged that they had not consulted with their consumers during the process.

This research resulted in implementation of Ron Coleman's 'Working to Recovery' approach because of its focus on person-directed care. This model of care had been embraced by Peninsula Health's Community Care Units (CCU) a few years earlier, so taking on this model allowed the collaboration of the two services to provide and further tailor staff training.

The 'Working to Recovery' approach sees recovery-orientated practice as a partnership where the person with the lived experience is the expert in their recovery, while mental health practitioners bring their understanding and expertise to support this journey (Coleman & Taylor, 2006). PSS was unable to match this model of care with a contemporary OM tool and so a decision was made to create a new tool. PSS contacted Ron Coleman (based in the UK) who granted permission to create a tool incorporating his philosophies.

During the development phase, consideration was given to providing a tool that was user-friendly. This was of particularly importance for people who experience difficulty in clearly articulating their needs, thoughts and feelings. These include people experiencing dual disabilities, acute distress or 'poverty of thought' (reduced thought, marked by lack of spontaneous speech or speech with unrelated associations).

It was also acknowledged that for many, long-term illness may cause disempowerment, resulting in a loss of 'voice' and hope for the future. Consequently, it was determined that the OM tool would need to:

- be person-centred and directed
- be written in plain language (non-clinical)
- enhance and accelerate the person/practitioner engagement process
- facilitate two-way communication that promotes a deeper understanding
- feature 'non-scripted' dialogue (questions) that allows the practitioner to be authentic
- enable people to track and measure their recovery and allow practitioners to accurately assess goal achievement and the supports needed/provided
- be evidence based
- enable PSS to capture and analyse the data collection to ensure contractual agreements and internal measures are met.

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PROMT: Developing, testing
and assessing a new Outcome
Measurement tool
By Cindy Keys and Jane Howard

Peninsula Support Services (PSS) was established in the south-eastern Melbourne catchment of Frankston and Mornington-Peninsula over 27 years ago and is now a well-respected and innovative Community Managed Mental Health Service Provider supporting people with severe and enduring mental illness with multiple and complex needs and their carers. PSS provides a range of programs including Mental Health Community Support Services, Breaking the Cycle: Homelessness, Partners in Recovery, Youth Prevention and Recovery Care (PARC) Group Program and Home and Community Care (HACC) Access and Support and Day Programs for older adults.

PH-CCU is a 24-hour supported residential rehabilitation unit for adults diagnosed with severe and enduring mental illness or with a psychosocial disability. It receives State funding and consists of nine purpose built residential units in a cluster arrangement located in a residential street in Frankston. The Units provide medium to long term residential psychosocial rehabilitation for 20 clients. Internal referrals to PH-CCU are sourced from current clients of Peninsula Health (PH) Community Mental Health Service.

The 'Personal Outcome Measurement Tool' (PROMT) was developed, trialled and re-worked for over six months in strong collaboration with consumers, carers, practitioners and the project team. Various workshops were held to capture ideas from the extensive experiences of both clients and staff. A final tool was created with 15 recovery-orientated indicators (questions) that were considered to be essential to measure personal recovery. Each offers five optional answers. The statement which best reflects how the person feels at that point in time is circled. From left to right, the measure is based in a Likert scale of 1-5 and follows a model of change which assesses:
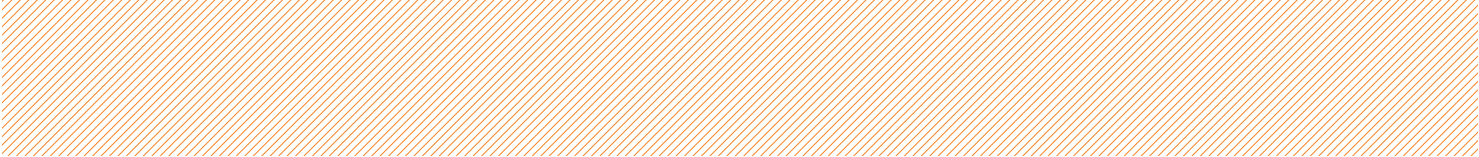
Growth (meaningful life, action)	**Rebuilding** (starting to actively work on change)	**Preparation** (taking stock, preparing to change)	**Awareness** (realisation)	**Moratorium** (feeling hopeless, unmotivated)

Numbers are not used on the working document to discourage a sense of choosing a higher score as being 'better'. The conversations begin with discussing what recovery means to the individual and what they are hoping to gain from being at the service. PROMT is delivered as a conversation tool, assisting both the individual and the practitioner to gain an enhanced understanding of where the person is situated within each recovery domain and why.

Both the person and the practitioner have their own copy of PROMT to work through and complete; comments or points may be added to provide future clarity. Using guided conversation and inquiry, seeking to elicit an honest reflection, the client decides where they are placed in each of the recovery indicators. As the therapeutic relationship develops, the practitioner may use future surveys to gently challenge negative self-perceptions held by the person, eliciting information regarding strengths, skills and abilities which may not be prominent in the consumer's mindset. PROMT is intended to provide a 'snapshot' of where the person 'is' at a given point in time.

The 15 recovery-orientated discussion points cover the following areas:

- Sense of hope
- Personal goals
- Physical wellbeing
- Vocational participation
- Activities of daily living management
- Relationships and informal supports
- Home (living arrangements)
- Addictive behaviour (substance use)
- Resilience/Relapse prevention
- Sense of personal control
- Community participation
- Trust (healthy)
- Sense of self (connectedness)

Practitioners reported that the tool assisted them to have those courageous conversations that were often difficult to raise with consumers and as a result, consumers were able to quickly identify meaningful recovery goals.

It was anticipated that this tool would detect change over time, with the survey to be repeated every three months or up to six months if the client was mentally unwell or experiencing personal crisis. To do otherwise would not give a true representation of the client's progress.

PROMT received glowing feedback from both staff and consumers during the development testing. Practitioners reported that the tool assisted them to have those courageous conversations that were often difficult to raise with consumers and as a result, consumers were able to quickly identify meaningful recovery goals. Although the project team believed the tool needed more work, it was decided that PROMT should begin its formal testing and independent evaluation. A partnership was created with Frankston-Mornington Peninsula Medicare Local to evaluate PROMT and, in collaboration with Peninsula Health's Community Care Units (PH-CCU) practitioners, a 12 month trial began in June 2013.

Trial and evaluation

The aim of the evaluation was to assess how useful PROMT was as a measure of client outcomes for people in recovery from episodes of mental illness. To test it across both community and clinical settings, the evaluation was conducted in collaboration with PH-CCU.

The PROMT trial was intended to be conducted over 12 months, with the survey being administered at three monthly intervals: baseline, middle and exit. The trial design did not incorporate benchmarking PROMT against other validated recovery outcome measures such as Behavioural and Symptom Identification Scale (BASIS-32), Individual Recovery Outcomes Counter (I.ROC) or Process of Recovery Questionnaire (QPR) in order to assess its psychometric properties.

Evaluation Aims

1. Document the efficacy and usefulness of PROMT as an effective OM tool for assessing mental health clients' personal recovery.
2. Identify what aspects of PH-CCU's and PSS' mental health programs influenced the effectiveness of PROMT for clients' recovery outcomes.

Methods

Quantitative and qualitative data analysis was conducted for the de-identified PROMT data and the open-ended responses (clients) and User Satisfaction Survey (both clients and staff). The evaluation findings were based on the data analysis.

The primary challenge in developing an effective OM tool for recovery is applying objective measures to subjective experiences. The approach taken by most of the personal recovery tools currently available – such as Recovery Star (Dickens et al. 2012); QPR (Neil et al. 2009); and I.ROC (Monger et al. 2013) – is to measure the individual experience over time and obtain a pre and post measure of individual change processes. Central to this approach is the ability of mental health community support services to generate local, collaborative approaches using client participation to develop OM tools for personal recovery (Kidd, Kenny & McKinstry, 2014).

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PROMT: Developing, testing
and assessing a new Outcome
Measurement tool
By Cindy Keys and Jane Howard

A client's PROMT story

At PSS I did two PROMTs with my worker. The first PROMT was difficult to do, as I was new to PSS, but I must say it was good to get a lot of things written down, it helped figuring out issues in my life. I was able to make some goals to work on.

The second PROMT was quite some time later and it was much easier to answer the questions. Personally the most important things were:

» Hope – in the second PROMT I was able to acknowledge more hope, I could do lots more things, like socialise with friends and in groups. My support systems had improved.

» My physical health was significantly better, even though I do have ongoing physical problems.
» I have also given up drinking and that is a positive achievement.
» Learning to trust is hard, but I am more able to trust people.
» It was hard to talk about spirituality, culture and identity, but I have recognised that I am quite a spiritual person and that is good.

A client's personal experience using PROMPT – in their own words.

Routine OM tools for personal recovery need to address the following areas:

1. Collection of consistent data for reporting to government/funding bodies to provide evidence of cost efficiency:
   a. attribution of improvement in client outcomes to services provided
   b. shift the emphasis from service activity (for example, hours of service/support provided) to outcomes arising from that service.
2. Quality control (monitoring) and improvement planning for individual services.
3. Assist workers to assess change and recovery for their clients.
4. Enable clients to 'see' and measure their own achievements and track their own recovery progress, thus bringing a sense of ownership to the recovery process (Ion et al., 2013).

In developing an OM tool, it is also important to consider its psychometric properties (Shanks et al., 2013), specifically:

• **Internal consistency** (that is, respondents answering different questions based on the same underlying construct will give similar answers)
• **Content Validity** (the extent to which a measure represents all facets of a given social construct, in this instance recovery)
• **Reliability** (consistent results are achieved for test-retest under similar conditions)
• **Sensitivity** to change (related to both validity and reliability – the test is able to detect change over time) (Burgess et al., 2011)

Trial participants

In total 69 participants, 33 men and 36 women, with an age range of 24–81 were recruited for the PROMT trial, three of whom were carers of people with a diagnosed and enduring mental illness. Apart from these three, all participants had severe and enduring diagnosed mental illnesses, which included schizophrenia, Schizo-affective Disorder, Bipolar Affective Disorder, Post-Traumatic Stress Disorder (PTSD), anxiety, depression and Personality Disorder (that is, Borderline). Participants articulated four key reasons (social acceptance, to manage their illness better, to start recovering from their illness, and support) for why they sought support from PSS or PH-CCU.

Trial results

The PROMT was administered twice over the duration of the trial, once at baseline and then six months later, not three monthly as anticipated. This was due to major organisational and sectoral changes (including the closing of several group programs) within the Victorian mental health sector at the time of the trial.

Overall clients reported that they found PROMT useful in helping them identify their recovery goals and assisting them to structure their recovery journey in planning for the future. Likewise, staff indicated that using PROMT had a positive effect not only for their clients upon their work practices as well. It was reported by staff that PROMT was particularly effective when used with clients who were presenting as mentally 'well' (i.e. recovered from a recent episodic illness). However, staff would need to allow sufficient time to go through PROMT particularly for clients presenting with dual disability or limited literacy. Both staff and clients agreed that PROMT enhanced the recovery process and was an appropriate mental health outcome measurement tool.

Overall Evaluation Findings

There was evidence that PROMT has the potential to be an effective recovery-orientated OM and that:

1. It was able to detect change over time (albeit from two administrations, six months apart).
2. It showed capacity to be implemented across different work settings (PSS non-clinical and PH-CCU clinical) and has potential to be appropriate for clients experiencing mental illnesses of varying severity.
3. It was accepted by both staff and clients and felt to add value to the recovery process for clients.

For PROMT to be accepted as a validated recovery-orientated OM in the mental health sector it requires:

1. Further refinement of the wording of questions and the written Likert scale anchors.
2. Further research to validate its psychometric properties, including direct comparison of PROMT against other recovery-orientated OMs that have been validated (for example, BASIS-32).

A snapshot of common themes derived from client comments about the PROMPT:

Table 1: Examples of open ended responses and themes detected for three PROMT questions

Question number	Indicator	Themes	Selected quotes
01	HOPE	**Personal meaning**	'That I will be able to see my children on a regular basis unsupervised.' 'Stability and security in life and being able to set achievable goals.' 'To live in freedom.'
02	GOALS	**Activity related**	'Writing a book and plan to buy windsurfer at end of the year.' 'Possibly go back to study or part-time/volunteer work.'
03	WELLBEING	**Life choices** **Living with medication** **Living with mental illness**	'I've gained 5 kgs and am eating a lot better. Exercising well.' 'Slowly working on my motivation, keeping healthy, diet and exercise.' 'I am attending an exercise program and dietician at Mornington Community health Centre – 12 week program.'

▶ ▶ ▶ FIND OUT MORE: To view the full Evaluation Report visit **www.pss.org.au**

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Adverse life events in childhood and mental illness – consumer perspectives and implications for treatment

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Mental health professionals often suspect that trauma is involved in the causation of many types of mental illness, but until recently research in the area was not conclusive (Bendall et al., 2008; Varese et al., 2012).

Research in the field of childhood adversity is difficult and previous research has been hampered by small numbers or inadequate comparison groups (Bendall et al., 2008). However, newer and more sophisticated investigations are helping us understand more about this important area, and they confirm the clinical wisdom – that trauma and adversity in young people has profound effects throughout the rest of life, greatly increasing the risk of serious mental illness developing as well as making substance dependence or depression more likely (Varese et al., 2012).
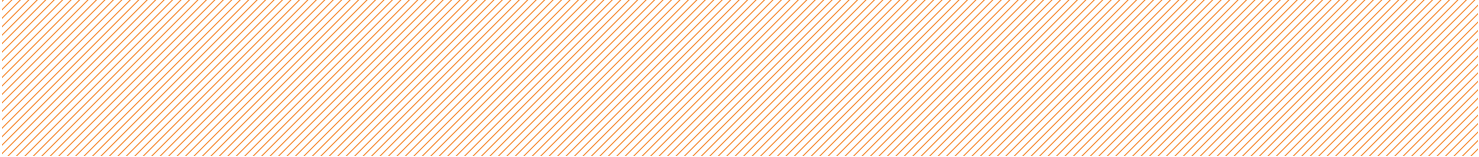
How this research came about

The Adverse Life Events (ALE) research project analysed data collected via the second Australian National Survey of High Impact Psychosis (SHIP) in 2010. During the course of the SHIP interviews, some of the Victorian interviewers were struck by the significant adversity during childhood described by participants (Morgan et al., 2012). In addition, interviewers perceived that while participants were grateful for the care they received, many felt their traumatic history had been overlooked by mental health services, even after long-term treatment (Morgan et al., 2012).

How the research was conducted

The SHIP was a cross-sectional survey. A random sample of 1,825 participants was selected and interviewed from 7,955 people who screened positive for psychosis and were attending specialised public mental health services and non-government organisations (Morgan et al., 2012). The survey contains details of screening and the survey methodology.

For the ALE research, histories of childhood adverse events, childhood losses and childhood abuse were summarised from SHIP interview responses. Analyses were conducted to see whether the number of adverse events experienced was linked with a range of clinical and social outcomes. For numeric analysis, logistic regression was used since it takes account of multiple characteristics so that genuine relationships of statistical significance can be reported.

For textual analysis, interview booklets from one site were audited for any participants' comments related to adverse childhood events. SHIP interviewers had been trained to code information as well as write down actual responses during the interviews in order to validate scores and clarify any responses. Analysis of these data explored patterns relating to adverse events over the life course in addition to personal accounts of what had helped and what participants believed services could do to help more.

Logistic regression revealed that the number of adverse events was significantly associated with greater rates of depression, internalising symptoms (combined depression, anxiety and suicidal ideation), hallucinations, victimisation, homelessness and a definite psychosocial stressor within 12 months of illness onset.

The ALE study overcame many of the limitations of previous research mentioned above. It had a large group of participants representing all those living with psychosis in the catchment areas, wide-ranging numerical information and an innovative data-mining technique which allowed some verbatim material to be collected to bring alive the consumer perspective.

Results

The final sample for statistical analysis consisted of 1,825 participants, of which 738 (40 per cent) were female and 773 (42 per cent) were aged under 34 years. Most participants were born in Australia (82 per cent), had a family history of mental illness (58 per cent), had no tertiary qualifications (51 per cent), had no children (61 per cent) and had never been, or lived as, married (51 per cent).

Eighty one per cent had a lifetime diagnosis of depression in addition to their psychosis; 67 per cent had thought about suicide, while 50 per cent had attempted suicide at some point in their life. Seventy nine per cent had a lifetime diagnosis of hallucinations, 47 per cent a subjective thought disorder and 87 per cent delusions of some type.

Over two-thirds described one or more adverse events before the age of 18. Of the total sample, 301 (17 per cent) reported experiencing childhood sexual abuse, 151 (8 per cent) childhood physical abuse, 104 (6 per cent) childhood emotional abuse and 59 (3 per cent) neglect in childhood. Of the interpersonal loss categories, parental separation or divorce was most common at 40 per cent.

Logistic regression revealed that the number of adverse events was significantly associated with greater rates of depression, internalising symptoms (combined depression, anxiety and suicidal ideation), hallucinations, victimisation, homelessness and a definite psychosocial stressor within 12 months of illness onset. In other words, the more adverse events reported the greater the chance of developing symptoms of mental illness or social difficulties as an adult. In Table 1, odds ratios indicate increased probabilities – for example, two or more adverse events are associated with twice the chance of developing internalising symptoms.

Adverse life events in childhood
and mental illness – consumer
perspectives and implications
for treatment

By Suzanne Turner, Carol Harvey
and Laura Hayes

Table 1. Logistic regression (adjusted) results using the number of adverse events in childhood as key predictor
Only results with statistically significant association displayed.

Symptom	Odds Ratio (95% Confidence Interval) p value	p value
Depression		
Number of adverse events in childhood		0.02
0	1.00	
1	1.3 (1.0-1.8) 0.064	
2 or more	1.5 (1.1-2.1) 0.007	
Internalising		
Number of adverse events in childhood		0.001
0	1.00	
1	1.3 (0.9-1.8) 0.149	
2 or more	2.1 (1.4-3.2) 0.000	
Hallucinations		
Number of adverse events in childhood		0.036
0	1.00	
1	1.4 (1.10-1.9) 0.011	
2 or more	1.2 (0.9-1.5) 0.327	
Victimisation		
Number of adverse events in childhood		0.001
0	1.00	
1	1.1 (0.8-1.4) 0.6	
2 or more	1.6 (1.1-2.0) 0.001	
Homelessness		
Number of adverse events in childhood		0.028
0	1.00	
1	1.7 (1.1-2.4) 0.008	
2 or more	1.4 (0.9-2.1) 0.094	
Definite psychosocial stressor within 12 months of illness onset		
Number of adverse events in childhood		0.005
0	1.00	
1	1.1 (0.9-1.4) 0.403	
2 or more	1.5 (1.2-2.0) 0.002	

In total, 72 per cent of participants reported having experienced at least one adverse event type in childhood, with 33 per cent reporting exposure to two or more. The study showed very high rates of trauma and adversity compared to the population in general.

Thematic analysis of the verbatim interview responses revealed some common issues for participants who had reported adverse events in childhood:

a. relationships (both intimate and friends) in later life were often abusive indicating possible linkages between childhood sexual abuse and re-victimisation in later life
b. descriptions of feeling separate and different to others, resulting in social isolation
c. participants described involvement in violent crime, and also "lashing out" to release anger
d. accounts of a lack of familial, social and service support across the life course
e. common to all people reporting childhood sexual abuse was an overwhelming sense of not having spoken to anyone about events, or alternatively, that when they did the response had been unsatisfactory
f. drug and alcohol use as an escape mechanism following adversity in childhood
g. connections in content between adverse events in childhood and content of delusions and hallucinations.

When asked how treatment and support might make a difference for them, three themes stood out. Firstly, the need to talk about their issues in a supportive environment: interviewees had often not spoken to anyone within the mental health service about the adverse events. Secondly, the need for social support beyond that provided by mental health practitioners and help with securing that support, given the risks of isolation described above. Thirdly, and most pertinent to people reporting childhood adversity, the need for safety and security. This was both a concrete and abstract concern, relating to safe housing (both hospital and home) as much as secure continuous relationships with clinicians:

'You start to feel comfortable with a doctor, that rapport, same with case manager, then have to start all over again. Start again. The system is really stuffed up.' (Tom, 26)

Discussion

In this research project both numerical and verbal data analysis revealed the high rates, multiplicity, and extremities of adverse events in people with a diagnosed psychotic illness.

In total, 72 per cent of participants reported having experienced at least one adverse event type in childhood, with 33 per cent reporting exposure to two or more. The study showed very high rates of trauma and adversity compared to the population in general. In this group the rate of sexual abuse was 17 per cent, whereas other research shows rates of 8 per cent in females and 1 per cent in males in the general population (Molnar, Buka & Kessler, 2001). Family separation and divorce was 14 per cent in the Australian community (Rosenman & Rodgers, 2004) and 40 per cent in this study.

Both numerical and verbal data showed patterns and associations between adverse life events and emotional and behavioural responses over the life course, highlighted by themes of relationship difficulties, re-victimisation, anger, and connections between adverse childhood events and delusion and hallucination content. The final results support the interaction of social and biomedical causes of mental illness, building on the idea that one is not born but rather becomes who they are by way of their life experiences. These research findings have significant implications for public policy and public mental health service delivery including the need for the provision of safe housing and secure therapeutic relationships and for staff to prioritise being trauma-informed.

Implications for service delivery

The results clearly imply there is a greater need for trauma-informed care in the mental health sector. This includes a focus on understanding the consumer's background story, taking a careful trauma history, as well as providing specific trauma-focussed treatments. There is also a need for supervision and support for staff when they are dealing with their client's trauma stories as well as adequate training regarding trauma management.

In addition, there is a need for awareness of how trauma affects engagement and trust with a service provider. This means safe housing and living conditions can be a pre-requisite for meaningful engagement in treatment. 'Safe' relationships with service providers can take some time to develop and be negated by systems issues, such as the high turnover of treating doctors and community case managers.

Hand-over within a service, for instance, may lead to unnecessary retelling of distressing material (notwithstanding the need for history taking identified above).

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Adverse life events in childhood
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These research findings have significant implications for public policy and public mental health service delivery including the need for the provision of safe housing and secure therapeutic relationships and for staff to prioritise being trauma-informed.

What have we learnt?

The results of this innovative research project show that adverse events in childhood are associated with a range of negative emotional, behavioural and social outcomes and this has important implications for the sector.

Abuse, trauma and adversity is common in those living with mental illness, and significantly impacts on their symptoms and treatment. Moreover, these narratives of adversity are often central to their identity, yet there is little opportunity in treatment facilities to explore these issues. It would appear that trauma is not yet systematically addressed in mainstream treatment for serious mental illness.

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Getting to the CORE of the links between engagement, experience and recovery outcomes

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A challenge in mental health research is the development of an evidence base that documents and shows which elements of engagement and service experiences are linked with health outcomes and how.

CORE is an abbreviation for The CORE Study: a stepped wedge cluster randomised controlled trial to test a co-design technique to optimise psychosocial recovery in the community mental health setting. The three year CORE study will trial a new approach that brings together service users, carers and mental health staff to identify areas for improvement in mental health services.

It has received $1.7 million from the Victorian Government's $10 million Mental Illness Research Fund which supports collaborative mental health research projects.

The 'holy grail' of engagement

Engagement, much like the concept of recovery in the mental health setting, has become central to the redesign of health systems. Indeed it has even been heralded as the 'holy grail of health care and the next blockbuster drug' (Carman et al., 2013, p. 223).

Engagement refers to a variety of processes and practices and includes:

- communication in face-to-face service delivery;
- shared decision-making in treatment choices and formulation of care plans;
- representation on committees, advisory groups and boards of health care organisations; and
- embedded consumer, carer and lay representation in service planning and design at all levels of the healthcare system.

Literature has highlighted that successful engagement can result in a more responsive and efficient health system (Altuna and Jun, 2014). The exact elements of engagement and service experience and the relationship with individual health outcomes have to date received little attention in research (Lietz et al., 2014).

A challenge in mental health research is the development of an evidence base that documents and shows which elements of engagement and service experiences are linked with health outcomes and how. In response to this, the CORE study will test an experience-based co-design (EBCD) technique (see Box 1) for its effectiveness in improving psychosocial recovery outcomes for people affected by mental illness in the community mental health setting.

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Getting to the CORE of the links
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The experience based co-design intervention for the CORE study

Experience based co-design (EBCD) has largely been used as a quality improvement method in health services. Improvement areas are identified through eliciting the 'touch points' of a service; that is, the places and ways that people come in touch with a service and how these interactions and engagements can be positive or negative.

EBCD is not only about eliciting the negative touch points, but it is about taking this information and developing actions for change through a facilitated co-design process. In the CORE study we will implement and test a specific EBCD methodology designed by the Victorian Mental Illness Awareness Council (VMIAC) and Tandem (representing Victorian mental health carers) called Mental Health Experience Based Co-design (MH ECO).

MH ECO draws on the principles and practices of EBCD but uses a modified approach to elicit information about service experiences. It is also one of the few purposefully designed methods to include both consumers and carers in this process. While other EBCD studies have used in-depth interviews and the development of trigger films to explore experiences, the MH ECO approach relies on a computer assisted telephone interview (CATI).

The CATI is used to identify commonly shared touch points from consumers and carers in mental health services and then explore these touch points further in face to face interviews and separate focus groups held with staff, consumers and carers. This is followed by co-design meetings where staff, consumers and carers all come together to set objectives and formulate actions plans based on the co-designed solutions.

The process will occur over six months in the CORE study.

The study will examine if the EBCD based intervention (Fairhurst and Weavell, 2011) improves recovery for consumers, increases carer mental health and well-being and changes staff attitudes to recovery

CORE design

The CORE study is designed as a stepped-wedge cluster randomised controlled trial with four data collection time points (baseline, 9 month, 18 month and 27 month follow up) (see Figure 1). The stepped-wedge design means that participating Mental Health Community Support Service (MHCSS) teams (clusters) are randomised to receive the intervention in one of three waves (W1, W2, W3) (Brown and Lilford, 2006; Hussey and Hughes, 2007).

Within each cluster the trial aims to work with 25 to 42 consumers and 25 to 42 carers of the participating MHCSS services including staff, for a total number of 252 consumers.

The study will examine if the EBCD based intervention (Fairhurst and Weavell, 2011) improves recovery for consumers, increases carer mental health and well-being and changes staff attitudes to recovery. Table 1 details the validated questionnaires that are being used for all three groups to document changes to outcomes (staff, consumers, carers) (Corrigan et al., 2004; Rocha et al., 2012; O'Connell et al., 2005; Crowe et al., 2006). All participants are asked additional demographic information and questions about service use and participation. Consumers are also asked to grant permission for the team to access de-identified Medicare Benefits Scheme (MBS) data about health services use and Pharmaceutical Benefits Scheme (PBS) information about medications.
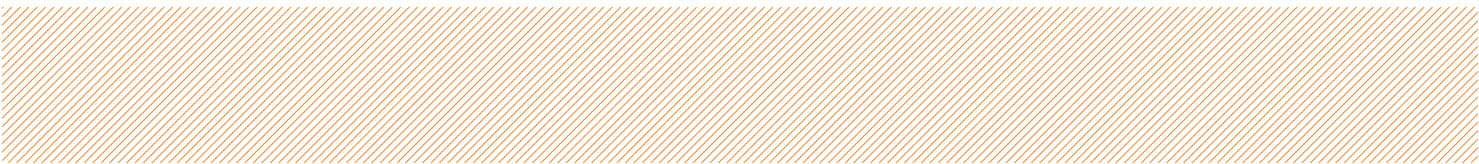
Figure 1: Design for a stepped-wedge cluster randomised controlled trial in the community mental health setting
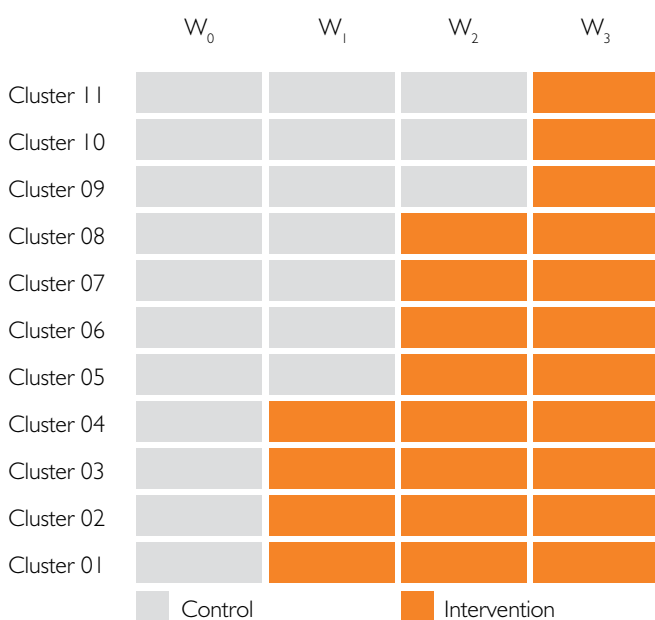

	W_0	W_1	W_2	W_3
Cluster 11	Control	Control	Control	Intervention
Cluster 10	Control	Control	Control	Intervention
Cluster 09	Control	Control	Control	Intervention
Cluster 08	Control	Control	Intervention	Intervention
Cluster 07	Control	Control	Intervention	Intervention
Cluster 06	Control	Control	Intervention	Intervention
Cluster 05	Control	Control	Intervention	Intervention
Cluster 04	Control	Intervention	Intervention	Intervention
Cluster 03	Control	Intervention	Intervention	Intervention
Cluster 02	Control	Intervention	Intervention	Intervention
Cluster 01	Control	Intervention	Intervention	Intervention

Control   Intervention

Table 1: Validated outcome measures for participant groups

Participant group	Validated questionnaire
Consumers	Recovery Assessment Scale-Revised (RAS-R) 24 Items
	EUROHIS-QOL 8 Items (a shortened version of the World Health Organisation Quality of Life- BREF Scale)
Carers	EUROHIS-QOL 8 Items (a shortened version of the World Health Organisation Quality of Life- BREF Scale)
Staff	Staff Attitudes to Recovery Scale (STARS) 19 Items
	Recovery Self Assessment (RSA) 36 Items

Gold standard for evidence

EBCD is becoming a popular method to understand and facilitate health service change based on user experiences and the CORE study will be a world-first study to trial this approach in the mental health setting.

To date, many co-design projects have occurred in hospital settings like emergency departments or head, neck, breast and lung cancer specialist units in the United Kingdom, Australia, New Zealand and Canada (Bate and Robert, 2007; Adams et al., 2014; Boyd et al., 2012; Donetto et al., 2014; Locock et al., 2014; Piper et al., 2012; Wiseman et al., 2011). Projects completed in the mental health setting have been service-driven projects in in-patient settings which have not documented the possible effects or otherwise on mental health outcomes (Donetto et al., 2014). Currently, the gold standard for evidence generation where these links between engagement, experience and health outcomes can be demonstrated is the randomised controlled trial (RCT) design.

The use of RCTs raises additional challenges around withholding of an intervention from one group in the trial (the control arm) while another group receives it (the intervention arm) (Palmer et al., 2011)

and reaching recruitment targets (Treweek et al., 2013). Further challenges relate to the translation and implementation of systematic research processes into complex organisational settings (Clavier et al., 2012) and the difficulties of recruitment of people living with persistent and enduring mental illnesses and their carers (Furimsky et al., 2008). Some of these difficulties are related with the perceived health state of someone whereby their motivation to participate is affected by symptoms or there is a concern that participation may lead to a deterioration in health status. Sometimes clinicians and staff may also feel protective of participants because of these risks and they may be concerned about people going into an unknown intervention (Hughes-Morley et al., 2015).

All of these important and documented issues need to be accounted for in the development of recruitment strategies, however resource and time pressures do affect the level of attention they are given. A systematic review of recruitment of RCTs by Treweek et al. (2013) found that delays in recruiting can increase financial costs. This can mean that an intervention may not be more widely rolled out because a trial was discontinued due to a lack of participants. There can also be an impact on statistical precision as targets for participant numbers are not met (Treweek et al., 2013).

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Getting to the CORE of the links
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To foster stronger, committed and mutually flowing relationships there needs to be a good understanding of the service context and how this may or may not shape people's decisions about involvement.

As a result, recruitment strategies have now become a major focus in clinical trials with a focus on utilising the infrastructure available (networks and existing groups), increasing professional and public engagement with research and developing an evidence base of effective recruitment methods (Bower et al., 2014). The CORE study will contribute to the development of this evidence base through its purposively designed relational model of engagement.

The implementation of this model constitutes what Treweek et al., (2013, p. 2) called a 'recruitment intervention'; that is, 'any method implemented to improve numbers of participants recruited to a RCT'. Some of the methods that have been shown to increase recruitment in other RCTs include:

- open designs (where participants know which treatment they will receive)
- an opt-out approach instead of opting-in (contact is made with everyone unless they say no)
- approaching participants using videos plus written information
- verbal education sessions
- presentations of treatments as faster
- telephone reminders
- SMS messages
- completing eligibility screening by telephone
- cash incentive offers with invitations to participate
- paid participation
- training lay advocates as recruiters (Treweek et al., 2013).

The CORE relational model of engagement has incorporated a number of these methods to enhance recruitment and seeks to address the issue of recruitment interventions being informed by theory (Bower et al., 2009).

We call this a relational model of engagement to highlight how the model is premised on relational ethical theories and informed by participatory action research principles where participants are encouraged to become co-researchers and collaborators in the process (Reason and Bradbury, 2006).

Relational ethical theories incorporate the view that people's identities and personal stories matter and that the relationships within which

we live our lives help to shape (and sometimes hinder) the decisions we make about the world. A distinguishing characteristic of this model, then, is the view that successful recruitment and implementation of this intervention is relationally constituted and premised on dialogue. To foster stronger, committed and mutually flowing relationships there needs to be a good understanding of the service context and how this may or may not shape people's decisions about involvement. This knowledge can only be generated through ongoing conversations out in the field. This also provides an opportunity for those who know our participant groups to have input into the iterative development of recruitment interventions that enhance participation but simultaneously assist to forge relationships that are likely to improve the retention in the study.

The practices undertaken within the CORE relational model include:

- regular phone calls to key staff (once a month)
- site visits every six months to talk with teams about study developments and progress
- raising awareness about the study through purposively designed study posters and postcards located in the wider community (libraries, community and neighbourhood centres, supported residential services and prevention and recovery services)
- staff distribution of study postcards to potential participants during regular clinical contact
- researchers holding study information days where verbal education sessions are provided, including independent and trained peer workers for support, and a short comedy routine delivered by WISE Employment Stand Up for Mental Health comedians (a comedy program taught by Canadian counsellor and comedian David Granirer to reduce stigma around mental health)
- tri-annual study newsletters to participants
- a study blog for staff and researchers to visit and stay up to date with research activities
- regular engagement events throughout the study offered to staff, consumers and carers.

This relational model is essential to getting to the CORE of the elements of engagement and service experience that are linked with psychosocial recovery outcomes for people living with mental illness in the community.

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PULSAR research: making mental health services more recovery-orientated

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Dr Lisa Brophy is Investigator, PULSAR, Melbourne University and Mind Australia
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Christine Thornton is Investigator, PULSAR, Ermha

There is a need for an approach to recovery-oriented practice that is locally tailored, clearly operationalised, thoroughly documented and comprehensively and robustly evaluated in Victoria. Principles Unite Local Services Assisting Recovery (PULSAR) is a four-year Victorian Government funded research project being undertaken in the Southern Metropolitan region of Melbourne that is aimed at responding to this need and builds on the work by Professor Slade.

To comprehensively adopt recovery orientation in mental health services requires system-wide transformation. Work towards such transformation has occurred in services in several states in the United States and in various parts of the British National Health Service (NHS), often in widely different service structures. Professor Mike Slade has articulated a number of principles (Slade, 2009) and has developed the REFOCUS intervention (currently trialled in the in the United Kingdom) which applies these principles in practice. These principles and research is valuable for Victorian mental health practice.
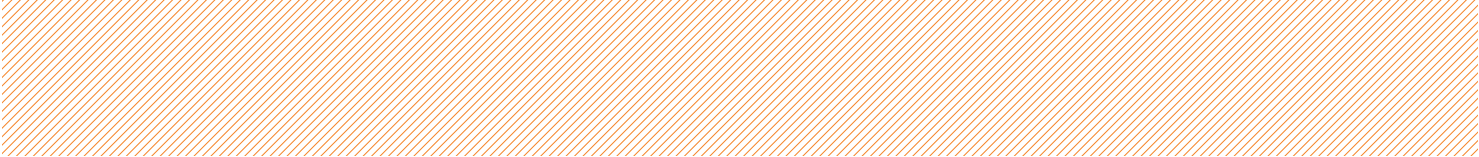
Mental Illness Research Fund (MIRF)

In the 2011-12 State Budget, the Victorian Government invested $10 million over four years to create a Mental Illness Research Fund (MIRF) to support collaborative research that may lead to better outcomes for Victorians with mental illness and their families/carers. The MIRF intends to create new knowledge across Victoria's research, treatment and support sectors that can be applied to improve treatment and recovery outcomes for people with mental illness.

There are five MIRF projects, with PULSAR being the largest grant at $2.33 million.

The MIRF projects have the following features (Department of Health Victoria, 2011):

- They are characterised by strong collaborations across different sectors, including involvement of consumers and families/carers in the development and undertaking of the research projects.
- They cover a range of service, community and custodial settings, and include clinical and psychosocial support interventions.
- They cover a spectrum of mental health conditions and age groups.
- They include a focus on quality of life and social participation outcomes for Victorians affected by mental illness.
- They support the development of evidence-based practice to deliver improved outcomes for consumers and families/carers.

The MIRF research projects were required to address one or more of the following three priority research themes and be consistent with the Victorian Government's strategic priority areas for mental health. These were defined with reference to the 'Because Mental Health Matters' policy documentation dating from 2009 as developed under the previous Labor Government and intended to lay out principles for service reform from 2009-2019:

1. Optimising psychosocial recovery outcomes and minimising disability for people affected mental illness.
2. Improving effectiveness of existing and new treatments for people affected by mental illness.
3. Increasing social participation by people affected by mental illness.

Research projects were also expected to demonstrate consumer and family/carer involvement, ensuring that their perspectives are included in the planning, development and conduct of the research projects.

Victorian Government alignment

In 2011, the Victorian Government released the document, *Framework for Recovery-Oriented Practice*. It detailed the state's support for a focus on Personal Recovery in addition to Clinical Recovery, with many of the principles and domains based in Professor Slade's work.

In addition to this document, the *Mental Health Act (2014)* was being drafted with a clear legislative direction that services were to be recovery focussed.

PULSAR – the beginnings

Following a trip to Melbourne, during which he met Professor Graham Meadows, Professor Slade obtained a research grant to test the success of the REFOCUS invention he had developed. When MIRF funding became available in 2012, Professor Meadows approached Professor Slade to suggest a trial of the intervention in Victoria. After agreement was reached, Professor Meadows brought together a broad range of experts and experienced people across Victoria to adapt the intervention to the local context and develop a MIRF application.

Design of PULSAR

While fidelity with Professor Slade's original research in the United Kingdom is key, some significant changes were made to the research group guiding the MIRF application and, subsequently, the project. Principal amongst these changes is the inclusion of a consumer researcher as an investigator and the inclusion of primary care into the intervention groups. The primary care study also builds on work independent of the REFOCUS intervention model on developing mental health treatment plans with recovery orientation, and a long history of collaborative work in General Practice (GP) shared care.

PULSAR is a complex research project involving providers of both primary and secondary care. In the Monash Health Catchment, GPs were recruited as primary care providers while three organisations – a Specialist Mental Health Service (Monash Health) and two Mental Health Community Support Services (MHCSS) (Ermha and Mind Australia) – were recruited as providers of secondary care. A four-module framework was adopted for the management of each component. Each module is chaired by one of the investigators and includes members of each of the module working groups. The four modules are:

1. Adaption, chaired by Christine Thornton, Ermha
2. Implementation, chaired by Penny Weller, RMIT
3. Research, chaired by Lisa Brophy, Melbourne University and Mind Australia
4. Dissemination, chaired by Vrinda Edan, Monash University

Adaption involved further changes to the REFOCUS intervention to suit the Victorian MHCSS sector, taking into account the different training needs of both the primary and secondary sectors. In the primary sector, the training consists of a Clinical Enhancement Module (CEM) and has been accepted by the General Practice Mental Health Standards Collaboration. This means that GPs completing the CEM will be eligible for continuing professional development (CPD) points. The adaption work included the development of training videos for both the primary and secondary sectors.

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Psychiatric Disability Services
of Victoria (VICSERV)

PULSAR research: making mental health
services more recovery-orientated
By Vrinda Edan, Prof. Graham Meadows,
Dr Lisa Brophy, Dr Penelope Weller and
Christine Thornton

The **Implementation** module focusses on the delivery on the intervention (the training for staff) and utilises the PARiH (Promoting Action on Research Implementation in Health Services) framework as an organising structure. The PARiHS framework examines the interactions between three key elements for knowledge translation: Evidence, Context and Facilitation, and this informs the transfer of research knowledge into practice (National Collaborating Centre for Methods and Tools, 2011). In the secondary sector, consultations with staff occur across the three organisations (Monash Health, Ermha and Mind Australia) and the data from these consultations is applied in the adaption and implementation stages of the intervention.

Applying a mixed methods approach, the **Research** module is organised to utilise the various expertise of the investigators which includes both qualitative and quantitative methodologies.

The quantitative component consists of a cluster randomised controlled trial with MHCSS, including Crisis Assessment and Treatment Teams (CATT), Continuing Care Teams, Mobile Support and Treatment Services (MSTS), Prevention and Recovery Care units (PARCs) and Outreach services. These have been randomised into two groups, one of which will receive the intervention in January and February 2015 and the other group in 2016. The primary care sector will include 30 General Practices, again randomised to receive the intervention in March 2015 or October/November 2015.

Consumers who attend any of these services will be approached to participate in the research, with the primary measurement tool to be the Process of Recovery Questionnaire (QPR). Participants will be asked if they are interested in participating in interviews with further measures assessed. Australian Mental Health Outcomes and Classification Network (AMHOCN) measures will also be used for secondary care.

The qualitative component of the research will be a longitudinal case study that aims to understand staff and consumer perspectives of re-orienting services so as to foster recovery-oriented practices by addressing three key questions:

1. What factors help and which hinder working in a recovery-oriented manner from a PULSAR program staff member perspective?

2. How do PULSAR recovery-oriented program participants with experience of serious mental illness view the PULSAR program – in relation to supporting them in their recovery?
3. What experiences and dilemmas are encountered within the different parts of the service system in implementing recovery-oriented practices and what strategies and adjustments are used to apply REFOCUS in an Australian mental health service setting from the perspectives of both program participants and staff?

The final module, Dissemination, will guide and support the Project staff and investigators to ensure there is a multi-level approach to knowledge transfer that influences mental health practice. It is envisioned that this may include: publication of a scientific book, training manual and information leaflets; scientific and practice-focussed conferences; website development so other interested parties can readily access project materials; and direct presentations to policy makers to ensure the findings are well understood and appreciated where key decisions are being discussed.

PULSAR progress

Recruitment of two Research Fellow positions to provide support for the greater research team is progressing well. The Project experienced some initial difficulties with participant recruitment – a brainstorm session and subsequent force field analysis was undertaken of additional strategies, ethics amendments made and the new strategies implemented. These additional strategies include promotional material for staff and consumers, increased payments to participants and increased strategies for approaching potential participants (social interactions, waiting room promotions and mail outs).

The intervention has been adapted and training was due to commence in the secondary care sector in January 2015. Trainers from each of the organisations have been included in finalising the material and preparing for delivery. Some adaption to the preferred training model was required to address the needs of the rostered services that are included, resulting in additional sessions being scheduled. This first group of training will be delivered to 106 clinical and mental health staff across the three participating organisations. At the time of writing, GPs were still enrolling in the study with the first rounds of training to commence in late February 2015.

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VOX POP

Respondents:

Lisa Sweeney, carer and a member of Tandem Inc.
Frances Sanders, General Manager, Organisational Initiatives, Mind Australia
Julien McDonald, Executive Director, Tandem Inc.
Victorian Mental Illness Awareness Council (VMIAC) advocacy team
Daniel Van der Pluym, MHCSS Implementation Program Officer, VMIAC
Jackie Crowe, National Mental Health Commissioner, National Mental Health Commission
A MHCSS Consumer Consultant

Our vox POP asked individuals and organisations for the views
of consumers and carers on developments in mental health support
services and where they would like to see more focus in future research.

**What do you see as the key opportunities or positives
for people with mental illness and their carers under
the new and changing mental health support services?**

Lisa Sweeney

Recognition of the role of carers will continue to better support
consumers in their recovery journey. The changing landscape of
mental health services will hopefully allow consumers and carers
to assert their needs and empower self-determination in treatment.

Frances Sanders

The key opportunity for consumers and families and carers is to
advocate for services across the course of mental health issues.
As the mental health space is evolving and not yet set, there is an
opportunity for people to provide rich information about how mental
ill-health impacts across life areas and the types of support they need.
It is a window to shape the system and broader understanding
of mental illness beyond crisis, acute and severe mental illness.

Julien McDonald

The key opportunities are requirements for services to undertake
carer/family needs assessments and to involve families in treatment
and care planning and decision making; the requirement for services
to provide opportunities for carers/families to participate in service
and system development planning; and, potentially, a more equitable
and easy-to-navigate service system.

VMIAC advocacy team

There are opportunities for services to deliver support which
ensures that consumer choice is at the centre of their practices.
Also, identification of services that capture needs and can set a
benchmark for best practice.

Daniel Van der Pluym

The opportunity for greater consumer and carer engagement in
shaping service delivery to better meet individual need. Services
need to work towards co-design to enable enough flexibility in
service delivery to truly meet individual choice and recovery goals.

Jackie Crowe

The Mental Health Peer Workforce is emerging rapidly with thousands
of workers in a variety of settings. The employment of people
specifically because of their lived experience is adding a wealth
of benefits to the broader workforce and consumers and carers.

A MHCSS Consumer Consultant

The positives include an increased focus on individualised person
centred support that provide an opportunity to redefine what
good care and support looks like when it is based on the wishes
of people receiving it.

Understanding of early intervention in episodes of illness, real impact of high prevalence disorders, the episodic nature of illness and the consumer recovery movement is low. – *Frances Sanders*

What current trends and issues in mental health support and service delivery are you most concerned about for people with mental illness and their carers?

Lisa Sweeney

There is a lack of information on the NDIS and the impact this will have on mental healthcare service delivery. Alarmingly, positioning mental illness as a 'permanent disability' is a sharp deviation from the contemporary contextualisation of a 'recovery model'.

Frances Sanders

The system is focussed on more rigid criteria, which means eventually you will have to meet illness or disability criteria to get any kind of help. The criteria for clinical and hospital care, community support and any specialist support is becoming narrower and narrower. Understanding of early intervention in episodes of illness, real impact of high prevalence disorders, the episodic nature of illness and the consumer recovery movement is low. Families and carers face a future where support is reliant on a consumer choosing to spend their package on a disability model of respite with no other funding apparent at state or federal level. Internationally, trials of client-based funding have shown that families face an ever-increasing burden of care, and investment in looking after the carer has been necessary to maintain their economic contribution. We need to think of this now, not after support is dismantled.

Julien McDonald

Impact of NDIS which is likely to leave many consumers without services, and will impact upon carers. Transfer of MHCSS/MSSH funding to the NDIS which will decimate support for consumers and carers. Reduction of over $4 million in funding for Ice and alcohol and other drugs (AOD) initiatives. Need for an individual advocacy service for carers. Need for informal centre-based drop-in type

opportunities for consumers. Need for training of mental health professionals in how to involve and support carers/families, and support their participation in service improvement and evaluation activities.

VMIAC advocacy team

Consumers with diverse and complex needs are increasingly at risk of losing access to appropriate support due to widening service gaps. Also, the eligibility criteria is a return to a deficits-based paradigm and does not align with recovery-based principles.
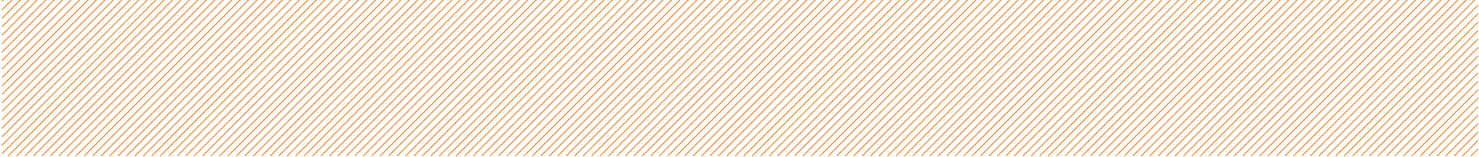
Daniel Van der Pluym

The movement away from service-based delivery of programs in the MHCSS is the most concerning as there are issues around suitability of wider community programs due to high costs, stigma, discrimination and greater feelings of social isolation in placing consumers in communities we do not choose.

Jackie Crowe

Unsatisfactory policy and frameworks that support interventions for the wellbeing of the family unit. Families are the foundational element in human communities; sustainable families are centre of a healthy society and when well supported are able to assist individual members in difficult times.

A MHCSS Consumer Consultant

A major concern is the apparent abandonment by MHCSS services of their role in the development of badly needed social capital. Our communities are not warm and welcoming places for people with severe and persistent mental illness and people will suffer as a consequence.

More research into the measurable benefits of social inclusion in communities of choice versus the detriments of stigma, discrimination and limiting consumers to communities of non-choice. – *Daniel Van der Pluym*

In what areas is there a lack of knowledge or information, that you would you like to see researchers focus on?

Lisa Sweeney

In the chaos of modern life, there is a greater need for education of preventative and adjunctive therapies for individuals experiencing mental illness. Development of a holistic model that includes carers will aid in reducing the expediential growth of mental health consumers.

Frances Sanders

Consultation with consumers, families and carers in systems design is still low, focus is often on the catch cry of 'the system is too complex'. This leads to endless entry points – research needs to drill down and capture the essence of this call. What people are really saying is: 'I got to the system but it didn't help, I am (or my family member is) still unwell and their quality of life is low.' Greater funding for research in low-funded areas such as peer support is also needed. Money primarily goes to medical model research – but there is little open to the community sector and carer groups.

Julien McDonald

Impact of: Carer Peer Workforce, reform of the MHCSS, implementation of the *Mental Health Act 2014*, Mental Health Complaints Commission, effectiveness of various models of carer support at various stages of carer journey. Comprehensive roll-out of Mental Health Experience Co-Design across services supported by Department of Health and Human Services funding.

VMIAC advocacy team

Research on increased admissions to acute inpatient units as a result of widening service gaps would be valuable. Also, research looking at the impacts of systemic abuse and trauma on mental health issues.

Daniel Van der Pluym

More research into the measurable benefits of social inclusion in communities of choice versus the detriments of stigma, discrimination and limiting consumers to communities of non-choice.

Jackie Crowe

While there is an overabundance of research relating to the effects of childhood maltreatment and related complex trauma in adulthood, the lack research being done to mitigate the effects of the related complex trauma is immensely problematic.

A MHCSS Consumer Consultant

I feel there is a real need for the sector to properly understand how services need to engage and work with people with complex and pressing needs; for example the homeless, people with substance abuse issues, personality disorder sufferers etc.

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