## new**paradigm**

TOWARDS RECOVERY HOPE, INNOVATION AND CO-DESIGN

6

THE AUSTRALIAN JOURNAL ON PSYCHOSOCIAL REHABILITATION

Autumn 2016

VICSERV'S MENTAL HEALTH CONFERENCE

19-20 MAY 2016

Melbourne Convention and Exhibition Centre

HOPE | INNOVATION | CO-DESIGN

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### newparadigm

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

- We encourage articles that are approximately 1500 words
   Brief articles should be approximately 500 words
   Letters to the editor should be under 300 words
   All articles should state:
   » a short name of the article
   » the author(s) name
   » the author(s) position or preferred title





Welcome to the Autumn 2016 edition of *newparadigm*.



Debra Parnell is Manager, Policy and Communications, VICSERV

### VICSERV is pleased to be hosting its biennial conference Towards Recovery: Hope, Innovation, Co-design in May 2016.

This edition of *newparadigm* explores the central themes of the Towards Recovery Conference:

- Hope and recovery
- Innovation
- Co-design
- Peer-led
- Transformation
- Empowerment/rights

Co-design, the role of people with lived experience and the opportunities and challenges for mental health sector in a changing landscape, have been key areas of discussion in recent times, and will all feature strongly in the 2016 Conference. Interest in these topics is reflected in this edition of *newparadigm*.

We open this edition with a discussion of the increased involvement of peer workers in various areas of the mental health system and the emergence of recovery colleges. Dianne Hardy, Director of Mind's Recovery College, focusses on the way recovery colleges role-model a consumer-choice culture where power is shared, first-hand knowledge is valued alongside other forms of evidencebased information, and consumers and carers feel themselves to be and are - an integral part of the College's operation.

Nathan Grixti also discusses peer support with a focus on the opportunities that the growing peer workforce could have in the changing landscape. He sees that a potentially strategic advantage for peer led services now exists, especially under the implementation of the National Disability Insurance Scheme (NDIS), by establishing themselves in ways which are not only consistent with the design of the scheme and provide greater choice for participants, but which also could represent unique, independent service offerings that are able to respond to the voiced needs of consumers in a way that is also financially viable.

Co-design has a lot of currency across the community sector at the moment. We provide an excerpt from a recent VCOSS paper which describes the value of co-design: a 'ground-up' approach to service design that begins by asking people what their needs are, and then exploring possible solutions with them.

### Co-design has a lot of currency across the community sector.

We could not explore the issues in mental health and the promotion of recovery without touching on the implementation of NDIS. Kate Fulton is a colleague of one of our keynote speakers, and a development consultant with the National Disability Insurance Agency (NDIA). In her thought provoking article she discusses and argues that, despite its flaws, the NDIS can be a catalyst for service providers to support people's active and full citizenship.

The recent announcements of the expansion of the role of Primary Health Networks (PHN) in the mental health space, adds to the environment of change and reform that is currently touching all areas of mental health service delivery and support. Associate Professor Chris Carter and Lyn Morgain explore some of the significant changes occurring in the service system for mental health, and identify some of the relevant opportunities and considerations under this development.

In the context of these reforms, we also provide an excerpt from the White Paper on Partners in Recovery in Victoria: Systems change and strategic partnerships to improve mental health outcomes which reflects on the PiR experiences and learnings from its first three years. With respect to the issue of rights and advocacy, Lynne Coulson Barr, the Victorian Mental Health Complaints Commissioner, provides an overview of this role and the way it contributes to the aims of the new Mental Health Act to protect the rights and dignity of people experiencing mental illness, and place them at the centre of their treatment and care.

Finally in our vox pop for this edition we ask 'What is co-design really and what opportunities does it offer?'

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

I hope you enjoy reading this edition, and that it whets your appetite for the Towards Recovery conference, which is shaping up to provide wide ranging presentations and valuable discussions on all our key themes.

### VICSERV'S MENTAL HEALTH CONFERENCE

HOPE | INNOVATION | CO-DESIGN

### REGISTRATIONS OPEN NOW

### 19-20 MAY 2016

Melbourne Convention and Exhibition Centre



**Psychiatric Disability Services** of Victoria (VICSERV)

### The biennial VICSERV conference sets the standard for Australian mental health conferences providing challenging content, provocative speakers and leadingedge thinking.

The conference marks our 30th year and will provide an opportunity to come together to showcase the latest research, share best practice, review industry trends and consider the future of mental health services within the context of an ever changing environment. The program will centre on key concepts such as innovation, coproduction, hope and recovery, peer leadership and empowerment.

Issues such as the impact and opportunities in the NDIS, the Victorian Government's vision and implications of its 10 year mental health strategy, consumer choice and control and the carer experience will form the backbone of the 2016 conference.

### **Keynote speakers**



### **Dr Simon Duffy (UK)** Director of the Centre for Welfare Reform

Simon is recognised as a leading international thinker on the philosophies of co-design, individualisation and peer involvement. He is a social innovator who works to improve the welfare state. He is a regular public speaker, consultant and international government policy advisor.

The Centre for Welfare Reform is an independent think tank and research centre which shares and develops social innovations to promote human rights and equal citizenship for all.

Simon will share his philosophy on citizenship and empowerment and how they form the basis of a powerful argument to include people in planning their own recovery as well as the services they access.



### Professor Mark Salzer (USA)

Professor Mark Salzer Ph.D. is Chair of the Department of Rehabilitation Sciences at Temple University. He is the Principal Investigator and Director of the Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities, a research and training centre funded by the National Institute on Disability and Rehabilitation Research (NIDRR).

He will focus on the importance of inclusion and participation as key to recovery and wellness and strategies that support and grow the inclusion of people with mental illness in their communities.

### **Master of Ceremonies**



Peter Mares

Journalist, social commentator and researcher.

For more information visit conference.vicserv.org.au or email conference@vicserv.org.au

### **TOWARDS RECOVERY**

Hope, innovation and co-design

### 'I feel like a real person and not a diagnosis': the Mind Recovery College, a new space for discourse and working together for recovery



Dianne Hardy is Director of the Mind Recovery College

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Individuals and organisations are searching for new and better ways to aid mental health recovery. This search has led to the increased involvement of peer workers in various areas of the mental health system and also to the emergence of recovery colleges. This article shares some information about Mind Australia's Mind Recovery College, particularly its experiences with co-production.

Established in 2013, the Mind Recovery College was the first recovery college in Australia. It operates on the basis of two ideas: that valuable knowledge and skills can be gained from first-hand experience of mental distress and that learning can aid people to recover a life they value. The College's co-production approach means that people with personal experience of mental distress are involved in the design and delivery of courses and the running of the College, as well as participating in its activities (Mind Australia, 2012).

The College began offering courses in 2013 and now offers over 50 different courses across seven campuses in Victoria and South Australia. The majority of these are run by people with lived experience of mental ill-health (46 per cent have personal experience and 11 per cent are carers or family). Examples of the many topics that are covered are:

- What is recovery?
- Understanding self-harm
- Medications
- Developing your own advance statement
- Confident me.

A full course guide can be viewed at the College's website www.recoverycollege.org.au.

The College provides a complementary alternative to existing case management approaches while being a practical vehicle for cooperation between individuals, services and the community. Everyone is welcome to attend courses and no one is asked to provide information about their diagnosis. Students describe the College as being different and 'real', and the following quotes from consumers and carers demonstrate its value:

'I found it ground breaking and proactive to consumers' needs.'

'I've used services for 10 years, and this is something really different.'

'I'm learning a bit more about my triggers towards how I'm thinking, and I'm learning that so many other people are feeling the same way that I do.'

'I usually struggle in groups, but I'm really comfortable. I am getting a lot out of this.'

'After this course, I feel like a real person and not a diagnosis.'

The College is role-modelling a consumer-choice culture where power is shared, first-hand knowledge is valued alongside other forms of evidence-based information, and consumers and carers feel themselves to be - and are - an integral part of the College's operation.

### 'I usually struggle in groups, but I'm really comfortable. I am getting a lot out of this.'

### Co-production is the key

The co-production of college activities is at the core of a model that gathers together the expertise of people with lived experience of their own and/or others' recovery. The model also includes people with professional expertise in mental health and education. Bringing such people together and believing that individuals' lived experience results in knowledge that is as valid as professional expertise allows innovative and responsive courses and programs to be developed. These differ from existing psycho-education courses and curricula in that they are co-delivered by people with a lived experience, are facilitated rather than didactic, and are grounded in practical experience. In this way, courses and other learning opportunities offer new strategies for assisting people to manage their mental ill-health and improve their social and economic participation.

### Four Pillars of co-production

Four pillars guide our approach to co-production, a process that is by definition fluid and experimental. It has the capacity to transform 'business as usual' for mental health services that are in search of better ways of doing things. If it didn't, it wouldn't be worth the effort.

The Four Pillars offer a useful reference point for determining whether any particular experiment in co-production is in keeping with the Mind Recovery College model. See the table below:

Pillar	Application to co-production
I. We are all people.	Co-production brings together people who have used mental health services, their families and carers, and mental health professionals. The process design helps people to step away from their roles, which is important as these roles can become fixed in a way that discourages an open exchange of ideas. The relationship between those involved is collegial, not a service provision relationship. We must all engage in the process as people first and foremost.
2. Living is learning.	Life experience is the most important form of knowledge at the College, although other forms of evidence-based knowledge are important too. Virtually everyone has some relevant experience of distress, and of supporting others through distress. Therefore, all those involved in the co-production process are invited to share and draw on their 'messy' life experiences.
3. Many heads are better than one.	When it comes to mental health, no one has all the answers. We invite as many people into the co-production process as we need to ensure that any given course is as useful as it can be. For sensitive or complex issues, more than one co-production workshop, with different participants each time, can be used to ensure that issues emerge and that there is confidence in the co-production outcomes.
4. Growth happens outside our comfort zone.	We ask individuals involved in the co-production process to engage with the topic of mental health in new ways, which often stretches their comfort zone. We ask first-time teachers to do something scary and new, and to work to develop their skills with our help. At a service level, co-production asks Mind and other providers to engage with different ways of thinking about mental health, some of which may challenge individuals' beliefs and assumptions.

newparadigm Autumn 2016 Psychiatric Disability Services of Victoria (VICSERV) The Mind Recovery College, a new space for discourse and working together for recovery by Dianne Hardy

# The relationship between those involved is collegial; it is not a service provision relationship. We must all engage in the process as people first and foremost.

### **Reflections on co-production at the College**

The Mind Recovery College is relatively young. It is experimenting and developing ways of working, including co-producing. However, a lot has been learnt already and it is clear that co-production provides exciting benefits and opportunities such as:

#### · Tailored and valuable courses and other learning opportunities

Feedback from students at the College confirms that it works to utilise the practical knowledge and skills of people with first-hand experience of mental distress to design and co-deliver courses: it results in high-quality courses that make sense and offer value for students.

#### Use of Anecdote Circles as an effective tool

Outside of the therapeutic arena, there is a wide range of group facilitation techniques that help people share, find meaning, identify preferred directions and solve problems together.

Narrative techniques such as Anecdote Circles (Callahan 2007, Cognitive Edge 2016) fall into this category, and the College has found them to be very effective. Facilitators encourage participants to share short stories focussed on responses to one or two targeted questions, bringing forward knowledge that is relevant to a given topic. This process prompts the inclusion of information that might not have emerged in another way. The technique allows content to be captured and grouped into themes that guide course design. Sometimes stories can also provide case studies or other content for learning. New teachers often emerge from these workshops.

### Increasing personal learning and sense of self-worth by helping others

The College is a welcoming and inclusive service model, and this is important in enabling people to find the confidence to come along and participate. Involvement in the College helps people to find connection and support from others in their community. Something very powerful happens when people come together for the purpose of sharing their knowledge and experience to produce something of value for others. This is particularly evident in co-production workshops, where between 10 and 20 participants are involved, usually for two to three hours. Participants often demonstrate the ability to discuss very personal and emotional experiences while retaining their cognitive ability to talk about the links to what might be important in course design. Being able to simultaneously engage with emotional and cognitive functions provides the opportunity for reflection and understanding. This is especially true in an environment where individuals are able to hear the experiences and thoughts of others who have similar challenges in their recovery.

Experiencing the acceptance, interest and value that others place on your ideas emphatically and insistently challenges the feelings of worthlessness that are commonly associated with mental distress.

### A new space for discourse to increase understanding and find better ways

One of the important benefits of the College model is that it provides a new space for discourse about mental health topics and issues between people with mental ill-health, family, carers, health professionals and a variety of other community members. This is a different space as it is outside the therapeutic settings where these matters are usually discussed. The focus is on understanding aspects of mental health that individuals can then draw on for managing their own health or helping others. This contrasts with a therapeutic search for what is wrong with an individual and finding ways to 'fix' them.

The exploration of effective ways to co-produce courses is a continuing journey. To date, co-production workshops using narrative techniques to facilitate story-sharing and the capture and utilisation of knowledge for course development have been particularly effective.

### Still exploring together

Recovery colleges are relatively new – even the most established colleges in the United States and United Kingdom have only been operating for around 10 years or less (Perkins et al., 2012). While there isn't much empirical research yet about their impact, anecdotal evidence has led to the emergence of recovery colleges in many countries.

The Mind Recovery College adds another option to the mix of therapeutic and other approaches to helping individuals with mental ill-health in Australia. In all aspects it is designed to place choice and control firmly with students so that they can better manage living with ill-health and help others to do the same. The plan is to keep exploring and experimenting with co-production and partnerships. The College is a model that fosters innovation and makes it easy for people to work together for stronger and more heartening recovery. It offers learnings and opportunities for partnering to transform experiences in the mental health system.

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### A changing world: Primary Health Networks and the redesign of the Victorian Mental Health Service System

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Associate Professor Chris Carter is Chief Executive Officer of the North Western Melbourne PHN Lyn Morgain is Chief Executive of cohealth

This paper explores some of the significant changes occurring in the service system for mental health, and identifies some of the relevant opportunities and considerations. It has a specific focus on how to establish shared principles around collaboration, transparency and evidence-based practice to support the realisation of benefits to consumers.

### **Background to the changes**

Primary Health Networks (PHNs) have been established by the Federal Government to:

- increase the efficiency and effectiveness of medical services for consumers, particularly those at risk of poor health outcomes
- improve coordination of care to ensure patients receive the right care in the right place at the right time (Department of Health, 2016).

PHNs became operational in July 2015. There are 31 PHNs covering the whole of Australia (including six in Victoria), replacing the previous 61 Medicare Locals. PHNs can be described as meso-level primary health care organisations.

cohealth is a community health support organisation with longstanding experience of providing community mental health services within the catchment of the North West Melbourne PHN (NWMPHN). cohealth has an explicit commitment to undertake advocacy in the interest of people who experience mental health and may need to access community-based services. NWMPHN and cohealth therefore share an interest in, and commitment to, the development of a coherent and effective service system in Melbourne's north and west.

### Mental health and the role of PHNs

There have been a number of recent announcements which have considerably expanded the scope of PHNs in community mental health and suicide prevention. Under new arrangements, Commonwealth funding that was previously provided to directly support the delivery of community-based mental health and suicide prevention will be allocated to PHNs to commission services.

The commissioning model emphasises the importance of identifying priority needs, funding evidence-based solutions and monitoring performance and achievement to drive ongoing investment decisions.

These changes have been made as a result of the Commonwealth Government's response to the Review of Mental Health Programmes and Services. Funding, which totals approximately \$350 million per year, has been redirected from a number of existing programs into regional funding pools. There is no new funding. A changing world: Primary Health Networks and the redesign of the Victorian Mental Health Service System By Associate Professor Chris Carter and Lyn Morgain

### The existing programs are:

- Access To Allied Psychological Services (ATAPS)
- Mental Health Nurse Incentive Program (MHNIP)
- suicide prevention programs
- headspace centres and other early psychosis programs.

The Partners in Recovery (PiR) program, Personal Helpers & Mentors (PHaMs) and the Day to Day Living (D2DL) program will transition to the National Disability Insurance Scheme (NDIS).

cohealth is one of many organisations that currently receives funding under the Commonwealth-funded mental health programs (D2DL, PHaMs, MHNIP, ATAPS). It is obviously of great importance to our organisation that the service system changes and evolves in a way that meets the needs of current and future service users.

### Policy trends in primary and mental health care

In addition to these immediate changes there are a range of other trends influencing approaches to the design and delivery of service systems in Australia. Responding to these new directions requires multiple partners to reframe their role within a new system.

A major shift is the trend towards consumer-directed care, which provides consumers with choice and control about how the resources allocated to them are spent. In a consumer-directed care model, resources follow the consumer in a joined-up system.

Another trend is a move towards integrated models of care. Fragmentation of care between community and acute health care settings is a key concern in north western Melbourne, which has a complex service system. This emphasises the importance of integrated care that is patient-centred, seamless across health care settings, and well supported by systems to support sharing information.

The Royal Australian College of General Practitioners (RACGP) has published its 'Vision for general practice and a sustainable healthcare system' (RACGP, 2015) that describes an approach to reforming health care which is based on the Patient Centred Medical Home model. This model introduces the concept of accountable care, where a single provider or group of providers (usually general practice) becomes the central coordination point for a client, and accepts a level of accountability for their outcomes. Fragmentation of care between community and acute health care settings is a key concern in north western Melbourne, which has a complex service system.

Similarly, there is currently a strong focus on evidence-based interventions and building a performance and outcomes focus.

Importantly, there is also an appetite for changed approaches to financing health and social care which recognises that the Australian system is one in which funding is generally associated with activities rather than outcomes. The new approaches being developed may include pooling funds and capitation – in which funding is aligned more closely with value and less with volume. Broadly these changes are aimed at delivering:

- better targeting and price control especially in relation to the uncapped Medicare Benefits Scheme (MBS)
- removal of program silos and fragmentation
- improved performance and monitoring at the local level
- social and community service integration.

There is no question that these changes will require considerable development on the part of current service provider organisations. As funding arrangements shift over time away from block funding models, provider organisations will need to:

- respond to a performance-oriented, activity-based, capitated environment
- develop a good understanding of cost of care at an individual level
- demonstrate evidence-based performance on outcomes.

There are other emerging trends in funding and financing, including impact investment models such as Social Impact Bonds.

In an ideal state, commissioning is heavily informed by consumers and the community, who can play a critical role in setting priorities, identifying desired outcomes, designing solutions and informing evaluation.

These models can provide an opportunity for non-traditional funders to invest in social and health improvements, and importantly have a clear focus on funding outcomes rather than activity.

### PHNs and commissioning

PHNs will operate as commissioning agencies, and will not have a role in direct service delivery unless there is a clear case of market failure. cohealth and a range of organisations will form part of a broad 'market' which can potentially provide the programs and services PHNs identify as priorities. At times, this will involve participating in competitive processes to identify preferred providers. NWMPHN has a strong commitment to, wherever possible and appropriate, engaging with the provider market through the commissioning cycle, including in the identification and prioritisation of need, and in the co-design of solutions. To this end NWMPHN is aiming to work with a diverse range of organisations, consumers and interest groups across the service system.

It is likely, and even desirable, that a commissioning approach will change the service delivery and market landscape over time. However, NWMPHN is also acutely aware of the possibility of instituting changes which have adverse, unexpected and irreversible impacts on health and social service markets, and is therefore committed to taking a phased rather than transformative approach to change. A phased, highly collaborative approach reflects international evidence about commissioning, and is consistent with clear feedback from the market about the need to take a considered approach.

In an ideal state, commissioning is heavily informed by consumers and the community, who can play a critical role in setting priorities, identifying desired outcomes, designing solutions and informing evaluation. Achieving meaningful engagement of consumers in the commissioning model will require:

- a thoughtful and nuanced approach to current existing processes for engagement of consumers
- understanding the means by which these are presently resourced
- an explicit respect for the role of consumers in service improvement and system redesign.

Identifying opportunities to build on the current, authentic relationships between existing trusted service providers will need to form part of the analysis of the current system and solution design. These relationships can also provide insight into the potential impact of any changes to service users.

#### The collaboration imperative

Taken together, the impact on service delivery relationships, changes to experience of consumers and range of interests across the system, underscore the necessity and importance of collaboration in achieving system reform.

cohealth has strong existing links and established relationships with NWMPHN, most notably through the Inner North West Melbourne Collaborative (NWMPHN, 2016). The Collaborative was established in 2012, and includes Merri Health and Melbourne Health as core partners. The Collaborative aims to:

- ensure a coordinated approach to service planning and delivery across our shared catchment, prioritising service gaps and challenges together
- · develop agreed common, seamless and complementary pathways
- work collaboratively to deliver more care in the primary care setting
- develop new ways of working together in partnership to improve patient care, access, outcomes and pathways



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Identifying opportunities to build on the current, authentic relationships between existing trusted service providers will need to form part of the analysis of the current system and solution design.

• create opportunities for our people to share resources, ideas, knowledge and experience to improve care through partnerships at the frontline.

The Collaborative is operationalised at multiple levels including regular meetings of chief executives and work on specific joint projects, in areas such as Advanced Care Planning and eHealth.

The Collaborative is one example of sector engagement that the NWMPHN is involved in and likely to draw on as it transitions to a commissioning model. It demonstrates a commitment to collaborative ways of working to bring about system improvement.

Steps have also been taken to move toward a more collaborative approach to system planning, including establishment of a partnership between NWMPHN and the Victorian Department of Health and Human Services regional office to support more streamlined and integrated population health planning. This is likely to be welcomed by other players across the system keen to avoid duplication and maximise opportunities for genuinely open and transparent system redesign in the interests of consumers.

### In summary

Implementation of the PHN program and the transition to meso-level commissioning provides an exciting opportunity to leverage the existing skills, insights and passion within the north western Melbourne service system to achieve genuine outcomes-focussed change.

Taken together, the impact on service delivery relationships, changes to experience of consumers and range of interests across the system, underscore the necessity and importance of collaboration in achieving system reform.

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# Recovery from a carer perspective



Rachael Lovelock is Consultant, Carer Leadership and Advocacy, MI Fellowship

### The concept of recovery is not a new one.

In 1993, Professor William Anthony, Director of the Boston Center for Psychiatric Rehabilitation, defined recovery as:

'a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness'.

Recently, it has also become popular to consider the recovery process as a 'journey'.

In this article, I will look at recovery from a carer's perspective, exploring how people become 'carers', the concept of recovery as it relates to carers, the similarities between the mental health consumer and carer recovery journeys, and my hope that carers can come to be viewed as being on a parallel journey of recovery to their loved one. I argue that the CHIME (Connectedness, Hope, Identity, Meaningful life and Empowerment) model employed by many mental health consumers is an effective framework from which practitioners can support carers on their own recovery journey.

### No-one is born a carer or consumer

Mental health challenges have a disruptive effect on identity. Before these challenges arrive, a person's identity is built on their concept of life's pathway and the supportive and mutual relationships they have with others. Parents guide a child's identity development and the necessary movement towards individuation. As young adults, we dream of the future and what might lay in front of us. In intimate relationships, our hopes and dreams are mutually developed alongside each person's unique journey. No one was born a carer. The role of 'carer', for many families and friends, is thrust upon them for the first time by crisis, often in a clinical or emergency setting. A family's first experience of mental health challenges is most often confusing, traumatic and emotional. At a moment's notice, the previously supportive and mutual relationship is turned on its head and a uni-directional 'caring role' is often thrust in its place. In a similar manner, the role of 'consumer' is often thrust upon the person who has become unwell.

In the early stages of 'illness', carers, as they find themselves now called, are often overwhelmed, confused, and fearful. They report having a lack of understanding of mental health challenges and the situation that they now find themselves in. Lacking in knowledge and wanting their loved one to be better, carers often find themselves aligning with 'professionals' who appear to offer solutions. This dynamic often fractures the relationship between 'carer' and now 'consumer', further shattering the individuality and mutuality of their previous relationship. Ultimately this situation doesn't support the recovery journey.

Lacking in knowledge and wanting their loved one to be better, carers often find themselves aligning with 'professionals' who appear to offer solutions.  newparadigm Autumn 2016
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Recovery from a carer perspective by Rachael Lovelock

At a moment's notice, the previously supportive and mutual relationship is turned on its head and a uni-directional 'caring role' is often thrust in its place. In a similar manner, the role of 'consumer' is often thrust upon the person who has become unwell.

### Profound impacts of a changing role

The experience and episodic nature of mental health challenges within a service system that reinforces the roles of 'carers' and 'consumers' can result in a carer's individual identity being subsumed by the caring role. As their loved one begins to move forward on their recovery journey, again seeking independence and freedom of choice, tension can develop if relapse occurs and caring roles are re-applied. In these circumstances, neither the consumer nor carer can break free of their enmeshed relationship. At the same time, carers often struggle to find systems of support and are left feeling powerless and stuck.

The pressures and demands of the caring role directly impact on a person's identity and life journey. The hopes, dreams and aspirations of carers often play a secondary role. Feedback from the Well Ways Family Peer Education Programs run by MI Fellowship illustrates that family members in ongoing caring roles are personally impacted by grief and loss, poor emotional and physical health, financial concerns and stigma.

'Tired, depressed, not coping, and going under. I spend a lot of time in bed sleeping. I try to keep going to art group to get out of the house and whilst this is hard work it almost always makes me feel better.'

'The caring role has impacted on my health. At times the stress and lack of sleep brings on a migraine and this then takes about a week to recover from. Being tired all the time impacts on everyday life, restricting my capacity to maintain a healthy mental and physical lifestyle.'

Over time, the roll-on effects of the caring role include social isolation, loss of friendship, community disconnection and unemployment. These impacts can also have devastating repercussions on the relationship between the carer and the person affected by mental health challenges. Carers often say that the caring 'role' puts their life on hold, keeps them stagnant, and results in grief for the 'parent' or 'partner' connection to their loved one. The deterioration of the mutuality in relationships can obscure a view of the potential and hope that 'recovery' can offer for all. There's a great need for carers to maintain these aspects of life, their identity and personal journey.

However, while there are many adverse effects of the caring role, many carers deeply value their life experiences and welcome an opportunity to reflect on their values, ideas and beliefs. These reflections can significantly contribute to the core of who they are and what they have learnt about themselves, others and what is possible.

### A model that rings true for carers as well

The CHIME recovery model (Leamy et al, 2011) offers guidance on establishing environments and relationships that can affirm and support recovery. The model identifies the five key areas of Connectedness, Hope, Identity, Meaningful life and Empowerment. It empowers people to take the steps towards having the life they choose, to rebuild a sense of who they are and what is important to them.

Arguably this model can also be applied to carers. As has been presented so far in this article, the experiences of consumers and carers can parallel each other, with each experiencing disconnection, loss of hope, loss of identity, disruption of the meaning in their lives, and disempowerment. In so saying, it is important to acknowledge that, while these experiences are similar, they are also profoundly different.

It is important that carers are supported in a recovery-oriented manner, focussing on the caring journey as separate but also parallel to their loved one's journey. Supporting carers to identify with their own journey and reconnect to wellness and a 'good life' is likely to deepen the understanding of their loved one's experiences, as well as their own strategies for moving towards recovery.

In the context of 'towards recovery' I encourage services to deeply understand and support the experience of carers. And, with the implementation of the National Disability Insurance Scheme (NDIS) upon us, I strongly urge Commonwealth and State funding bodies to retain explicit funding to support carers to move towards their own recovery, and for services to be innovative in their service design. Services should consider the use of CHIME in the development of individual support for carers and integrate the use of outcomes tools such as 'Carers Star' (Triangle, Outcomes Star) (developed in the UK for supporting and measuring change when working with people) to assist carers on their journey to a 'good life' for all.

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# The goal is Citizenship not the NDIS

Psychiatric Disability Services of Victoria (VICSERV)



Kate Fulton is a Development Consultant with the National Disability Insurance Agency.

As the National Disability Insurance Scheme (NDIS) begins its roll-out beyond the initial trial sites, this article explores what support providers should be considering about their role to ensure that change actually delivers better outcomes for those who will access support through the NDIS.

Australian health and community services are currently undergoing one of the biggest and most significant changes in their history, with the development of the NDIS. Promising 'is the insurance that gives us all peace of mind' (National Disability Insurance Scheme n.d), the scheme aims to increase the social and economic independence of people with a disability and enable full participation in community life.

The NDIS is built on a movement that was led by people and families arguing for better and fairer access to services, including greater control over resources. The movement culminated in the national public campaign, *Every Australian Counts*, which highlighted the need for people with a disability to be included and given a fair go and with the creation of a national scheme that offers fairness, transparency and equity. *Every Australian Counts* was supported by people with a disability, families and service providers, tapping into the collective consciousness of wider society about inclusion.

The movement was consistent with international campaigns for more choice, control and autonomy to assist people to be active citizens in their local communities, as supported by the United Nations Convention on the Rights of Persons with Disabilities.

Alongside this, slightly different in its fabric but fundamentally similar in its principles, we have also seen the development of the international movement of recovery. Essentially this demands that people with experience of mental illness themselves need to be the co-creators of their support strategies and in control of their lives now and into the future. We know that recovery is maximised when people and families are in control, have real choice in accessing the right supports and can tailor this support in a way that makes sense to their lives and connects them to their communities.

The NDIS is a mechanism. At its simplest, it offers a process of individual planning and recourse allocation, which assists people to understand their budget and secure their support locally. Simple and, when kept simple, beautiful!

However, if we are genuinely supporting people to live meaningful lives, able to contribute economically and as an active citizen in their local community, I have learnt it takes more than an individual plan and an individual resource allocation. I believe that the success of the NDIS not only sits in the hands of people and families, but also in the creativity of service providers.

### Are we simple suppliers?

The NDIS is built on the principles of market economics: demand will drive supply. The National Disability Insurance Agency (NDIA), the independent statutory agency whose role is to implement the NDIS, has taken the role of regulator and market shaper – facilitating and regulating the costs of the 'products' in local communities.

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## I believe that the success of the NDIS not only sits in the hands of people and families, but also in the creativity of service providers.

The 'products' are driven by an essential component of the NDIS, the NDIA Price Guide. This is a catalogue of human service strategies or service interventions considered to be useful.

This catalogue offers the scheme a simple mechanism to identify the cost of each strategy that individuals may require to achieve their outcomes. This is not in itself bad: it can be seen as a transparent pricing mechanism or a transparent resource allocation process.

However, the catalogue offers line items that are not necessarily contemporary or individually tailored. It's unlikely that a catalogue can ever offer individually tailored items. By its very nature, it can only ever offer a standard product that needs to be further developed in partnership with people and families.

For example, a person seeking support to explore friendships and support for household budgeting may be offered 'visiting support' in the catalogue – however for this to really work well for the individual, this needs to be individually tailored. With this mindset we are in danger of replicating a fundamental error that we saw in the United Kingdom in the early days of Personalisation – the process, outlined in the UK Government's 2007 paper 'Putting People First', by which people with long-term illnesses or conditions received support that was tailored to their individual needs and wishes. After the first three to four years of offering individual 'personalised' budgets, people and families began to report the benefit of having an individual allocation. However, they also began to share their disappointment about what was available to buy, with service providers continuing to provide the same things that hadn't worked for people for many years (Crosby and Fulton, 2007).

For example, many UK participants were being placed in hostel or group living supports, despite these models previously not working in their experience. However, this was the prevalent model of support to purchase in the early days of self-directed support.

My experience of working alongside people and families over the last 20 years has clarified one fundamental principle: people and families do not want simple standard supply.

My experience of working alongside people and families over the last 20 years has clarified one fundamental principle: people and families do not want simple standard supply. They want individually tailored, co-designed supports that make sense for them in their own context, in their own communities and in ways that build their own capacity and connection.

Many tell me they want their supports with a partner of their choice, in a relationship that is respectful, and in the hope that this partnership will evolve flexibly over time. This way of thinking is not new – however in our new context we are in danger of losing sight of the lessons that people and families have taught us over many years.

Many service providers are simply supplying line items: 'what's on the plan is what we deliver'. The NDIA recognises the need for flexibility and has created line item flexibility in its catalogues, but this will not in itself change the reality for people and families. Poor system design can significantly impact on the real outcomes for people and families and we need to be mindful of how we counteract this to create good solutions.

Providers are central to this change. Providers must remember that people and families are not looking for simple suppliers. They are looking for partners who will work with them to co-design their supports and then deliver this design flexibly and in a way that evolves over time.

This will take creativity and the development of relationships between people and providers; respecting the person as not only the customer with the money, but the designer and leader in how this partnership needs to look. Providers must remember that people and families are not looking for simple suppliers. They are looking for partners who will work with them to co-design their supports and then deliver this design flexibly and in way that evolves over time.

### Our business is supporting Citizenship

Under the NDIS, as elsewhere, we are living with the very real tension of balancing consumerism and social justice. Although this tension is not unfamiliar, the power of consumerism is ever increasing.

Balancing our business requirements with our foundational purpose is an art we need to develop quickly in our leadership and in our workforce. As the NDIS rolls out across Australia, the temptation to get swept away in the mechanics of the scheme and its development is immense and potentially a great distraction from the real work. Have we already bought into the notion that we are simple suppliers who deliver line items? Or are we Community Development organisations whose aim is to support local citizens in their local communities?

I believe with all of its benefits and flaws the NDIS can be a catalyst for service providers to support the active and full citizenship of people. Acknowledging the resources people have via the NDIS is the starting point to then design supports in partnership with people and families that assist people to:

- find their sense of **purpose**
- have the **freedom** and support to pursue it
- have enough money to be free
- have a home where they belong
- get **help** from others they choose
- make a life in the **community**
- find love and relationships that matter.

The elements of Citizenship, as described above by Simon Duffy (The Centre for Welfare Reform, 2006), help us to understand what a full and meaningful life may look like. This cannot possibly be delivered by the NDIS alone.

Avivo in Western Australia is an organisation that is working hard to challenge the concept of 'supply' having developed an approach of flexible management. This has the explicit aim of developing capacity in the individual and their family to direct and manage their supports in partnership with the organisation. This approach is about assisting the person to take on the level of responsibility that is right for them today, whilst learning to become an employer and decision maker in the future. Flexible management offers at least three options to people who choose to work in partnership with Avivo. People can choose to manage their supports themselves, using Avivo as an advisor in the recruitment process and ongoing problem solving. People can choose either for Avivo to manage their supports on their behalf, or for shared management of supports. This approach works to invest in people as the Director of their support system.

In supporting organisations that have freed themselves from the Provider paradigm and work towards a Community Development context, there are some fundamental business structures that impact on good quality support in our current context.

#### These include:

**Promoting an understanding of Citizenship across the organisation**. Potential partners should be assisted to understand their role, to move from paternalism to partnership. There needs to be an understanding that the people who use the services, not those who work in the system, are the experts of their own lives. Through working in partnership with people and families, we can offer some expertise in navigating the system and exploring solutions.

**Co-design, co-production or simply working together?** For all levels of the service provider, people and families are the best advisors who provide access to a wealth of knowledge about what future supports need to look like and what is likely to make a difference. This will be the future demand.

Facilitating and supporting peer support. The benefits of connecting citizens to each other who are facing similar situations are well documented. Any service provider focussed on supporting Citizenship must work in a way that promotes peer to peer connection.

Accountability. Whilst partnership is the foundation of our future practice, we are now working in a context where service providers are accountable to the person. This includes ensuring what was agreed upfront is what actually happens. This is the fundamental basis for people to really direct their own recovery. Accountability offers so much strength to people and families, knowing that if this partnership is not working in the way they had hoped, there is plenty of opportunity to go elsewhere.

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**Creativity.** The need for organisations to be creative is so important. For many people, a lifetime of traditional supports is evidence that more of the same will have minimal positive results. Creative solutions require the confidence to postpone certainty and the need to really understand the person and what they see as important. This in itself takes a different level of courage and integrity in how we work alongside people.

We are the early days of understanding the NDIS and its implications, but we are not alone in this experience. There is much to learn from our international allies in what works and what doesn't. Experience has taught us that if we don't keep our eye on the fundamental aim, then we continue to do what we have always done around the system changes.

Doing the same thing in a new context is guaranteed failure with minimal positive change for people and families. Community services have an opportunity to respond to the new context as allies and partners of people whose lives literally depend upon it. Community services will play a vital role going forward – the challenge is here and now. Doing the same thing in a new context is guaranteed failure with minimal positive change for people and families.

Kate Fulton is a Development Consultant with the Centre for Welfare Reform in the United Kingdom, who worked to support local government and the community service sector to implement early trials of Self Directed Support across the UK. Kate has been based in Australia for three years, working with the National Disability Insurance Agency to support service providers to respond to this significant sector transformation. Kate qualified as a Mental Health Social Worker.

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### Walk alongside – Co-designing social initiatives with people experiencing vulnerabilities

The following is an excerpt from: Victorian Council of Social Service, Walk Alongside: Co-designing social initiatives with people experiencing vulnerabilities, VCOSS, July 2015.

## Co-design begins with the people – their experiences, perspectives, values, challenges and understandings.

### Introduction to co-design and 'ground-up' solutions

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Co-design involves coming alongside people who experience vulnerabilities, to work with them in creating interventions, services and programs which will work in the context of their lives, and will reflect their own values and goals. This involves letting go of professional assumptions about a group's perspectives and experiences and actively learning from what people say and do. Expertise, professional knowledge and research can then be considered in relation to group input, to add colour to the possibilities of approaching social problems with specific groups. This is different from traditional feedback methods which ask user groups to comment on their use and satisfaction of services that have already been planned or implemented. Co-design begins with the people – their experiences, perspectives, values, challenges and understandings.

### Looking beyond vulnerability: Challenging professionalism and the way we work with people experiencing vulnerabilities

Co-design changes the way practitioners conceptualise and approach *vulnerability* in the pursuit of social change. In many cases, identifying someone as 'vulnerable' leads us to focus on their weaknesses and the need to protect them from possible harm. This intention is important and is rightly reflected in ethical protocols and guidelines for working with groups identified as vulnerable. However, an overemphasis on vulnerability may underestimate the degree to which people can determine visions for their own wellbeing and participate in decision-making processes.

This point is largely canvassed in research concerning youth participation in policy and program development (Daley, 2015; Newman, 2005). Young people occupy a precarious position in

society, where they have reached a level of physical and cognitive maturity but do not enjoy the breadth of social freedoms afforded to adults. These 'inbetweeners' are considered vulnerable due to their limited worldly experience, psychological development, predisposition for risk-taking behaviour and lack of material resources. The status is heightened when they are impacted by adverse circumstances or trauma, such as a natural disaster, mental health concern, or dysfunctional family environment. The need to protect young people from further risk, and a concern for triggering adverse psychological reactions, can prevent decision-makers from deeply engaging with them about their worldview (Daley, 2015). This may result in policies or interventions being informed by broad risk factors, such as the common age a young person first uses an illicit substance, rather than contextual information, such as the immediate environment which conduces first use (Daley, 2015).

Focussing on vulnerability can also undermine resilience and capacities. Internationally, young people who have been affected by crises demonstrate a strong capacity for managing risk, employing coping strategies, and actively influencing their environment to direct personal outcomes (Newman, 2005). Despite this, young people affected by war are often represented by aid agencies as helpless victims, leading to erroneous priorities in their support. For example, young people often choose to separate from their families in order to find employment or increase their chances of survival. Aid agencies, however, prioritise efforts to reunite families, creating a support gap for young people aiming to become self-sufficient (Newman, 2005). It is important that young people, and other groups experiencing vulnerabilities, are able to speak for their own needs and values.

Many people who have experienced profound trauma and disadvantage have demonstrated significant resilience and skill which needs to be recognised and respected in engagement initiatives. 2 newparadigm Autumn 2016 Psychiatric Disability Services of Victoria (VICSERV)

Walk alongside – Co-designing social initiatives with people experiencing vulnerabilities

An overemphasis on vulnerability may underestimate the degree to which people can determine visions for their own wellbeing and participate in decision-making processes.

This includes people who are homeless and use strategies to protect themselves on the streets, children who have taken on caring responsibilities, and individuals who experience chronic mental illness. Working from a dominant assumption of vulnerability (Daley, 2015), rather than capacity, can underestimate the contribution people can make in offering insight, sharing ideas and determining the best outcomes for their lives. In collaborative work, this can result in a paternalistic approach which constrains open communication, resulting in 'tokenistic' partnerships which reinforce the assumptions and ideas of professionals without giving critical weight to the insight of people impacted by social problems. Looking beyond vulnerability to see capacity is critical for working alongside people to promote positive change in co-design. It enables facilitators to remain open, responsive and respectful of their perspectives and living realities.

### Practice in focus: Providing better support for Aboriginal families

The Australian Centre for Social Innovation (TACSI), with the support of the South Australian Government, wanted to find out why family support services weren't working for Aboriginal families in the northern suburbs of Adelaide (The Australian Centre for Social Innovation, 2013). They began with the question, *'How can services enable sustainable change for Aboriginal families?'* To find the answer, they spent time with Aboriginal families as they went about their normal lives, doing the shopping, visiting the playground, and spending time in their homes. They recruited participants through service referrals, but they also wanted to talk to people who were not involved in existing programs. To do this, they set up a stall at the Playford Family Fun Day to meet new families. The team also spent time with staff from 15 different service providers in areas such as Child Protection and Home Visiting Programs (The Australian Centre for Social Innovation, 2013).

A major insight from this process was how the concept of *cultural* appropriateness had become a barrier for staff to having genuine and tough conversations with Aboriginal people, for fear they would say something that appeared racist or insensitive. This was described by one Aboriginal community member as 'tip-toeing around'

(The Australian Centre for Social Innovation, 2013) the real issues faced by families. Cultural appropriateness had also come to represent the expectation of lower service outcomes for Aboriginal families than for non-Aboriginal families. Staff were conscious of the long history of discrimination and injury experienced by Aboriginal people, which made progressive change feel 'too hard' or unrealistic. Though practitioners did not have ill intentions, their assumptions about their clients' vulnerability prevented them from asking questions and engaging with them in open dialogue. Staff also generalised broad lessons from 'Cultural Awareness Training Days' and were hesitant to talk directly to families about what culture meant to them. As a result, Aboriginal people were frustrated that they were not being understood. They experienced and expressed culture in different ways and they wanted to see real change happen for their families.

Through their work, TACSI identified four shifts which needed to occur in order for services to create progress for Aboriginal families in the Playford area. Services needed to shift:

- from being 'culturally appropriate' to being 'culturally adaptive,' where staff are flexible and responsive to what is important to different families
- from expecting too little to expecting change, where staff are driven to see significant progress through their work
- 3. from seeing families as recipients of services to seeing families as a resource, where organisations support families' capacity to multiply change through their own social networks
- 4. from focussing on getting by to focussing on goals, where staff seek to understand unique family objectives and measure progress along the way.

This example demonstrates how co-design can help facilitators understand the root cause of discord and maladaptive practice, and discern barriers they unknowingly create for social change. The required shifts also reflect the change in organisational thinking that needs to occur for genuine support of ground-up solutions at an

### Many people who have experienced profound trauma and disadvantage have demonstrated significant resilience and skill which needs to be recognised and respected in engagement initiatives.

individual and community level. It involves being responsive to different support or engagement needs in real time, optimistically envisioning change to drive the pursuit of better program solutions, and valuing people as change agents within their own environment. Critically, it also requires practitioners to reflect on how they conceptualise vulnerability for different groups, and the way this impacts communication to the detriment of service outcomes.

To make these identified shifts possible for service providers working with Aboriginal families in Adelaide, TACSI generated ideas for solutions through their own research and professional experiences. This included 'Culturally Adaptive Training', involving 'Reflective Practice Groups' which are widely used by Japanese manufacturing workers to think about what is working well, what is not, and how they can plan to try things differently. The technique has also been previously adapted by TACSI for teachers and nurses in a process called 'Care Reflect'. Using a similar tool may also help other organisations shift their approach for supporting responsive practice.

To build better relationships with families, a 'Get To Know You' toolkit was also suggested to facilitate open dialogue. This included the use of 'Culture Cards', depicting a range of broad concepts such as 'Going to Country', 'Indigenous Language', and 'Respecting History'. To use this tool, family members would select the cards they were drawn to and practitioners would use this as a starting point to discuss what these concepts meant to them and how they could be reflected in their support. Other inspirations included the 'Harvard Social Capital Building Toolkit,' for strengthening positive community networks and an 'Online Clearinghouse' to help practitioners share and find out about different practice methods used (The Australian Centre for Social Innovation, 2013).

Co-design involves challenging the way we approach vulnerability, and fostering a sense of curiosity which leads us to ask questions, to be open and honest, and to be deeply inquisitive about people's lives. Tension and miscommunication occur when we let our assumptions narrow or constrict our conversations. It inadvertently creates a professional-client divide, where the intention to 'protect' or avoid seemingly messy conversations amounts to patronisation (The Australian Centre for Social Innovation, 2013). Being tuned in and responsive to people in real time and allowing them agency within the engagement methods that we use will enable us to naturally sense where and how far we can go in our conversations. It will also allow us to pick up on valuable insights which go unsaid but which are reflected in peoples' 'doing' and manner of response. The trick is not to speak or act from a place of 'knowingness'. We need to drop the idea that professionalism or expertise means getting it right straight away or knowing all the answers. If anything, this adds pressure to our relationships and stops people from exploring their own changemaking capacities. An Aboriginal support worker engaged with TACSI described this well when she said, 'You've got to get to know people, get in there. Don't be too scared that you don't start. Be upfront, make mistakes. Don't think you know everything. Be honest, that's showing respect.' (The Australian Centre for Social Innovation, 2013).

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### Safeguarding rights, empowering consumers and carers, and upholding Victoria's mental health principles



Lynne Coulson Barr is Victoria's first Mental Health Complaints Commissioner

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The office of the Mental Health Complaints Commissioner (MHCC) was established under the new *Mental Health Act 2014* and began operation on 1 July 2014. This new legislation aims to protect the rights and dignity of people experiencing mental illness, and place them at the centre of their treatment and care.

It introduces a set of mental health principles and a number of new initiatives and protections to promote and support recovery and facilitate strong communication between mental health professionals and consumers, families and carers.

The MHCC is a key component of the increased safeguards, oversight and service improvement provisions introduced in the new Act. Our office provides an independent, specialist avenue for progressing complaints about public mental health services and promoting service improvements. We work to safeguard the rights and dignity of individual consumers, families and carers, and resolve complaints in ways that support recovery and improve services. We also help services to develop effective complaint resolution processes and drive improvements in the mental health system.

### Upholding the right of Victorians to make a complaint

The right to make a complaint is essential for protecting all other rights, providing a critical safeguard for preventing and addressing alleged harms and rights breaches. The Act requires services to assist us so we can perform our functions, and prohibits services from taking detrimental action against anyone who makes, or intends to make, a complaint to us. It also requires services to implement their own complaint processes, which are essential for service improvement. They provide a window into people's experience and give services the opportunity to respond in ways that improve outcomes for the person involved and for others.

### Introducing a supported decision making framework

The Act introduces a supported decision making framework to enable people to make or participate in making decisions about their assessment, treatment and recovery. This new framework requires different conversations between consumers, families, carers and services to ensure a person's views and preferences are heard and considered.

In our approach to complaint resolution, we work to build the capacity of everyone involved to have these conversations and use the decision-making mechanisms available in the Act to minimise and resolve complaints. These mechanisms include making an advance statement about their treatment preferences, nominating a support person to receive and provide information about treatment and care while a compulsory patient, and having access to a second psychiatric opinion.

In 2014–15, a number of complaints made to our office related to consumer concerns about how a service considered and responded to these rights when providing care and treatment. In instances where the person was very unwell or had difficulty expressing themselves, we asked services to explain how the person's views and preferences had been considered.

We also promoted the use of these mechanisms to help resolve complaints and prevent concerns that were raised from happening

# The right to make a complaint is essential for protecting all other rights, providing a critical safeguard for preventing and addressing alleged harms and rights breaches.

again. Many services proactively discussed these options with people when working to resolve a complaint, and we have seen how a person's confidence and trust have been restored when services take steps to understand their experience and consider their views and preferences.

### Receiving least restrictive assessment and treatment

A key objective and principle of the Act is for people to receive assessment and treatment in the least restrictive way possible, with the least possible restrictions on human rights and dignity. Many consumer complaints that have been made to our office include concerns about compulsory treatment and whether their treatment was the least restrictive.

Whenever a person raises concerns about their compulsory status, we talk to them about the Mental Health Tribunal's role and make sure that they understand their rights in relation to the Tribunal. We also ask the service to confirm that they were providing information about the Tribunal's processes, as well as support to enable the person to exercise their right to seek a hearing for a decision about their order.

The right to the least restrictive treatment is also a key consideration in complaints about the use of seclusion and restraint, medication and particular treatment settings such as high dependency units and secure extended care units. In dealing with these complaints, we review and assess the extent to which the service considered less restrictive options and any steps that could be taken to ensure treatment is least restrictive. We also assess whether the specific requirements and protections under the Act have been met, and, where appropriate, consult with the Chief Psychiatrist, who has the statutory function of monitoring the use of these restrictive interventions.

### Safeguarding dignity, ensuring safety and protecting from harm

We pay close attention to enquiries and complaints that raise issues of risk, safety and alleged harm. In these cases, we assess the adequacy of the service's immediate and longer-term response, including any investigation and reporting to police. We also assess the steps the service has taken to respond to the person's needs, to address risk issues, and to prevent a recurrence. The action we take is informed by this assessment and consideration of the roles of other key bodies such as the Australian Health Practitioner Regulation Agency, the Coroner, Victoria Police and the Chief Psychiatrist.

We are engaging the Department of Health and Human Services and the Chief Psychiatrist around options for ensuring greater consistency in the way services report, investigate and review incidents and use open disclosure in relation to adverse events.

We acknowledge that services, particularly those with older inpatient units, face a number of challenges because of the physical layout of units. Of particular concern is the location of staff stations, the design of high dependency units, and the limited physical amenities in courtyards and common areas. Variable gender ratios and high demand for inpatient beds can also make providing gender-specific areas difficult.

We draw on our experience and knowledge to inform our approach to addressing specific complaint issues and any recommendations that we may make for addressing the broader quality and safety issues identified in complaints.

### Providing holistic and individualised care

We have received a number of complaints from consumers about whether their individual needs, including those of culture, language, communication, age, disability, religion, gender and sexuality, were being met. We have also received complaints from consumers and carers expressing concern that consumers' holistic needs, including physical health and alcohol and drug related treatment needs, had not been met while receiving mental health services.

These complaints usually occurred when people were compulsory inpatients and unable to access their usual community supports or services, or where they needed additional support to access appropriate services. We were often able to resolve these complaints in the early stages by supporting the person to communicate directly with the service about their needs. In some instances, we engaged services on the need to develop coordinated treatment and care plans with other services, such as disability services, to respond to the specific needs identified in complaints. Psychiatric Disability Services of Victoria (VICSERV)

Safeguarding rights, empowering consumers and carers, and upholding Victoria's mental health principles by Lynne Coulson Barr

Many consumer complaints that have been made to our office include concerns about compulsory treatment and whether their treatment was the least restrictive.

The Act also requires services to recognise and promote the best interests of children and young people, and recognise and promote their wellbeing, needs and safety. This requires services to adopt an holistic and individualised approach to care and treatment planning. Through some complaints, services have agreed to adopt tailored approaches to visits by children during a parent's inpatient admission and reconsider their approaches to discharge planning for consumers with parental responsibilities.

Our experience in dealing with complaints about services to young people and our visits to all Victorian public youth mental health services, including Youth Prevention and Recovery Centres, has reinforced the importance of such tailored and individualised responses.

#### Acknowledging and respecting the role of carers

The recognition of the role of carers and acknowledgment that carers should be involved in decisions about assessment, treatment and recovery wherever possible are significant changes in the Act, and are important for promoting supported decision-making.

In dealing with carer enquiries and complaints, we have identified the need for services to develop new approaches for understanding and responding to the concerns of carers, and implementing processes to ensure carers of compulsory patients are notified and consulted, as required by the Act.

Where we are unable to formally deal with a complaint, the Act allows us to support the person to resolve their complaint directly with the service. We have provided advice and guidance to carers about how to navigate a complaint process, advised services about the rights of carers under the Act, and facilitated complaints back to the service for local resolution.

### Providing compulsory patients with a statement of rights

Under the Act, compulsory patients must be given a statement of rights when they are placed on an assessment, treatment or a temporary treatment order. The service must explain these rights in a way that helps the person to understand their rights and how they are going to be assessed or treated. The Act also requires the service to provide copies of assessment or treatment orders to the person.

Some complaints have raised concerns about the timing of the provision of the statements of rights and copies of orders or reports relating to the Mental Health Tribunal. In most cases, the service has agreed to explain the rights again directly to the person, and provide another copy of the statement. We have also encouraged services to see this practice as part of their ongoing conversation with the person and ensure it continues throughout the period of compulsory treatment.

#### Upholding the right of consumers to communicate

The Act sets out the right for consumers to communicate with people outside a service, and requires staff to ensure reasonable steps are taken to support this communication.

We have received a number of enquiries and complaints about the lack of access to, or confiscation of, mobile phones, tablets or laptops from consumers during inpatient admissions. We have identified variable practices across services, and questioned whether all practices were consistent with the rights and requirements of the Act, including the principles concerning least restrictive treatment and recoveryoriented practice.

Following discussions with the Department of Health and Human Services and the Chief Psychiatrist, we have formally referred the need for policy and practice guidance on access to mobile phones and other communication devices for consumers during inpatient admissions to the department for consideration.

We have also identified a small number of complaints where a person has not been supported to contact, or has been prevented from communicating with, a person or agency (for example, the police), despite there being no direction to restrict communication by the authorised psychiatrist. We have communicated with services about their responsibilities in relation to this right, and have made recommendations to a number of services to review their policies and procedures to ensure they comply with the Act.

### Overcoming barriers and empowering Victorians to speak up

For people experiencing mental illness, families and carers, their experience with mental health services can be associated with severe distress, trauma and, at times, the loss of liberty. People have told us how difficult it is to speak up about their concerns in the face of these challenges, when already dealing with the difficulties inherent in mental illness and the social stigma it still carries.

Since starting operation, our work has focussed on mitigating these barriers and ensuring people feel supported to raise their concerns in the midst of these challenges. We have been raising awareness of our role, encouraging new ways of thinking about and responding to complaints, and starting new conversations between services, consumers, families and carers. In all our work, we have focussed on our role in safeguarding rights and promoting service improvements, and have worked to resolve complaints in ways that support people's recovery.

In doing so, we have given close attention to the Act's mental health principles, working with consumers, families, carers and services to achieve outcomes that respond to consumers' individual needs, supporting the consumer's central role in making decisions relating to their treatment, and enabling carers to be involved in decisions wherever possible. We are also working to improve our data capture and analysis, better understand the demand for our service, improve our resolution processes and communication with all parties, and work with greater agility to achieve optimal outcomes for our efforts.

### **Our vision**

Our vision is a public mental health system that welcomes and learns from complaints and makes quality and safety improvements to embed the rights of consumers, families and carers and uphold the principles of the Act in all aspects of service delivery.

We look forward to continuing to work with consumers, families, carers and services to achieve this goal.

In dealing with carer enquiries and complaints, we have identified the need for services to develop new approaches for understanding and responding to the concerns of carers, and implementing processes to ensure carers of compulsory patients are notified and consulted...

### Peer Leadership in an evolving sector: Is the time right for consumer owned and run services?



Nathan Grixti is an Independent Consumer Consultant and Peer to Peer Mentoring, Education, Community and Support Provider in Barwon, Victoria

In recent years there has been enormous growth and development of the Peer Support and lived experience workforce among the community-managed and public mental health services sector.

While there remain issues with regard to understanding, acceptance and acknowledgement of lived experience work, we are seeing more mainstream recognition of the value, diversification and specialisation of consumer workforce roles and practice. These roles are not just limited to Peer Support work, but cover a broad scope of practice principles, evidence-based disciplines, academic research and social movements.

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As this workforce has continued to grow, so has the sophistication and nuance of lived experience work and the need for continued development and support of this space. There is growing consensus among many consumers and consumer workforce members about the need for true peer leadership and the development of wholly consumer owned and run services.

### Landscape of change: new directions, ongoing uncertainty

Late 2015 saw the release of the 10 Year Plan for Mental Health in Victoria. While we are yet to see any clear strategy about implementation, we at least now know that the current Victorian Government supports the development and growth of the paid lived experience workforce (Victoria's 10 Year Mental Health Plan, 2015). However there is much uncertainty still in Victoria with the pending implementation of the National Disability Insurance Scheme (NDIS), particularly about what it might mean for state funded community-managed mental health services and other important and complex issues raised by the NDIS design and trials.

The NDIS also represents an emerging and unprecedented opportunity for consumer led and owned services to be established, though uncertainty surrounds that too. The NDIS supports the development and growth of small business enterprises which enable greater choice and control for participants, however we still do not know what potential exists for sole traders, boutique services and new organisations to build themselves in ways which reflect this principle.

The current focus is appropriately on key systemic issues and challenges that the NDIS poses, such as the tensions around concepts of permanent disability, functional impairment and recovery; restrictive eligibility criteria which is dependent on psychiatric diagnoses being assessed as lifelong and enduring, and evidence which highlights the often harmful nature of diagnostic labeling (Daya & Grixti, 2014; Slade & Longden, 2015). As a result, little attention has been directed towards what potential the scheme might hold, if any, to delivering on its own underpinning principle of greater choice and control of supports for participants.

### A strategic advantage for peer led services?

There are currently a number of options available to new services and sole traders to establish themselves as either registered or non-registered providers. While concerns have been raised about the pricing of NDIS support clusters for registered providers not being commensurate with the level of skill or experience of consumer roles, participants who self-manage their plans can choose nonregistered providers to deliver supports which also enables them to negotiate fees with a little more flexibility.

Many have also raised justifiable concerns about the emerging market economy and privatisation of the sector. However – given the evidence in favour of Peer Support work and other consumer

### The NDIS also represents an emerging and unprecedented opportunity for consumer led and owned services to be established, though uncertainty surrounds that too.

roles (Daya, 2015), and the disproportionately low number of specialised and experienced consumers in the mental health workforce – there now exists a potentially strategic advantage for peer led services. This could mean establishing themselves in ways which are not only consistent with the design of the scheme and provide greater choice for participants, but which also could represent unique, independent service offerings that are able to respond to the voiced needs of consumers in a way which is also financially viable.

One of the issues for non-registered providers, aside from obvious concerns about industry standards and participant safety, is that the number of people currently self-managing their plans in the trial sites is still low, at around 6 per cent (Joint Standing Committee on the National Disability Insurance Scheme, 2015). Anecdotal evidence tells us that self-management by mental health consumers in Barwon is almost non-existent.

The NDIS focus on consumer, carer and community capacity building has been seen with the implementation of initiatives such as the Disability Support Organisations (DSO) Capacity Building Project and the much anticipated Information, Linkages and Capacity Building (ILC) framework. There is no reason that participants shouldn't be supported and *encouraged* by the DSO project and other capacity building initiatives to self-manage their plans, funds and supports in a way which promotes self-direction and empowerment as the scheme moves to full rollout. Of course the question still also remains about how people who are not eligible for NDIS funding will access support, but many are optimistic this will be addressed with the proposed ILC framework when it is finalised.

## A personal reflection on inner states and mainstream training

When I was initially invited to submit an article about Peer Leadership for this edition of *newparadigm*, I found myself reflecting on my own trajectory over the past three or four years and asking whether or not it is representative of what we all mean when use the word 'Peer'. It's a question I ask not so much in relation to my own skills or experience, or even whether or not I consider myself to be a 'consumer', a 'Peer', or a 'leader', but rather in the context of *how* and *why* I work in the way I do, and the way it relates to other forms of Consumer or Peer work.

While I have worked across a range of designated consumer and non-consumer roles that employ a variety of skills and levels of mental health training, much of the focus of *my own* lived experience has been increasingly informed by a number of political, social and cultural factors, while simultaneously moving further and further away from models of mental illness and recovery. In a way I have found my path through the mental health system over the years coming full circle. My inner states, my interpretations of them, and the ways I integrate them into my life share almost nothing with the dominant models of mental health that I have been trained in. It is almost an ironic twist that the experiential qualities and ideas I expressed as a young person entering the mental health system for the first time were classified as characteristic of psychotic illness, but these days I am invited to speak about those same experiences as legitimate forms of human expression and creativity which are not only meaningful, useful and helpful in my own context, but also relatively common.

### The positive aspects of 'voice hearing' and other non-ordinary states

It is a view which is echoed by many people within the International Hearing Voices Network (IHVN), and it is reflected in the outcomes of such consumer driven initiatives as the Voice Exchange Program implemented through Voices Vic at UnitingCare Prahran Mission, with reports of some people approaching Peer Support Workers for support to hear *more* voices which they identify as helpful (Dent Pearce et al., 2014).

Current estimates suggest that up to 13 per cent of the population experience voices, visions and other forms of sensory phenomena typically classified as hallucinatory experiences, with most having no history of contact with mental health services or requiring care (Slade & Longden, 2015). There is a growing consensus among leading researchers and clinicians about the frequent neglect of the positive aspects of 'voice hearing', and the potentially transformative and therapeutic value of exploring meaningful experience and content of voices, visions, and other non-ordinary states, as well as an urgent need to address the ever growing demand for alternative and non-pharmacological approaches (Thomas et al., 2015). new**paradigm** Autumn 2016 **Psychiatric Disability Services** of Victoria (VICSERV) Peer Leadership in an evolving sector: Is the time right for consumer owned and run services?

The NDIS also represents an emerging and unprecedented opportunity for consumer led and owned services to be established, though uncertainty surrounds that too.

Research also shows that many experiences of 'voices' demonstrate a number of phenomenological similarities in people, whether or not they need psychiatric interventions, and that many people in the general population have similar beliefs about their experiences as do people who have been diagnosed with psychotic disorders and otherwise are considered to have delusions (Slade & Longden, 2015).

This isn't to say that people who experience voices, visions and other hallucinatory phenomena don't also experience distress, but it does raise the important question of why some people find voice hearing distressing or receive diagnoses of mental illness, while others live well with their experiences and even utilise them in their daily lives. Evidence suggests that people who live well with voices and visions often also communicate and set boundaries with their voices, speak about their voices with others, and have explanatory frameworks for their experiences, with distressing voice hearing experiences often being linked to trauma (Romme, 2008). Evidence also suggests that, for many individuals, the voices and visions themselves aren't necessarily the problem. Rather, their distress or difficulty coping with voices and visions can be triggered by how people might react to them or interpret them, including family, other members of the community, or even mental health professionals (Slade and Longden, 2015).

### Support or systems of oppression?

For many people who identify their experiences as being positive or meaningful in the context of alternative explanatory frameworks, such as spirituality or mysticism, this also raises valid questions about the often potentially iatrogenic nature of the majority of mental health services and treatments. Psychiatric diagnoses are, by their nature, often subjective interpretations of subjective experiences. Meanwhile, diagnostic criteria draw relationships between voices and visions, an individual's beliefs about them and clinical concepts such as anosognosia (lack of insight), treatment resistance and non-compliance. These often leave people with little to no recourse to express views which self-identify and contextualise experiences as anything other than mental illness. Compounding this issue for many is legislation which not only permits the use of compulsory treatment and restraints, but also legitimises the pathologising of otherwise ordinary human experiences. This can create tensions between many consumers and services which act more like systems of oppression and civil rights movements, such as the Lesbian, Gay, Bisexual, Transgender

and Intersex (LGBTI) community which has also had its struggle with sexual and gender diversity being classified as mental illness, than supportive relationships which promote wellness and healing (Grixti, 2015).

Much like the LGBTI community, many people both within and outside of the IHVN are now increasingly reframing their experiences as an aspect of human diversity which is as naturally occurring as sexuality, red hair or left handedness, but which presents its own set of unique health and discrimination challenges in the context of being a person who 'hears voices' in our contemporary Western culture. It recognises that many people don't want treatment or find treatment ineffective for their experiences of voices and visions because there is actually nothing inherently wrong with hearing voices that needs treating. Anecdotally, the type of support people are often asking for in this space is validation of their experience, and a way to express it without fear of judgment or reprisal.

This small snapshot of just one of the elements of the IHVN (which overlaps with elements of the spiritual emergence and psychiatric survivor movements) relates to a very specific discourse for a relatively small group of people in the context of the wider mental health system. Of course it does not reflect the views or experiences of many other consumers; it does not even resonate with all people who have received diagnoses of psychotic disorders, and nor should it.

In the context of 'Peer Leadership' though, exploration of these issues which acknowledges, respects, and at times critiques all of the complexities, subtleties, power dynamics and nuances of human experience and mental health paradigms is an important and emerging area. It is one which increasingly demonstrates that consumers are not a homogenous group, but rather cover a broad and diverse cross-section of the community with equally diverse voices and needs which can sometimes appear at odds with mainstream support structures, dominant narratives around mental illness and recovery, and even with other consumer voices. Perhaps more importantly, this emerging complexity and sophistication highlights that, for many people, mental health isn't just about 'mental health' but also illustrates the social, environmental, spiritual and political dimensions of peoples' experiences in the context of larger systems of disadvantage, discrimination and oppression (Daya, 2015).

For many other people though, working towards good mental health and wellbeing, as opposed to recovery from the impacts of mental illness, can often feel completely at odds with what the mental health system has to offer.

### Coming full circle on Peer approaches and experiences

Recently I made the decision to commence my own independent, specialist Peer practice in Barwon. My aim is to offer wholly consumer owned and operated services based on the principles of Intentional Peer Support and the Hearing Voices Approach to people who experience voices, visions and other forms of altered states or sensory perception. It is a highly specialised focus, and one which is founded primarily on experiential qualities and explanatory frameworks that people identify with. It builds on the principle that Peer Support is not based on psychiatric labels, diagnostic criteria or concepts of recovery which seek to delineate between wellness and unwellness, but instead is a reciprocal system of both giving and receiving which is founded on principles of respect, shared responsibility and learning, and mutual agreement of what is helpful (Mead, 2003).

Ultimately the issues I have sought to raise in the Breakout section may also be where the true potential of the NDIS lies for Consumer and Peer led initiatives which seek to embed the social, political and spiritual into support structures. This is not simply in an effort to inform practice and service delivery, but to make it an integral aspect of the support which is available. For many consumers who want to explore these dimensions of their experience, finding support is often not focussed on dealing with functional impairments and rehabilitation into society. For them it is more about connecting with others in a way which not only helps to reclaim power from oppressive systems, both within and outside of the mental health system, but also fosters

...for many people, mental health isn't just about 'mental health' but also illustrates the social, environmental, spiritual and political dimensions of peoples' experiences in the context of larger systems of disadvantage, discrimination and oppression. the development of communities built around shared experiences and values. For many people, supports which are built around disease models of mental health and promote social and economic participation as benchmarks of recovery are not only ill-equipped to meet these kinds of needs, they are also not designed to do so.

Many of the supports offered by the community-managed sector are built on decades of research and evidence which tells us that these supports can be extremely effective and helpful for the types of people who find them effective and helpful, which is ultimately a good thing. For many other people though, working towards good mental health and wellbeing can often be completed at odds to working towards recovery from the impacts of mental illness. It can be about finding a space where individuals feel validated and communities are supported to challenge dominant paradigms and power imbalances, where people are encouraged to explore their inner states in the context of their own worldviews, and to express their values and beliefs in a free and open exchange of ideas. If the level of choice and control being promoted within the NDIS is able to extend into these areas for consumers *and* consumer owned and led services, then the time for something new might just be right.

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### A systems approach to improving mental health outcomes: views from Partners in Recovery, Victoria





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Psychiatric Disability Services of Victoria (VICSERV)

**The Victorian Partners in Recovery Organisations (PiROs)** are Eastern Melbourne PiR, Frankston Mornington Peninsula PiR, Gippsland PiR, Grampians PiR, Hume PiR, Inner East Melbourne PiR, Loddon Mallee Murray PiR, Lower Murray PiR, Northern Melbourne PiR, and South Eastern Melbourne PiR.

Building better mental health and resilience in ways that promote social inclusion and economic participation is foundational to the wellbeing of communities. Better community outcomes are driven by actively addressing inequality, disadvantage and discrimination at the same time as promoting protective factors.

People living with severe and persisting mental health problems have complex multiagency needs that result from greater vulnerabilities to physical illness, homelessness, discrimination and, for many, living with significant disability.

People living with complex mental illness are some of the most marginalised and disadvantaged Victorians. However, many of these consumers are also disengaged from the service system, having either disconnected through service gaps or while navigating a system with obstacles and delays in referral pathways. Exclusionary thresholds for eligibility also create barriers for some people.

In order for the National Disability Insurance Scheme (NDIS) and other upcoming reforms to be able to deliver the right services at the right time in the right place, the system underpinning their delivery needs to be effective. System reform outcomes relating to mental health service coordination will by default provide outcomes for people with a disability.

### Embedding systems change into practice

The Partners in Recovery (PiR) program has been working for almost three years to drive a fundamental shift in the way mental health programs and services are delivered. Addressing complex and persisting mental health problems requires the mental health and broader service systems to be working well together. The interactions and relationships among the elements that characterise the entire system need to be robust and sustainable in order to work towards better client outcomes. The PiR approach is driven by systems thinking and strategic partnerships at all levels, with a primary focus on addressing the issues that arise as a result of the gaps and barriers in the current service system. The embedding of systems change work into the practice of PiR is fundamental to achieving service integration and provides additional value to the experience for consumers and the system of PiR.

In Victoria, PiR is implemented through 10 Victorian PiR organisations (see the list above). Ahead of key reform agendas underway through NDIS and the Commonwealth mental health reform, now is an opportune time to reflect on their experiences, and to synthesise, consolidate and share the program's learnings from the first three years. In order for the NDIS and other upcoming reforms to be able to deliver the right services at the right time in the right place, the system underpinning their delivery needs to be effective.

The key features of the PiR approach which are making contributions to long-term sustainable reform include:

- a dedicated Support Facilitator to coordinate support and drive system reform
- social determinants approach to mental health
- regional and community approach
- systems approach which facilitates change and strategic partnerships at all levels
- valuing of ongoing consumer and carer involvement

• use of flexible funds for individual support and to drive innovation. Some of these are discussed in more detail in the following sections.

### Working with social determinants and whole-of-life needs to address inequity

PiR aims to improve the health of those people whose health is poorest, including those who often have fewer financial and social resources than the rest of the population. Social inclusion, freedom from discrimination and violence, and access to economic resources are significant determinants of mental health. People with severe and persistent mental illness can be burdened with these inequalities as well as being at greater risk of physical illness.

Many of the Victorian PiROs run projects and use innovations funding to emphasise the interconnectedness of physical and mental health. They recognise that physical illness for consumers living with complex illness is often normalised, dismissed, or misattributed to concurrent mental illness, in a bias termed 'diagnostic overshadowing'. This can lead to under-diagnosis and missed opportunities for treatment. Importantly, we take a life course approach to prevention, early intervention and recovery, recognising that different population groups have different needs.

The program works actively to promote protective factors through access to appropriate and high-quality services that meet a full range of physical, mental, social and emotional health and wellbeing needs, in ways which are not illness-saturated. Reducing inequities includes providing a holistic approach to health, with programs working together with other health and social care services and sectors. Examples of approaches include:

- regional cross-sectoral approaches to health
- partnering with social work teams at Centrelink
- exploring partnerships with all points of contact with the justice system.

### Diagram 01: Social determinants



The ongoing national evaluation of the program has found participating consumers commonly prioritise participation and productivity as key unmet needs in their lives. Victorian PiR organisations have been trialling different approaches to meet the local needs of those who experience greater social and economic disadvantage, with the intensity of targeted efforts increased proportionate to need.

### Better targeting services to meet needs: towards a stepped care approach

Consumers with complex needs need to be able to reach the services they need, when and where they need them. Resources in the mental health system architecture need to be matched to levels of consumer

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# Addressing complex and persisting mental health problems requires the mental health and broader service systems to be working well together.

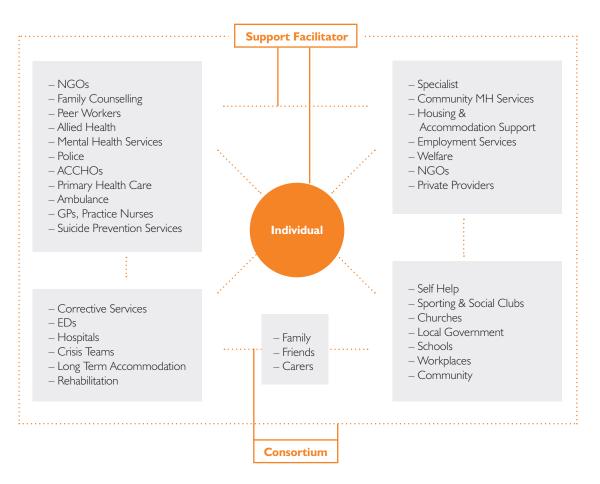
need, not driven by service-centred outcomes. Reorienting services more directly to the individual reduces inefficiencies and improves quality and safety.

For people living with severe and complex mental illness, a stepped care approach seeks to ensure a full continuum of services to match their range of clinical and recovery needs. While stepped care improves service integration and navigation, especially between clinical and non-clinical supports, it can also shift the service focus upstream, from acute and crisis support towards early intervention.

PiR negotiates and facilitates a stepped care approach for consumers within the existing service architectures in Victoria. Service coordination attempts to deliver a continuum of services through personal and flexible packages of care to accommodate the gap between need and supply and to provide wraparound services. Flexible funding is used by local programs to commission services to fill remaining gaps.

The role of Support Facilitators is to provide the coordination and capacity building to support consumers reach the services they need, when and where they need them. Importantly, and what makes this role unique, is it also assumes some of the systems reform responsibilities which emerge from this coordinating work. For example, some teams of Support Facilitators maintain a log of systems issues which are brought to monthly meetings for reflection and strategic planning. The role is also critical in supporting consumers to familiarise themselves and step through new system structures during system reform, as work continues on local system readiness ahead of coming changes.

### Diagram 02: Individual-centred Support Facilitation



## Social inclusion, freedom from discrimination and violence, and access to economic resources are significant determinants of mental health.

### Effective early intervention across the care continuum: shifting the balance

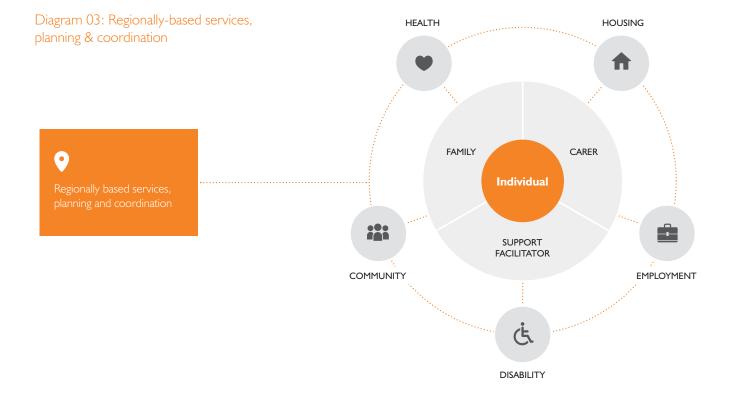
The focus of recovery for people living with severe and complex mental illness is to live a meaningful and contributing life in the community with or without symptoms of mental illness. In order to shift the current service and support models upstream, it is important to identify people who don't utilise enough services or are disconnected from any services. Once program participation and contact is established, a program can support people to manage their own health needs and to prevent the onset of crisis and subsequent intervention. Flexible funding is often used as an early intervention strategy to support urgent or emergency needs.

Increasing widespread public knowledge and understanding of complex mental illness also contributes to upstream efforts by instilling a whole-of-community approach to recovery. The PiR approach aims to do this by broadening the definition and understanding of what constitutes the mental health system. This includes more clearly defined pathways and interdependencies between health and mental health, and by emphasising the various non-health supports needed to assume a determinants-based approach to recovery, including the importance of housing, employment, education and justice.

### Developing an outcomes-focussed program for people living with complex needs

The measures and data which assess mental health outcomes in Victoria vary between programs and services. A more consistent approach is required to enable clearer outcomes for people living with severe illness, with measures reflecting the social determinants of mental health and wellbeing.

PiR works towards better recovery-oriented outcomes for people living with complex needs. Better coordination of services improve both consumer outcomes and service efficiencies. System collaboration promotes collective ownership of consumer outcomes and system innovations. The regionalised consortium approach provides a mechanism for a locally-shared agenda for change and action across multiple services systems – collective action for collective impact.



 
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The focus of recovery for people living with severe and complex mental illness is to live a meaningful and contributing life in the community with or without symptoms of mental illness.

### A flexible funding pool for individual support and innovation

Each regional PiR program has access to flexible funding which can be used to meet individual client needs and to build regional system capacity. For individuals, PiR flexible funds can be used to commission services to support client recovery when other funding sources are not available, to assist with consumer engagement, or for early intervention/ relapse prevention strategies. Flexible funding can commission services to meet local needs and to strengthen stepped care pathways. Consumers benefit from more targeted services and PiR benefits from a better targeting of investment.

For the system, innovation funding allows the consortium and relevant stakeholders to collectively address local system needs and gaps. This might involve regional training, relationship building and/or bringing new cross-sectoral partners together.

Each of the 10 programs takes a different approach to system reform driven by local needs assessment. PiR creates an opportunity for possible system solutions to be piloted in one area and to be replicated elsewhere if appropriate to regional needs. Examples of use of innovations funding for projects include:

- developing assertive 'inreach' models for Supported Residential Services
- improving access to private rental housing, including by informing real estate agents and other service providers about general mental illness issues and specific issues of hoarding and squalor (such as through capacity building events, representation on accommodation committees/working groups, and 'rent-ready' programs)
- · online mental health services directory
- television and media campaigns
- partnership with regional oral health network to prioritise consumers living with mental illness, reduce barriers to service access and provide secondary consultations
- supporting access to best practice therapeutic interventions for borderline personality disorders (including availability of dialectical behaviour therapy)
- developing a framework for inclusion to improve access for consumers to mainstream health and community services
- challenging stigma in the Chinese community using bilingual workers and a slow, intentional, consumer-informed model
- piloting a 'telehealth in the home' project enhancing access for consumers to mental health clinicians through technology

- supporting the Mirabinda Mental Health Support Group, which is a consumer-led peer support group to promote self-advocacy and innovations
- recruitment of specialist/portfolio Support Facilitators (CALD, Aboriginal, corrections, family violence)
- developing and distributing a Flexible Recovery Services directory
- co-locating a mental health nurse at a Corrections setting
- driving and supporting regional Intake Workers Network meetings.

### **Moving forward**

In a very brief time, PiR has shifted the conversation in mental health to focus on service coordination and integrated care, principles of recovery-oriented practice and systems thinking. PiR coordinates a model which is flexible and driven by needs and aspirations, to provide more targeted individual and recovery-oriented services, resulting in more optimal use of the mental health and other support services workforce. People with severe and complex mental illness are benefiting from these innovative local approaches that coordinate available services and flexible funding to better meet their multifaceted needs. In order to keep moving forward with localised system improvements, Primary Health Networks (PHNs) will need to commit flexible funding to support tailored innovations projects to best meet local needs.

Long-term and entrenched sector issues take significant focus and concentrated policy reform to drive service and system change. A longer-term commitment is required to ensure changes are systematically embedded into routine practice across all services. It is opportune that various major system reforms are underway. The Victorian PiR organisations look forward to supporting those reforms through partnerships, evidence and accountability to ensure service continuity and smooth implementation.

This paper is an excerpt from the White Paper on Partners in Recovery in Victoria: Systems change and strategic partnerships to improve mental health outcomes. The White Paper reports on the 10 Victorian programs and offers a snapshot of how PiR has improved the efficiency and sustainability of the mental health system at a regional level throughout Victoria.

### new**paradigm** VoxPOP

Psychiatric Disability Services of Victoria (VICSERV)

### **Respondents:**

Alyson Miller, CEO, Pathways Sue Grant, Mental Health Services Coordinator, Centacare Marie Piu, Senior Systemic Advocacy & Policy Advisor, Tandem

# In this *voxPOP* we find out what community mental health organisations think about co-design. What is co-design really and what opportunities does it offer?

### What, in your opinion, are the essential elements for successful co-design?

### Alyson:

Co-design reflects a way of thinking rather than a specific process. Fundamentally organisations need to truly believe and support the ethos of lived experience and what people, families and community contribute to designing and improving service delivery.

At the heart of co-design is the service users' experiences, attitudes, values, challenges and understandings.

### Sue:

Co-design essentials include:

- collaboration and regular meetings between case managers and mental health providers (including clinical and non-clinical organisations)
- carer and consumer involvement in design and decision-making
- consumer access to skill development, capacity building and resilience
- common understanding, respect and communication
- transparency
- advocacy.

### What are the opportunities, and challenges, for successful co-design of mental health support and services?

### Marie:

Successful co-design provides a safe forum for concerns and challenges to be addressed by all parties together. It empowers consumers and carers and enables the delivery of better services.

The challenge is ensuring that all parties are clear about the parameters of the working relationship and what can and cannot be discussed.

### Sue:

There are opportunities to break down historic barriers to collaborative service delivery, to reduce rates of consumer relapse, to promote recovery, to reduce carer stress and to improve transparency around mental health information. Improving consumer outcomes in turn has a flow-on positive effect on community.

A big challenge is to effectively include consumers and carers in design and service delivery. There is also the challenge of NDIS implementation and what effect that will have on co-design as competition increases amongst service providers.

### How has co-design changed, or could change, your organisation?

### Alyson:

Co-design offers many opportunities to foster innovation, creativity and genuine collaboration. Organisations need to be more accountable to the people purchasing our services. We have responded to this by ensuring that lived experience is met at every level of our organisation, including:

- establishment of Participant Advisory Committee
- lived experience at the Board level
- development of Peer Support framework and practice values
- re-design of our Service Access with a participant and staff.

### Marie:

Tandem is committed to co-design. Our vision is that families and other carers of people with mental health issues will be partners in treatment, and service delivery, planning, research and evaluation. The lived experience of families and other carers should provide underpinning knowledge for policy and program formation.



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