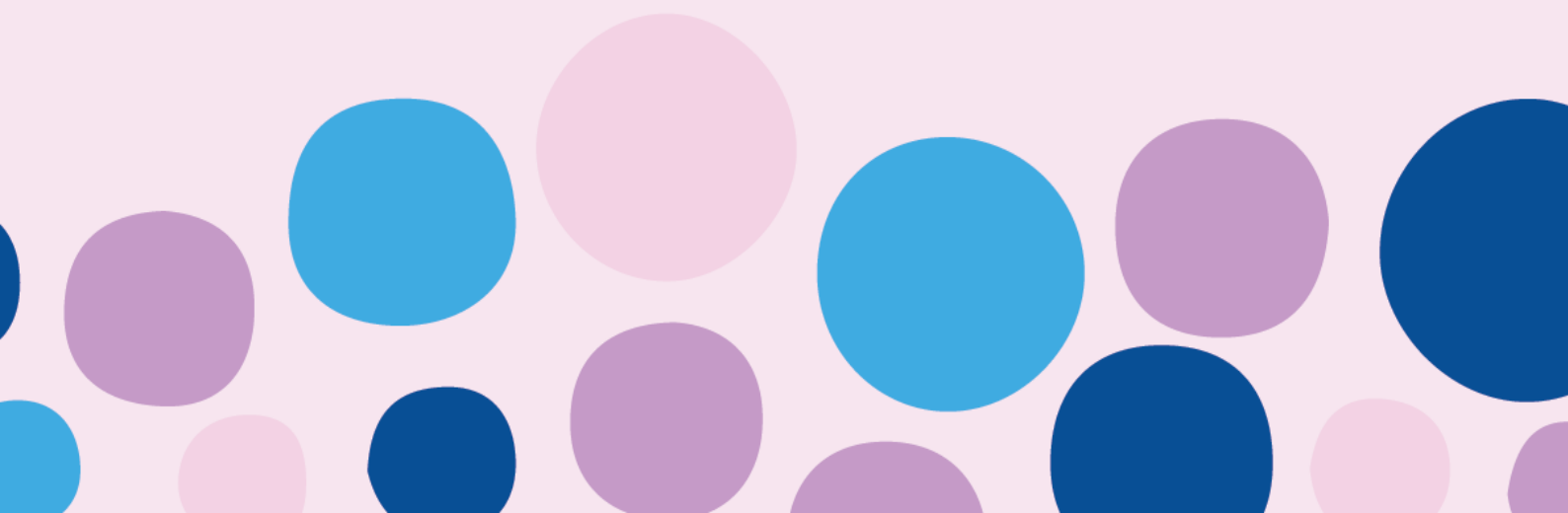


PERSON-CENTRED AND CONSUMER DIRECTED MENTAL HEALTH CARE: TRANSFORMING CARE EXPERIENCES

SUMMARY REPORT

Produced for the National Mental Health Commission by the Mental Health and Suicide Prevention Research and Education Group,
University of South Australia.

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Acknowledgement of Country

We acknowledge the Traditional Custodians of Country across Australia. We respect and value their cultural and spiritual practices and connections to Country. We acknowledge and pay respects to Elders past, present and emerging.

Acknowledgment of Lived Experience

We acknowledge the expertise of people with a living or lived experience of mental health issues and distress. We acknowledge people who have been lost through suicide and people bereaved, and the impacts of system failures. We recognise the learning, support and strength that lived experience wisdom generates. We value the courage and leadership of people sharing lived experience perspectives.

Acknowledgments

We would like to acknowledge the contribution and involvement of project participants throughout the consultation and codesign phases of the project. Thank you for sharing your experience, wisdom and perspectives on person-centred and consumer directed care, and talking together on how we can improve, reform or create services that meet the true aims of these principles and practices.

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Research team

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**University of
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What is this project about?

Increasingly, mental health services have been adopting person-centred care (PCC) and consumer directed care (CDC) principles in their mission statements and practice guidelines. These concepts are used to guide public mental health care, National Safety and Quality Health Service (NSQHS) Standards, and the provision of psychosocial support services through the National Disability Insurance Scheme (NDIS). These concepts were initially developed outside the mental healthcare environment but have gained prominence through the advocacy of consumer and carer leaders, mental health practitioners, and disability rights leaders.

Given their increase in use, we wanted to see how these concepts of PCC and CDC are perceived and implemented within mental healthcare services. We explored these concepts through five key objectives:

- » Understanding the way PCC and CDC are perceived as concepts and how they guide the provision, delivery, and experience of services.
- » Understanding how the concepts are linked to service and health outcomes
- » Documenting the challenges, issues and barriers that occur for PCC and CDC in mental health services
- » Highlighting the gaps, tensions, and opportunities that occur between these concepts and clinician led mental health care
- » Recommending actions and strategies for better achievement of person-centred and consumer directed services

What did we do?

We collected perspectives about PCC and CDC in two phases: consultations and co-design. We conducted 50 consultations with consumers, carers, providers, and peak bodies across Australia. Interviews included people across various roles and communities to understand the breadth of the mental healthcare landscape. Consultations covered these areas:

- » What participants understood about the concepts of PCC and CDC
- » The range of service and health outcomes associated with these concepts
- » Whether PCC and CDC are achieved in current systems
- » What challenges and barriers exist to the implementation of PCC and CDC
- » What shifts need to occur to allow PCC and CDC to be implemented, and
- » Examples of good practice PCC and CDC

Once consultations were complete, a co-design process over three sessions involving 20 participants was completed to guide thinking on barriers and possible shifts of practice and services to enable more consistent experiences of PCC and CDC. The outcome of this co-design was the recommended shifts described in the report, as well as key considerations about context, outcomes, and good practice examples.

What did we learn about PCC and CDC?

The perspectives and experiences shared by participants enabled the team to describe what PCC should be in the mental health sector. PCC is care that:

- » starts with the person's own story and situation
- » values the person's lived expertise
- » shares decision making power
- » values identity, culture, wishes, hopes and strengths
- » works with the person's wider life/ social needs
- » offers flexible and tailored care
- » feels safe from a consumer perspective
- » includes carers in meaningful ways
- » occurs through respect, trust and empathy between consumers, carers and practitioners
- » does not feel imposed or coercive

We also analysed participant views and experiences on CDC. We came to describe CDC as care that builds on and extends the above points. CDC is care that:

- » provides the person with decision making power and choice about care
- » helps the person to define what care is needed for recovery
- » encourages the person and their carers to evaluate whether services are working for them
- » offers flexible options for using a wider range of accessible services and supports
- » encourages good quality information provision and informed consent
- » assumes the person can make good judgements and decisions about their care
- » occurs where respect, trust and empathy in relationships enables consumer choice and autonomy.
- » promotes feelings of safety through listening, connection and having supports in place.
- » needs good quality communication, information sharing, support coordination and navigation of services

Challenges and barriers in achieving PCC and CDC

From the consultations we found that the experience of PCC and CDC is inconsistent, with many consumers and carers describing a stark difference between rhetoric and reality. Practitioners highlighted a wide variety of challenges, barriers, and issues relating to the ability to consistently deliver PCC or to develop programs based on CDC. We describe these barriers as broad themes that are relevant to both PCC and CDC. They are about the areas of 1) knowledge, power and decision making 2) service and system design, 3) risk and consumer autonomy, 4) service skills and capacities, and 5) recognition, awareness, and diversity. Collectively analysed, the top 13 themes for challenges and barriers were:

AREA	CHALLENGES, BARRIERS AND ISSUES
Knowledge, power, and decision making	<ul style="list-style-type: none"> » Paternal culture and limits of the medical model » Professional power and knowledge can disempower lived experience
Service and system design	<ul style="list-style-type: none"> » Inflexibility of services provided » Limited funding and restrictive service rules » Lack of pathways for people experiencing complexity » Limited information about available services
Risk and consumer autonomy	<ul style="list-style-type: none"> » Mental health laws and experiences of coercion » Too much focus on risk
Service skills and capacities	<ul style="list-style-type: none"> » Inconsistency of practitioner skills » Lack of true commitment and support for implementation of PCC and CDC » Resource/time limitations and practitioner burn out
Recognition, awareness, and diversity	<ul style="list-style-type: none"> » Stigma and stereotyping about consumers » Need for accessible services for specific communities



What can we do differently?

Over the project, participants offered many thoughtful strategies for encouraging services and sectors to better achieve PCC and CDC. We themed the various strategies into eight possible 'shifts' that would generate action at a systems and services level, and then further developed these through the co design sessions. This involved exploring what value the shifts would create, what was important, and what needed to be considered. The result is eight shifts that respond to key barriers and challenges and encourage different levels of action. They encourage PCC and CDC leadership, changes to practice, mental health care models and assumptions, improved organisational governance, supports and funding new programs. We encourage discussion and exploration of these strategies.

Shift 1: Strengthen practitioner education and training on essential knowledge and skills.

Why is this shift important?

It is important to strengthen service delivery through education and training processes for practitioners, empowering them to deliver PCC and CDC. Key topics are shared power and decision making, empathy, interpersonal communication, LGBTIQ+ health, cultural safety, carer involvement and trauma informed care.

What could this shift achieve?

This can support practitioners to be flexible and confident in delivering services that meet the needs of consumers and carers, improve consistency of skills, communication and connection within and across services.

“Education and training of staff about holistic views of health and what it means is needed. To do it well, risk averse practices need to change so that people can take calculated risk for themselves and use their own strengths to manage issue and build their capacity. We need to shift the culture from service-centred to person-centred, providing care that is safe as defined by the person.”

Practitioner leader

Shift 2: Embed supported decision-making practices including mental health advanced care directives and ‘nominated’ support people, as well as other ways of recognising autonomy within mental health legislation.

Why is this shift important?

It is important to support the use of practices that act to protect the autonomy and human rights of consumers when they are receiving care. Advanced care directives and nominated support people convey a person’s preferences and wishes. These can help service providers deliver principles of PCC and CDC.

Safety is the biggest concern for people engaging with mental health services, and people often feel that current services are unsafe

What could this shift achieve?

Working towards developing legal frameworks and policies that recognise and embed practices protecting the wishes and autonomy of people accessing mental health services can help to enhance informed consent and self-determination for consumers.

Consumer leader

Shift 3: A national approach for strengthening leadership and championing organisational change in public mental health services

Why is this shift important?

Encouraging strong national leadership that can champion PCC and CDC ideas within the mental health service provision and policy development is needed to provide consistent action and resourcing for change.

“Reform needs to be attacked at multiple levels. Leadership and workforce changes are required. There is the need for lived experience and people who understand person-centred concepts to develop services from the ground up. Some existing leaders attempt to block reform at every opportunity and highlight the fails of new approaches. ‘I told you so’”

What could this shift achieve?

Strong and consistent leadership will create a workforce culture that is supportive, compassionate and recovery driven via PCC and CDC principles. Leaders will generate required resources and structures to improve levels of coproduction of programs, enable supports for practitioners to deliver PCC and CDC and increase accountability and transparency on service outcomes.

Policy leader



Shift 4: Increasing and strengthening lived experience leadership in service governance and in the workforce

Why is this shift important?

Embedding lived experience leadership within systems and governance improves recognition of the needs, preferences and wishes of consumers and carers, enabling systematic and sustained codesign of new services, and uptake of peer-led or collaborative models of care.

What could this shift achieve?

Strong lived experience leadership will steer the consistent development of PCC and CDC through influence at governance levels. Leadership of the lived experience workforce will elevate its profile and utilisation across the mental healthcare landscape, and the broader community. Consumers and carers will have improved access to peer led or collaborative models of recovery and support.

“We need leadership at the systems level needs; we need to broaden and change the lens and have more of a lived experience and allied health model of support. We need a rebalancing of the workforce.”

Peer practitioner leader

Shift 5: Develop a focus on ‘relational recovery’ and fund new programs which work holistically to respond to intersecting social determinants and related drivers of distress and crisis.

Why is this shift important?

A relational recovery focus aims to create services which respond to a person’s social needs, wellbeing and connections. Practitioners can provide a more holistic response that understand the impacts of social issues, trauma, and lost opportunities that consumers and carers experience.

What could this shift achieve?

This will allow a broader range of services for people, with multidisciplinary input that is able to both work with people experiencing crisis, as well as prevent mental health issues in the future. Recovery goals are set by the person, considering their unique circumstances.

A systemic, holistic approach working in collaboration with the person, family and community is essential. A focus on strengths, individual goals and hopes is vital.

Carer leader



Shift 6: Promote and fund crisis response models that emphasise dignity, personal safety, and cultural safety.

Why is this shift important?

Responses that are centred around connection, safety and dignity can assist in providing PCC and CDC for people seeking care for mental health and suicide-related crisis. Consumers require responses which are culturally and psychologically safe to use and where autonomy is maintained when disclosing issues about risk.

What could this shift achieve?

Increasing the availability and accessibility of designated crisis response centres that are safe and kind for consumers to use. Practitioners are more understanding, accepting and tolerant about risk issues and work in connected ways to help consumers through distress and find ongoing support.

Arming clinicians with as much knowledge and experience as possible will help them to be confident in providing PCC. Less focus on risk and adhering to policy, and more focus on empowerment and consumer voice.

Practitioner leader

Shift 7: Fund lived experience organisations to co-design local mental programs in partnership with specialist public mental health services

Why is this shift important?

This shift increases the accessibility of services available to meet the needs of local communities. Lived experience organisations can partner with mental health services to design programs that understand and respond to the specific interests, strengths, diversity and networks of communities. This can embed helpful self care practices, health literacy and information resources within community networks.

What could this shift achieve?

With increased mental health literacy, skills and support capabilities within local community organisations, consumers, carers, and families will have increased access to supportive environments.

Despite being the preferred method of service delivery for many, peer services are often underfunded and maintained through voluntary positions. Grassroots movements have a particularly rich history within LGBTIQ+ community history and provides a wealth of experience that can be harnessed for good

LGBTIQ+ advocate leader



Shift 8: Fund lived experience organisations to provide peer navigation services and develop better care pathways within health systems

Why is this shift important?

There is a strong need to develop accessible care pathways for consumers experiencing multiple life issues and complexity. Lived experience organisations and peer navigators can enhance the design and coordination of pathways so that they work for consumers and carers. Coordination, support, and navigation are important aspects of both person-centred and consumer directed care.

We need trans specific health services like we have in the Aboriginal Controlled Community Health Organisations. We could help provide peer navigation and support

What could this shift achieve?

Stronger referral and care pathways can help people to stay connected with mental health services, and bridge access gaps and barriers that occur due to culture, language, gender, sexuality, disability, and locality.

LGBTIQA+ advocate leader

The full report of this project, *Person-Centred and Consumer Directed Mental Health Care: Transforming Care Experiences*, is available at:

<https://www.unisa.edu.au/research/mental-health-suicide-prevention/initiatives-resources/>

