

Person-Centred and Consumer Directed Mental Health Care: Transforming Care Experiences

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

Online Appendices

Appendix 6: Aligned approaches for person-centred and consumer directed care

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Appendix 6: Aligned approaches for person-centred and consumer directed care

Introduction

The consultation process produced suggestions of strategies and shifts for organisational change and policy formulation. The eight core shifts identified encompassed several levels of actions – including changes to mental health care delivery, organisation supports, funding and commissioning, and models of conceptualising mental health and recovery.

As a part of this, participants highlighted approaches and practice models which they saw as helping to achieve person-centred care (PCC) or consumer directed care (CDC). There were many suggestions across the consultations. These included:

- » Aboriginal Social and Emotional Wellbeing
- » Advanced Directives
- » Alternatives to Suicide (Alt2Sui)
- » Codesign
- » Connecting with People
- » Emotional CPR
- » Friendship Bench
- » Health literacy strategies
- » Intentional peer support
- » Lived experience led clinician education
- » Open Dialogue
- » Passport tools (such as wellbeing passports)
- » Peer Navigators
- » Power Threat Meaning Framework
- » Relational recovery approach
- » Safe Haven's models of crisis response
- » Safeside Prevention
- » Safewards
- » Shared Decision-making
- » Soteria Program
- » Suicide Narratives

- » Supported Decision-making
- » The Scottish Recovery Model
- » Trauma-informed care
- » Triangle of Care

In generating research evidence for the project, we haven't been able to focus on all these approaches and models. We have focused on the approaches which were more prevalent across the conversations and embedded in the shifts that people highlighted or recommended. These are described below, with a focus on outlining strategies relevant to PCC and CDC and presenting evidence around impact where available.

Codesigned service development and outcomes

In terms of this shift another focus is to consider the outcomes emerging from codesign projects, where consumer and carer leaders work with practitioners, policy makers and community to rethink and create new services, information resources and support programs.

This area of research is complex as there are 1) multiple levels of process outcomes considering good quality codesign practices and decision-making, as well as 2) service performance quality/fidelity outcomes and 3), whether codesigned programs result in better recovery or quality of life outcomes for consumers

The evidence about the third question remains underdeveloped in terms of well-designed comparison studies.¹ Studies are emerging. Pocobello et al.² compared an Italian co-produced mental health centre with traditional day centres in a cross-sectional study to measure hospitalisation rates and use of psychotropic medicines. The study reported a significantly reduced rates of hospitalisation in the coproduced service with higher rates of medicine reduction or withdrawal. Consumer perspectives on the new service highlighted the importance of parity and respectful relationships, a focus on strengths, continuity of psychological supports, social inclusion and a recovery focus.

The Victorian CORE study,³ which aimed to codesign recovery-oriented services within four mental health services (two government and two non-government non-clinical community mental health services) measured the impact of codesigned services on recovery and quality of life outcomes. The study did not find any significant differences in these outcomes between the codesigned services and the control services. Discussion points from this study noted the range of improvements that the process had made to communication and information processes, consumer flow in and from services, and information about activities and programs to connect with. The authors highlighted the complexity of whether the null change in recovery outcomes was connected to the effectiveness of codesign in identifying and supporting the central drivers of recovery, the lengths of time participants had lived with mental health issues, or other potential difficulties with the codesign that was undertaken.

Palmer et al.³ highlight the important considerations of all the key stages and processes of codesign are encouraged via lived experience leadership and facilitators, and are valued by participants when done well. These are recognition of lived experience and narrative knowledge, balanced dialogue and power, cooperation and working through decisions, accountability and shared responsibility, mobilisation of action, enactment of changes, creativity in planning and achievement of the design. Similar processes have been identified in mental health codesign processes in engaging with CALD communities⁴ and for information technology design for improving the mental health of young people,⁵ noting the need to carefully consider the transferability of codesign for work with these groups. A focus on the value of process outcomes for outcomes is in itself very important. High quality codesign identifies barriers and issues of service use from diverse consumer, carer, and community perspectives. The opportunities for consumers and carers to codesign enable important outcomes in engagement, participation, being heard, being valued and gaining new skills.

Codesigned/community led social and emotional wellbeing programs for Aboriginal and Torres Strait Islander people

Evidence on strategies and practice for promoting the social and emotional wellbeing (SEWB) of Aboriginal and Torres Strait Islander Australians point out that cultural affiliation and engagement are associated with resilience and wellbeing. Service provision must be based on a culturally appropriate model of mental health care, in ways that support language use, literacy needs and value Aboriginal world views. Service provision that is not based on cultural competency and has low levels of community ownership, meaning and support or that do not address the effects of intergenerational trauma, past and current racism and structural inequalities (e.g., poverty, homelessness) are unlikely to be helpful in promoting Aboriginal people's SEWB.⁶ This also applies to how program parameters and KPIs support self-determined program outcomes, or provide a barrier

A scoping review on the key practices adopted by programs and services designed to support Aboriginal people's SEWB identified a strong alignment between services' practice and the principles of the *National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2017–2023*. The principles – developed through a national consultation process – include: 1) health as a holistic concept; 2) the right to self-determination; 3) the impact of history in trauma and loss; 4) the impact of racism and stigma; 5) recognition of the centrality of kinship; 6) the need for cultural understanding; among others. Although these have pointed as central principles to observe in promoting Aboriginal people's SEWB, only one of the assessed services applied all principles altogether in a cohesive framework. The findings point that the selective application of nationally designed principles and a scarce scholarship on effective practices in SEWB program and services are areas that demand urgent attention from commissioners and service providers.

A recent study on experiences and perceptions of culture and wellbeing of Aboriginal young people reinforced the importance of events, activities, and practices that provided experiences of cultural connection, the role of elders as teachers and sources of knowledge, and the central role of family and community relationships in promoting wellbeing and resilience.⁷ Additionally, scholarship on what works

for improving the SEWB of Aboriginal people has included community and stakeholder capacity building or the establishment of community-driven health promotion initiatives.⁸

Emotional CPR

Emotional CPR (eCPR) is an educational program based on effective skills to support people experiencing emotional crisis. The 'CPR' reflects the three aims of **C**onnecting, **e**mPowering and **R**evitalising that the communication is about. The original approach was developed by lived experience psychiatrist, Dan Fisher. It was further established through peer contributions and collaboration, and peer led delivery of the training.

Connecting is about using skills of deep and active listening, being present, and creating safety in supportive conversations. EmPowering seeks to help people feel engaged and more hopeful, while Revitalising is about supporting the person to reconnect with relationships and supports, or work towards health and wellbeing.⁹

The approach is taught as a community program for community members, service providers and practitioners, to help promote skills for responding to emotional crisis as a universal human experience. A network of trainers exists across different countries including Australia. Research to identify the outcomes of eCPR is mainly descriptive work on roll out and application. A recent study on program fidelity and feasibility reported that training enables learners to demonstrate skills for identifying emotions, supporting others in distress, supportive nonverbal communication, sharing emotions, self-care and social connectedness.¹⁰

Health literacy strategies

Empowering consumers to facilitate their participation in decision-making includes investing in strategies to increase mental health literacy; the consumer is empowered and supported in the decisional process.¹¹

Quantitative findings indicate that mental health literacy predicts help-seeking behaviour, beyond the impact of self-stigma of seeking mental health support, demographics (gender, ethnicity) and psychological (help seeking history, depression and anxiety symptoms) factors.¹²

Mental health literacy can be improved by use of decision supports to inform and prepare consumers for making decisions¹¹ (See also Shared decision-making below).

Qualitative evidence based on the perception of health care practitioners in hospital-based palliative care suggests consumers with low literacy levels can benefit of extra time during consultations – which needs to be supported by health settings-management. Practitioners must be able to know and recognise low health literacy and adapt their communication to the characteristic of consumers; screening for health literacy levels can be helpful, as well as supporting consumers who need help with

communication skills. This is also about the practitioner encouraging positive and supportive role of family and social networks to seek, understand, and use health information.¹³

Health literacy strategies in mental health include building links across organisations and settings. Planning from the Mental Health Commission of NSW indicates a focus on accessibility of information, engaging with young people, and finding ways to not stigmatise or exclude people in how information communicates, and building capacity in schools and community services.¹⁴

Intentional Peer Support (IPS)

IPS is a well-established approach and training program in the mental health peer movement, led by Sheryl Read. The focus promotes peer support which promotes peer conversations, dialogue and relationship that can grow understanding, awareness and possibilities. IPS is about mutual peer support, where both people in the conversation learn and share, rather than one person being the helper to the other. It works from a trauma-informed way of relating to experience, avoids assuming a problem as the basis of conversation, while encouraging peers to explore how issues are being understood and to whether there are other ways of seeing, thinking and doing. There is a focus on mutually accountability relationships and helping peers to move towards things they want to achieve. IPS training is available in Australia.¹⁵ IPS has a peer based understanding of crisis.¹⁶

The competencies in IPS practice are focused on¹⁷

- » Nurturing and cultivating connections with other.
- » Having a focus on learning together rather than helping.
- » Developing awareness of self and others' worldviews.
- » Shifting a focus from the individual to the relationship.
- » Fostering mutuality, creating space to share perspectives, and share risk and responsibility.
- » Moving the focus towards hope and possibility from fear.
- » Moving towards hopes, values and dreams rather than moving away from what is wrong or bad.
- » Self-reflection on experience, assumptions, feeling power, connection and transparency.
- » Giving and receiving feedback, and co reflection.

Lived experience leadership: service governance, education, and peer support

There are numerous studies describing the activities of lived experience leaders. Many of these are about systems advocacy activities, the development of peer organisations and the engagement of leaders within public mental health services. Most of the studies are focused on consumer leadership and use this term, while some articles use lived experience leadership to also include carer perspective leaders.

Lived experience leadership is about leading change from the lens of lived experience in ways that move across personal, organisational and public boundaries. While leaders often occupy roles as advocates, researchers, peer workers, community educators and activists, it's the leadership action, and use of peer values and knowledge that is central.¹⁸ Consumer leaders bring value to organisational and policy decision-making. This includes critical insights and consumer perspective on justice issues, stigma and service preferences and advocacy goals.¹⁹ Leaders also bring links with consumer networks, credibility and recovery values.²⁰

There is a significant body of research work on the value provided by lived experience leaders in professional education, particularly in mental health nursing. Teaching roles occur via employed consumer or carer academics or via casual teaching staff. Most of these projects have centred on consumer led education. Content and learning exercises make use of consumer perspective, critical reflection and appropriate use of personal stories to illustrate personal effects and impacts. Learning is centred on recovery values, person-centred practices, addressing stigma and a more holistic appreciation of consumer experience. It's also about exploring the social determinants of mental health. Qualitative research indicates that students report significant learning and reflection on these themes²¹ including exposing stereotypes²² and promoting a human first, rights-based approaches.²³

There are valuable older US studies on the connections between lived experience leadership, consumer run organisations, empowerment and learning new skills. These include recognition of the diverse knowledge and skills that consumer leaders bring to organisational roles. These can include governance skills, decision-making and business management, articulating visions for change, voicing values of the movement and negotiating relationships with external stakeholders for influence.²⁴ Consumer-led organisations in the US often encourage higher levels of involvement of members in organisational decision-making and volunteering than other mental health organisations.²⁵ Being a part of the organisations life through leadership or participating in social support activities was found to increase personal empowerment and recovery.²⁶ Personal changes can include as improved self-esteem, problem solving and communication and social skills.²⁷ The empowerment movement encourages a shift from passive receiving towards contribution and valued social roles.²⁸ These are important findings that promote the potential of consumer-led organisations and recovery outcomes for member participants.

Open Dialogue as a social – psycho – bio approach to mental health care

Open Dialogue (OD) initiatives can be found on several countries across Europe, in the United States and Australia. There is a significant roll out of the approach in the NHS in the UK. It corresponds to a person and network-centred approach to the supporting people experiencing mental health conditions: it aims at involving social and professional networks in discussions around treatment options and provide continuity of mental health care following presentation to services. OD privileges community treatment over hospitalisation and addresses the power imbalance experienced by mental health service users, fostering consumer's autonomy in decision-making.²⁹ Open Dialogue also has training programs for specific peer practitioners. Early Open Dialogue studies indicate reductions for people in the use of medicines, increased rates of reconnection with employment over time, and less use of hospitals.

A narrative synthesis of evidence on the efficacy of Open Dialogue as a therapeutic intervention has been published in 2018. The review included twenty-three mixed-methods, qualitative and quantitative designs, and case studies.²⁹

The review points that no conclusions can be achieved about OD efficacy as a therapeutic intervention and that implementation variations across studies make evaluation difficult. The evidence at present is of low quality due to small samples, variation of outcome measures, lack of randomisation and inadequate comparison groups, lack of blinding for rating of outcome measures and conflict of interest.²⁹

A multi-site randomised trial is being planned in the UK. The trial will assess the clinical and cost-effectiveness of Open Dialogue compared to treatment as usual for consumers presenting in mental health crisis to six mental health services in the United Kingdom. The specific aims of the study is to explore whether OD is more clinically and cost effective than treatment as usual in 1) increasing time to relapse after recovery; 2) reducing time to initial recovery, increasing overall days in recovery, and increasing service-user defined recovery; 3) reducing service user and societal costs and improving health-related quality of life; and 4) increasing service user's satisfaction with care.³⁰

Peer navigators: themes in the literature

Peer navigation roles have been developed in different spaces including LGBTIQ+ health,³¹ mental health, the homelessness sector³² and the criminal justice system.³³ While peer work in mental health is a specific discipline with a unique history, values and models, navigation and community linking roles are common across broader peer practice. Peer navigators show promising outcomes in supporting consumers to access integrated care, where mental health services are co-located in primary health settings.³⁴ They can also assist consumers in terms of supporting access to housing, nutrition and engaging with criminal justice assistance, as well as developing/sharing skills in problem solving, working through crisis and goal setting.³² Peers have influence on multiple levels including role modelling, helping to generate trust between consumers and services and acting as community

resource brokers to connect consumers with different services.³³ Peers use their expertise to help others work through barriers and promote better access to mental health services.³⁵

In terms of care delivery for specific groups, peer-led services have been a key feature of many LGBTIQ+ services and programs. For example, essential roles have included information provision, sharing lived experience, creating safe environments, promoting trust and inclusion and access to services. LGBTIQ+ organisations also work with an intersectional focus, developing specific peer responses with Aboriginal and Torres Strait Islander and CALD communities, or diverse age groups.³¹ Peers can provide important supports for CALD communities in terms of providing emotional supports, helping provide information and support for decision-making and problem solving. They can help consumers with appointments, communication, referrals and coordination.^{34, 36}

The recovery leadership, knowledge sharing, coordination and navigation roles provided by peer support workers within mental health services were evident in a recent evaluation of NSW's Peer Supported Transfer of Care Program (Peer STOC).³⁷ Qualitative outcomes from this study indicated that peers contributed to improved system integration by helping consumers to bridge relationships with clinicians and navigate across mental health and other services. The person-centred care and recovery outcomes identified included: being easier to leave hospital, reconnecting with life, daily routines, and community, feeling better understood and cared for, less traumatic experiences in hospital, improved hope, and gaining new strategies and knowledge. The quantitative outcomes from the evaluation found that consumers within Peer STOC programs were significantly less likely to be readmitted to hospital within 28 days of discharge, and for the next 12 months, compared to NSW LHN consumers not in the program. Peer STOC participants also had significantly higher rates of community mental health service use, compared to other consumers. There was no difference in rates of presenting to emergency departments for participants over time, or compared with non-program participants.³⁷

Safewards as an example of nursing-based leadership on person-centred care

The Safewards model aims at providing a safe and therapeutic environment for both consumers and staff in inpatient psychiatric services. It is an approach that involves inviting consumers to meet with nurses on the group level to discuss experiences, safety and preferred ward practices and routines. The processes of the model are focused on generating safety and mutual support for consumers and nurses, reducing conflicts, restrictive practices and coercive outcomes.³⁸

Evaluation of the implementation of the 'Safewards' model in two inpatient psychiatric wards in Germany has produced encouraging outcomes where the approach reduced the number of consumers exposed to coercive interventions as well as reducing the duration of coercive interventions.³⁹

A systematic review on mixed-methods studies on the efficacy of Safewards interventions was published in 2021. The findings suggest Safewards interventions reduced rates of conflict (one study included no statistically significant results), reduced rates of containment practices, reductions at follow up, and both staff and consumers' perceived experience of safety in the ward. The review concludes

that staff and consumers reported that the intervention improved therapeutic relationships, cohesions, and ward atmosphere, leading to consumer-centred and recovery-oriented care.⁴⁰

A study aiming at identifying nursing staff perceptions of the main barriers in establishing Safewards in acute adult inpatient wards was conducted in three general hospitals in Queensland, Australia.⁴¹ Based on quantitative analyses of the perception of 15 nursing staff, the main challenges identified corresponded to staff lack of communication when engaging with the intervention, poor support from management, lack of training and education for staff, and need to invest in reviewing training materials. Suggestions for successful implementation of the model include management support and investments in training, supervision and support during intervention implementation, and reviewing of training material to ensure the strategies fit within the ward context.⁴¹

Safety and risk and person-centred conversations: themes from research literature

Though it might mitigate immediate levels of risk, a medical-custodial model of care delivery can be experienced by consumers as ineffective in managing long-term risk. Person-centred care thus involves moving beyond a 'crisis management' model of care and towards long term collaboration and promotion of autonomy, privacy and dignity in the care relationship.⁴² Within this, there is also a need to shift from risk prediction to engagement with consumer's individual needs, specific concerns and circumstances.⁴³

These shifts require rethinking and providing alternatives to traumatic practices and processes experienced in involuntary admission, policy intervention, emergency department processes, enforced medication compliance, psychologically unsafe physical environments, and admission processes. Clear communication and transparency in the care delivery process is also fundamental to consumers' perception of safety.⁴⁴ Redesigning alternatives can occur by coproducing well-considered interventions in contrast to engaging with consumers as part of a 'professional routine'.

In the context of considering mental health treatment orders, services should facilitate consideration of benefits and costs of care options for consumer. Short term risk management that excludes the consent of a consumer can result in traumatising experiences, that have long term consequences. The principles of maintaining connection, recognising autonomy and dignity of risk should apply, promoting the consumer's right to make decisions involving risk.⁴⁵ Practices of acknowledgment, reinforcing consumers' ability and amplifying opportunities for empowerment should be facilitated in care conversations.⁴⁶

There should also be considerations to alternative options to psychiatric hospital admission, such as prevention and recovery care services.⁴⁷ A further important practice for person-centred outcomes is facilitating the transition from hospital back into the community and continuation of care when hospital admission cannot be prevented.

Shared decision-making as a model to facilitate person-centred decisions

Shared decision-making (SDM) is a model of practitioner–consumer decision-making that is gaining prominence across all of health care. It involves informed and facilitated decision-making when practitioners and consumers, including carers, are considering which treatment options to pursue, including specific medicines. The emphasis on shared decision-making focusses on considering the best available evidence on the efficacy or benefits and costs of a particular treatment, when compared with other treatments or no treatment at all. Another emphasis focusses on involving the consumers, in terms of their views, needs, preferences and experiences in the different steps of decision-making and action.⁴⁸

Decision aids are pamphlets, booklets, pictograms, webpages, or other ways to present recent information and evidence about the treatment being discussed. Decision aids often help consumers to understand the likely benefits, risks and costs (including side-effects) of using a treatment. They can help consumers and families to identify how their own needs and preferences will matter in the decision. They lift health literacy. Some tools and resources have been developed to help consumers to identify and document their views prior to their medical consultations. These help consumers to be more prepared, knowledgeable and involved in care planning.⁴⁹

The evidence on outcomes of SDM is underdeveloped due to the difficulty of studying decision-making processes over time. However, research is building.⁵⁰ Huang et al.⁵¹ report promising outcomes in terms of better continuation with medicines, satisfaction with decisions, more positive feelings about medicines, fewer unmet needs and better recovery. Zisman-Illani et al.⁵⁰ suggests that mental health specific SDM practice is associated with outcomes of increasing empowerment, self-determination, hope and recovery. SDM requires further time for consultations and regularly builds on good therapeutic relationships. Multidisciplinary/interdisciplinary collaboration should also be a basis of sharing decision-making with consumers.⁵¹

Skills for promoting autonomy and choice in decision-making: literature

Qualitative research on the preferences and experience of mental health orders, and inpatient care highlights practice themes and skills for promoting autonomy and choice, and grounding collaborative approaches. Practitioners should consider:

- » Promoting supported decision-making over substituted decision-making.
- » Valuing carer lived expertise on providing care for their loved ones as an important source of information.⁴⁴
- » Decentralising decision-making from clinical staff and including the voices and lived experience of other support staff working with consumers (e.g., Community mental health support workers).⁴⁵

- » Exploring alternatives to coercive practices such as Community Treatment Orders.
- » Open conversations about medication efficacy and side-effects, offering choice around medication intake whenever possible.
- » Involving people with lived experience in the identification of gaps and co-production of research on consumer experience with care delivery.
- » Avoiding coercive practices as it is experienced as emphasising deficits, leading consumers to feel powerless and trapped.
- » Coercion contributes to consumer distress, and activation of trauma responses to feel in control (e.g., self-harm), can contribute to iatrogenic trauma.⁴²

Supported decision-making: an approach promoting person-centred and consumer directed decisions

SDM is an approach that is guided by the Convention on the Rights of Persons with Disabilities (CRPD), and seeks to replace traditional forms of substituted decision making. It is about ensuring that people with disabilities are able to make their own life decisions on an equal basis with others and have assumed legal capacity to do so. SDM shifts power on decision-making processes from clinicians to consumers and emphasises the consumers expressed wishes. SDM can be facilitated by processes such as advanced directives and nominated/ trusted decision support people. Consumers are considered the experts in relation to their own mental health experience and SDM promotes personal agency and rights to choose.⁵²

Its implementation requires good communication skills, positive attitudes and skilled practice among mental health practitioners. Health systems must be based on all-encompassing, whole of organisation approach to care and support services that maximise self-determination, choice and goal-achievement for consumers. Trust, transparency and connection shape the motivation and ability of consumers to express their decisions. Practitioners must pay attention to wishes and preferences previously specified in advancement directives; such legal support decision-making practices can facilitate implementation of SDM in care delivery.⁴⁶

Trust and trauma-informed relationships: themes from the literature

Qualitative research points to key practices and outcomes from a trauma-informed care approach. There is a major focus on avoiding coercive measures, as these traumatise or replicate the experience of past trauma for consumers, promoting fear and hypervigilance, and hindering trust. Practices identified in the literature for trauma-informed mental health care delivery include:

- » Valuing the consumer as a person with a unique history.
- » Encouraging consistency in support and awareness from carers.
- » Offering a context for validation of consumers' distress.
- » Provision of clear explanations and transparency around decision-making and implementation of routines of care.
- » Translating the consumer's preferences into outcomes whenever possible – consumers need to feel that they are influencing decision-making. The provision of consumer run and peer-led mental health care delivery – lived experience can highly contribute to reducing inequality and reinforce safety in the care provider and consumer relationship.^{42, 44}

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