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.

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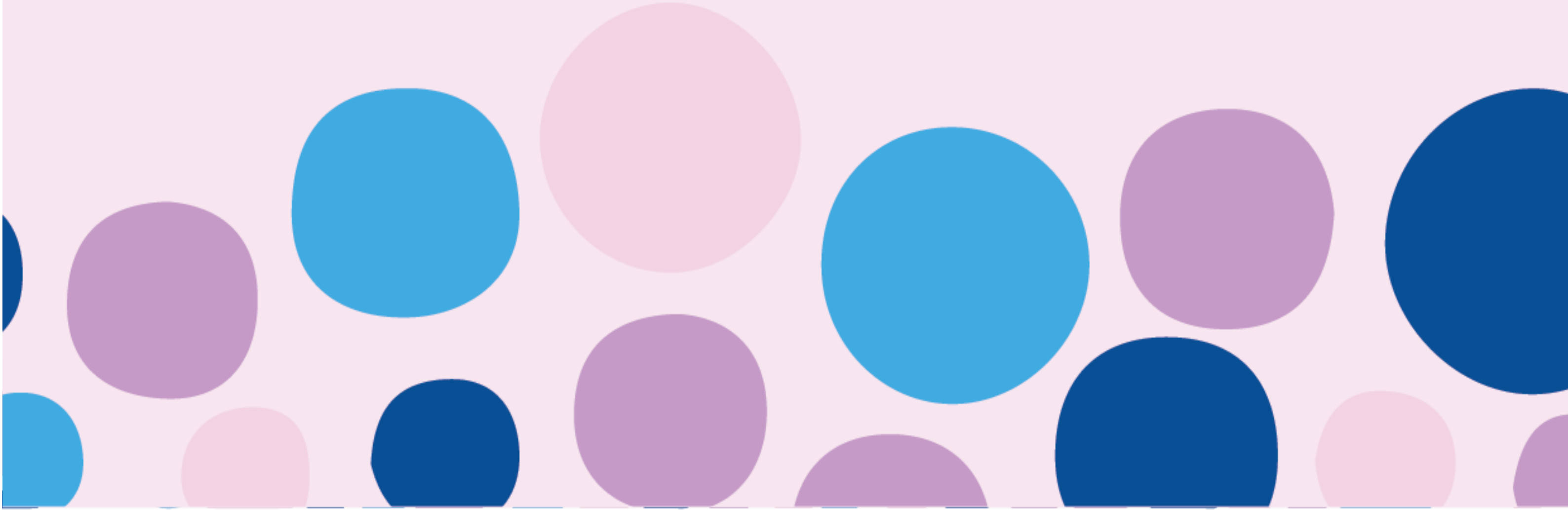

Acknowledgement of Country

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.[1]

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TABLE OF CONTENTS

Acknowledgments

Foreword

Glossary

Executive summary **1**

Section 1 Context and Background **5**

- 1.1 Aims of the Spotlight report project 5
- 1.2 Who is this report for? 6
- 1.3 Outline of the report 6
- 1.4 Person-centred care 6
- 1.5 Consumer directed care 8
- 1.6 Consumer and carer experience and preferences 10

Section 2 Methodology for consultation and codesign **13**

- 2.1 Consultation participants 13
- 2.2 Consultation structure 14
- 2.3 Analysis 15
- 2.4 Role of literature 15
- 2.5 Codesign 15

Section 3 Findings on concepts and challenges **16**

- 3.1 Concepts of person-centred care and consumer directed care 16
- 3.2 Different concepts and different service contexts 18
- 3.3 Experiences of person-centred care and consumer directed care 20
  - 3.3.1 Knowledge power and decision making 22
  - 3.3.2 Service and systems design 24
  - 3.3.3 Risk and consumer autonomy 27
  - 3.3.4 Service skills and capacities 29
  - 3.3.5 Recognition, awareness and diversity 32
- 3.4 Summary of section 3 33

Section 4: Creating shifts toward person-centred and consumer directed care 34
    4.1 Developing the Shifts 34
    4.2 Shift 1: Strengthen practitioner education and training on essential knowledge and skills 37
    4.3 Shift 2: Embed supported decision-making practices within mental health legislation 39
    4.4 Shift 3: Create a national program for strengthening leadership 40
    4.5 Shift 4: Strengthen lived experience leadership 43
    4.6 Shift 5: Develop a focus on ‘relational recovery’. 44
    4.7 Shift 6: Promote and fund crisis response models 46
    4.8 Shift 7: Fund lived experience organisations to co-design local mental health programs 48
    4.9 Shift 8: Fund lived experience organisations to provide peer navigation services 50
    4.10 Summary of section 4: shifts, practice approaches and outcomes 51
Section 5: Summary and recommendations 54
List of appendices 59
References 60

GLOSSARY

This guide recognises that within the mental health space, language is an important consideration to enable empowerment and reduce stigma. Language used in mental health can often vary, and below we have identified which terms we have used in the report, as well as defining some of the key concepts discussed.

TERM USED	DEFINITION
Advanced care directive	A document that details an individual's preferences for receiving treatment and care. It is used as a guide for care providers to ensure that individuals receive the care they want, how they want it when they are unable to communicate these wishes at a point in time. It also allows individuals to identify decision-makers to guide decisions about their care on their behalf.
Agency	A person's ability to make decisions that actively create meaning in their lives. This can include deciding to participate in an activity (e.g. returning to work), or to assert a basic human right while facing an injustice.
Consumers	A person with a living or lived experience of mental health issues. Consumers include people who have a formal diagnosis and have engaged with services, as well as people who have not engaged with services or received a diagnosis. Other words people may use include service user, peer, person with lived experience, or survivor.
Carers	People, often family members and/or families of choice (including children and young people), who have provided ongoing personal care, support, advocacy and/or assistance for a person with mental illness. Carers include people in the consumer's support networks who play a meaningful support role. This role differs from the role of a paid carer, who is a person employed to care for someone.
Codesign	An approach to designing, planning, and evaluating services, and outcomes in which consumers, carers, and health professionals work as equal participants and partners. The approach is guided by awareness of, and actions towards, balancing power dynamics and an

	understanding that the products (programs, services, and outcomes) must effectively respond to consumer and carer experience and interests.
Dignity of risk	An idea that an individual’s self-determination and the right to take reasonable risks in their life is central to their feelings of dignity. Individuals can be supported when engaging in activities which carry risk. Overly cautious providers focused on duty of care can impede opportunities for personal growth, self-esteem and quality of life.
Engagement	The methods, practices and actions that enable someone to become involved in organisational planning and decision-making. This can include consumers, carers and other community members.
Intersectionality	An analytical framework used to understand how a person’s multiple identities overlap and interact to create simultaneous experiences of discrimination and marginalisation. Aspects of a person’s identity, such as gender, nationality, or socio-economic status, can lead to discrimination based on social attitudes and systems, such as sexism, racism, and stigma. This interaction between identity and attitudes can simultaneously contribute to mental health issues, as well as create systemic barriers to accessing care.
Kinship group	A term that refers to the relationships, roles, responsibilities and obligations of many Aboriginal and Torres Strait Islander people. Kinship relations and culture are not easily understood in terms of relationships in the Western definition of family.[2] An important aspect of kinship care and responsibility concerns which people can be involved in a person’s care, and the people who can play leadership roles in the community.
Lived experience	A broad term that refers to the personal perspectives on, and experiences of, being a consumer or carer, and how this awareness and knowledge can be communicated to others. The term covers people’s core experiences around significant mental health issues and service use that may have occurred in the past or may be ongoing (sometimes called living experience).

Lived experience advisors	Lived experience advisers are people active in the following roles: Consumer adviser: A consumer with expertise in this area who participates in consultation or decision-making groups and speaks and acts from a collective consumer perspective. A consumer adviser works to ensure that the rights, interests and needs of consumers are heard, recognised and responded to. Sometimes they are called consumer advocates. Carer adviser: A carer adviser plays a very similar role to that of a consumer adviser in contributing to decision making groups but speaks and acts from a carer perspective. Carer advisers work to ensure that the rights, interests and needs of carers are heard, recognised and responded to. Experienced carers understand the need to recognise consumer voices rather than speaking for them. Lived experience roles are still developing in the health contexts of Aboriginal and Torres Strait Islander peoples, [3] and culturally and linguistically diverse communities.
Lived experience leader	An umbrella term that includes people with lived experience who are recognised as leaders within consumer and carer communities in actively promoting perspectives, creating collaborative action and leading change.[4] These roles include people who are active as advisers, consultants, representatives, community and peer educators, peer workers, advocates and activists.
Mental health issue	A broad term that refers to experiences which impact on a person's cognitive, emotional, interpersonal and social wellbeing. Many people may prefer to use this term rather than use illness related language.
National Disability Insurance Scheme	A scheme that is funded by that Australian Federal Government to assist in the cost of supporting individuals with a disability. Funding packages are administered to individuals/caregivers through the National Disability Insurance Agency. Funding plans enable individuals to access a range of supports that they identify as needed.

Practitioner	An umbrella term, referring to a variety of professionals involved in delivering mental health services in both clinical and non-clinical settings.
Psychosocial disability	A term used to describe disabilities that may arise from mental health issues. These may include difficulty in managing the social and emotional aspects of life, and impacts on some everyday tasks such as communication, social interactions, self-care and organisation. Many people with psychosocial disability experience social marginalisation and disadvantage.
Recovery	Recovery is a personally defined process. A common definition is ‘being able to create and live a meaningful and contributing life in a community of choice with or without the presence of mental health issues’. Values associated with recovery are hope, personal choice and self-determination, empowerment, transformation, discovery, connection, dignity and justice. Increasingly, recovery is seen not only as a psychological process, but also as a social and relational process.[5] This development recognises that change occurs through relationships and opportunities that consumers choose, which results in healing and empowering experiences. Recovery is about transforming relationships in community life, especially around employment, education and other areas of citizenship. This requires action on the social determinants of mental health and upholding human rights to promote understanding, acceptance, and inclusion. As such, the term ‘relational recovery’ is often used to encompass the social aspects of recovery.
Social determinants of mental health	A framework describing how life aspects can impact on mental health. This framework includes demographic, economic, environmental, social and culture factors of living. Common factors included within social determinants frameworks include health care access, experiences of discrimination, trauma, poverty, housing, income and education.

EXECUTIVE SUMMARY

More than ever, consumers, carers, families and kinship groups in Australia are demanding more person-centred mental health care responses. There is significant movement towards mental health service planning and models of care as co-produced enterprises, where collaborative methods make the best use of lived experience and professional knowledges. This reflects a growing transformation of mindset and practice, whereby the movements of lived experience, recovery and disability rights, as well as the paradigm of trauma science are requiring shifts from older custodial practices and practitioner centred decision making.

Mental health and suicide-related crisis are unique areas of human experience and require specifically designed care and comfort approaches. These acknowledge and respond to the whole person, their family and social context. While current care models enable involuntary care for people in emergency situations, there are urgent reforms required to transform the care experience to ensure that care consistently empowers, maximises consent and autonomy, and maintains a positive, ‘compassion first’ connection between consumers, carers and providers. The experience of care should not be traumatising, restrictive, disempowering, or burdensome. Practitioners need the professional guidance, organisational and work role structures, supports, time and resources to meet their expectations of high-quality recovery orientated care.

This spotlight report has been generated to explore how the concepts of person-centred care (PCC), and consumer directed care (CDC) are being conceptualised and experienced in Australia’s mental health and suicide prevention systems. The aim of the report is to highlight the contexts and tensions involved and identify possibilities for improving levels of person-centred and consumer directed care. These are two different concepts, with PCC being a foundation approach in the public health system, including public specialised mental health services, and CDC being the defining approach of the NDIS and many recovery-oriented providers. Many consumers experience both approaches, across multiple services and systems, and both approaches need to be explored from the perspectives of lived experience and practitioners.

The project consulted Australia wide with 50 consumers, carers, mental health practitioners and policy leaders across 24 group and individual interviews. The themes and ideas generated through consultation were then discussed and explored via a co-design process focused on preferred shifts in thinking, practice and funding. The co-design process brought the academic team together with 20 participants to discuss potential shifts, identify important outcomes, highlight key examples of aligned approaches. There was a focus on both systems change and point of care practices. Alongside these conversations, the team has reviewed literature specific to PCC and CDC outcomes, and conceptual models for improving collaboration, decision making and recognition of consumer experience and rights.

Understanding person-centred care in mental health

Through thematic analysis, we found that participants described PCC in mental health as care that is centred on the person’s story and expertise, and that decision making should be shared between practitioners and consumers with a balancing of power. PCC encourages significant and meaningful carer, family and kin inclusion. Service offerings should be flexible, accessible and be able to meet a person’s wishes, preferences, strengths and holistic needs. There is a focus on the social context of relationships, roles and connections that are central to recovery. PCC is facilitated through high quality communication and information sharing and should feature trusting, empathic and safe relationships, without imposition or coercion.

The identified outcomes of PCC reported by participants are about quality of service and positive care experiences. Participants identified self-determination, empowerment and inclusion in decision making as key outcomes. They also highlighted that PCC is better able to meet identity related needs and cultural values. Descriptions emphasised important outcomes of psychological and physical safety, and better-quality care relationships where respect, empathy and trust between practitioners, consumers and carers is the foundation. We found these outcomes were well aligned with published research in literature reviews.

Understanding consumer directed care in mental health

CDC was described by participants as a concept that overlaps with PCC in many aspects. CDC builds on PCC and strengthens consumer choice and self-determination, where decisions about what services are required and desired are made by the consumer. CDC also emphasises the need for flexible and accessible services, with a focus on seeking supports to meet a wide variety of recovery interests. CDC promotes a dignity of risk or risk tolerant approach and reflects a disability rights approach, rather than a sole medical approach; practitioners privilege capability rather than assessing for capacity. CDC acknowledges that a range of different services and practitioners are often chosen by consumers. As such, there is a need for high quality support and information systems, coordination and navigation across services.

CDC outcomes identified by participants were about quality-of-service experience. These were centred in empowerment and choice, while being effective and contributing to recovery. As in PCC, empathy and psychological safety in consumer-practitioner relationships were other outcomes considered to be important to CDC. Similar outcomes are apparent in mental health studies relating to self-directed care from the USA.

Challenges, barriers and issues

From the consultations we identified that the experience of PCC in public mental health services is inconsistent, with many consumers and carers describing that there is a stark difference between rhetoric and reality. There were also significant challenges to achieving CDC in psychosocial or community sector programs. Practitioners highlighted a wide variety of challenges, barriers, and issues relating to the ability to consistently deliver PCC or to develop programs which enabled CDC outcomes. Collectively analysed, the top 13 themes for challenges and barriers were:

- Paternal culture and limits of the medical model
- Professional power and knowledge can disempower lived experience
- Lack of service flexibility
- Funding and service parameters that limit program design
- Lack of pathways for people experiencing complexity
- Lack of information about available services
- Mental health laws and experiences of coercion
- Too much focus on risk
- Inconsistency of practitioner skills
- Lack of true commitment and support for implementation
- Resource/time limitations and practitioner burn out
- Stigma and stereotypes about consumers
- Need for accessible services for specific communities

Recommended shifts to mindset, practices and service models

Through the analysis and co-design processes, this report identifies eights shifts for change. These reflect systems level actions targeting practitioner education, legislation, service and lived experience leadership, and commissioning of new models of service. The report defines each shift, the range of outcomes that should guide action, and important considerations for planning and discussion. The shifts are:

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

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.

3. Create a national program for strengthening leadership and championing for organisational change in public mental health services.

4. Strengthen lived experience leadership in service governance and in the workforce.

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.

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

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

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

The research team also recommends that further research should be funded to co-design and evaluate development of a national outcomes and impact framework for PCC and CDC. This should be guided by lived experience, and be applied at the program and service level, as well as the national level.

SECTION 1 CONTEXT AND BACKGROUND

1.1 Aims of the Spotlight report project

Health care concepts and approaches such as PCC and CDC guide the planning, delivery and evaluation of services. They drive and reflect what we value in the delivery of health care and help to set expectations across health and disability services. This report has been funded by the National Mental Health Commission to encourage better understanding about both PCC and CDC within publicly funded mental health services.

The aim of the project was to gain more clarity and detail on how service providers, consumers and carers see person-centred and consumer directed care in practice. This includes:

- 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 and analysing perceptions of PCC and CDC, including a focus on challenges, issues and barriers that occur in mental health services.
- Highlighting the gaps, tensions and opportunities these concepts offer in the mental health sector.
- Recommending actions and strategies for better achievement of person-centred and consumer directed services.

One of the important features of the project was to discuss person-centred and consumer directed care in the unique context of mental health care, where legislation guides decisions impacting the lives and wellbeing of consumers, carers, families and communities. This report therefore acts as a key information resource to help readers identify and work through some enduring tensions and issues that impact the achievement of PCC and CDC in mental health services.

The project used consultation and co-design processes as the main methods to identify themes and ideas for this report. As consumers and carers received services across a variety of providers, it was important to have a broad scope across the mental health sector. The project therefore focuses on the care concepts across specialised public mental health services including hospitals and community teams, services provided by private or non-government organisations (NGOs) and NDIS funded supports.

1.2 Who is this report for?

This report has been developed to encourage discussion, reflection and action by key stakeholders in mental health. This includes:

- Mental health service providers, the different mental health professions, researchers and educators.
- People with lived experience, including leaders, advocates and representative organisations.
- Health provider executives and leaders.
- Policy makers and funders.

1.3 Outline of the report

This report is made up of five different sections to explore the concepts of PCC and CDC.

- This section is about the project purpose and aims, as well as the background to the concepts of PCC and CDC.
- Section 2 discusses the methods of the project, including consultation, co-design, analysis of results and the use of evidence from literature.
- Section 3 reports the findings from the consultation and co-design processes. It focuses on how PCC and CDC were collectively defined by project participants, as well as the most prevalent challenges, barriers and issues identified. This section also highlights gaps, tensions and possibilities that were identified by the team's analysis and are also noted in literature.
- Section 4 presents the results from the co-design process on recommended shifts and actions concerning change. Each of these actions is linked to outcomes and considerations that were generated by a co-design process. This was done as an intentional and collective way of promoting discussion, reflection and action for better PCC and CDC.
- Section 5 provides an overview of the project and summarises the recommendations of the project.

1.4 Person-centred care

History

Despite a long history of personalised health care PCC, as a concept in modern practice, has arisen over the past five decades as the definition of health has transitioned from a biomedical model to a biopsychosocial model. Over this time, PCC has been conceptualised in many ways, including patient-centred care, person and family-centred care, relationship-centred care and personalised care, among others. Initially included in the delivery of primary physical health care, PCC is increasingly being discussed in the context of mental health care, both in primary and specialist settings. Recently, the concept of PCC has been included in considerations of human rights to health care as facilitating safe and high-quality care which upholds consumer rights.

Definition and principles

PCC is about providing services and support that pay close attention to individuals' unique needs, preferences, circumstances and goals. Here, the focus is on what is needed to be helpful and what is effective for each person. Consumers are viewed holistically, meaning their physical, emotional, social and spiritual needs are considered in health care delivery. Where appropriate, PCC approaches may be expanded to *person and family centred care* approaches. This involves family or kinship groups in the decision making around a person's care. The aim of PCC is to deliver care that is respectful of—and responsive to—individual preferences, needs and values. Specifically, PCC considers the individual in the centre of decision making, and is often guided by Picker's Principles of PCC:[6]

- Respect
- Emotional support
- Physical comfort
- Information and communication
- Continuity and transition
- Care coordination
- Involvement of family and carers
- Access to care

Use in mental health services

PCC principles have been introduced and developed across the wider public health system via the development of National Safety and Quality Heath Service (NSQHS) Standards.[7] There are eight standards which set expectations about the way services are organised and delivered to people using health services such as public hospitals and community health services. Six of the standards are especially relevant for mental health services and encouraging person-centred mental health care. These are:

- Clinical governance – helping opportunities for consumers, carers, families and kinship groups to be involved in governance committees, feedback and complaints management and consumer centred leadership.
- Partnering with consumers – services should involve consumers, carers, families and kinship groups in their own care and support lived experience involvement in the planning, delivery and evaluation of services.
- Medication safety – producing information to help consumers' knowledge about medicines, benefits and risks – involving consumers in medication safety procedures.
- Comprehensive care – encouraging services to use care planning which involve consumers and the broader health care needs/responses. Also minimising harms and using a trauma-informed approach.
- Communicating for safety – enhancing continuity of care and consumer and carer involvement at handovers or other times such as discharge, moving to another unit.

- Recognising and responding to acute deterioration – identifying when consumers experience deteriorating mental health and require increasing level of supports.

Many within the mental health sector regard the NSQHS as a key framework guiding person-centred health care in Australia, as all public health services are formally accredited using these standards. It is important to acknowledge that limits to PCC and decision making may occur due to mental health legislation, and the use of treatment orders or other restrictions on consumer autonomy and decision making.

Outcomes and evidence associated with PCC.

The research literature on PCC in mental health care is mostly focused on consumer experience outcomes, rather than longer term health outcomes. This is evident across several literature reviews. These emphasise the importance of high-quality therapeutic relationships, which are characterised by respect, empathy, trust and reliability outcomes for consumers.[8-10] The reviews also highlight the importance of increased participation and deliberation in care decision making for consumers (shared decision making) This is connected with outcomes, such as empowerment and inclusion,[8, 9, 11] and more inclusive recognition of culture and gender. [9] A related benefit incorporates greater levels of information offered to consumers and carers that occurs through high quality and transparent communication from practitioners. This includes service and treatment related information,[8-10, 12] and case note information.[8] Other evidence associated with shared decision making includes better continuation of medicines, more positive feelings about medicines, fewer unmet needs,[13] increased self-determination and hope[11] and improved recovery.[11, 13]

A significant focus in several reviews is the quality of physical environments (mostly focused on inpatient settings) which help consumers to feel conformable and safe.[9, 10] This includes factors such as including colours, spaces to allow for walks/gardens, private bedrooms, facilities for making hot drinks and snacks, and environments which are free from conflicts and arguments.[9] McKay et al. argue that provision of person-centred care in involuntary care environments is possible. This can occur by promoting consumer agency and choice, transparent communication, safe environments and respectful relationships.[10]

1.5 Consumer directed care

History

The concept of CDC has predominantly come from within the disability sector, where people with disabilities campaigned for rights to independence, participation and citizenship. CDC principles have also been applied to aged care to meet the needs and desires of the aging population.

Definitions and principles

CDC aims to give individuals greater decision-making capabilities over the care they receive, including what type of care, where they receive it and who provides it. CDC principles are distinguished by choice and control for service recipients, allowing them to tailor the care they receive to meet their needs. Mostly, CDC programs are what is labelled a ‘cash-for-care’ scheme, where individuals are provided funds for their care, which they can spend on the services they want, or stop spending on services they no longer want. CDC utilises budgeting and marketisation concepts to drive the quality and quantity of care services provided.

Use in mental health services

CDC in the Australian mental health settings mostly occurs via people using the National Disability Insurance Scheme (NDIS) for psychosocial disability. The scheme is directly designed following CDC principles and was developed to help people with a wide range of disability needs, and later included mental health and psychosocial disability. Consumers approved for an NDIS plan by the National Disability Insurance Agency (NDIA) can use their designated budget to buy in services they prefer. There is opportunity for consumers to develop their plan with the NDIS, and then look for services that can be useful for meeting daily needs or areas of growth and learning.

NDIS funding includes itemised services such as support workers, recreation, therapists and recovery coaching. As NDIS supports a ‘market’ of service providers, many individual or small business providers have become active. Larger organisations have also adjusted their workforces to offering peer support, general support or therapeutic services to consumers.

CDC and recovery principles

Apart from the NDIS as a nationally funded scheme, some mental health services choose to have a philosophy of CDC based on recovery principles of empowerment and peer support.[14] These services also work from a framework of trauma-informed care, which is committed to consumer empowerment, choice, power sharing, trust and transparency. Examples are NGO services or consumer-based organisations. These services have a strong commitment to support consumers to find and receive the care and support they want, rather than what they are eligible to receive.

Outcomes and evidence associated with CDC

CDC based programs vary by country and target groups, which impacts on the way outcomes are documented and evidence is generated. Current research on outcomes includes the aged care sector and some areas of disability. There is also research evaluating the outcomes of self-directed care or personalised medicine from the USA which are similar programs in principles and approach.

In the aged care literature, commonly reported outcomes and benefits from CDC include increased positive experiences of care, empowerment and choice, better quality of life for carers,[15] more flexibility in the timing of care services, a broader range of life needs met, fewer unmet needs and improved medicines management.[16] Continuity of care and support, and credible relationships with providers have also been valuable outcomes described by aged care consumers.[17]

In terms of CDC in disability sectors, the research on an improved range of service or life outcomes is limited. However, it does acknowledge the promise of CDC based programs from improving control of decision making, quality of life, better levels of care and psychological wellbeing.[18] A review on the Australian NDIS and services for people with psychosocial disability found very little in peer reviewed literature on the experiences and outcomes of the Scheme.[19] Rather, the literature reported on extensive issues with implementation, accessibility of NDIS and the difficult connection with the NDIS and recovery perspectives.

More broadly, there are some studies reporting on the benefits of CDC type service models. A study from the USA reported that consumers in a self-directed care program reported improved levels of self-rated recovery, self-esteem, autonomy support, coping, employment and education compared to participants in the control group. They also had higher rates of satisfaction with services.[20] Another USA study found that consumers were better able to draw on a wider range of support services under the model compared to traditional mental health agency care. These include buying in services relating to engagement in life activities, transportation services, ways of working through stresses and services to assist with diet and fitness.[21] Other studies report cost benefits associated with consumer directed care – suggesting improvements in social relationships and connection come from accessing non-clinical supports that help people reach their recovery goals.[22] Avoiding higher economic and social costs associated with unmet needs, including hospitalisation, homelessness, residential care and contact with criminal justice systems, is an important outcome.[23]

1.6 Consumer and carer experience and preferences

It is important that development of PCC and CDC concepts are well connected with consumer and carer experience. In undertaking the project, we have reviewed several key areas of documented consumer and carer experience to identify themes that provide an important context. These include lived experience peak body consultation reports, Your Experience of Service (YES) survey trends, and various PCC considerations for diverse population groups. This range of supporting information is available as Appendix 1.

Various consultation reports and submissions of state-based lived experience peak bodies argue for important improvements in PCC and CDC within public services (see Appendix 1 for a more information). As peak bodies operate as systems advocates, these reports often reflect the views of people who have experienced service gaps, poor quality care, trauma within services and other iatrogenic harms. There are significant examples where consumer groups have reported on issues relating to access to care, engagement experiences, preferred language, stigma and discrimination, service design, flexibility and ideas for improved service pathways.[24, 25] Carer groups continue to report that improvements are required in the availability of carer supports, inclusion of carers in care planning and improved crisis responses for consumers and families.[26, 27]

A major source of reporting consumer experience of public mental health services across Australia is the YES Survey, a 26-question instrument that consumers complete during care. The Australia Institute of Health and Welfare publish some aspects of annual data results and some states (NSW, QLD, and WA) have produced specific reports. The results from YES surveys need to be interpreted with some caution given differences across states in the number of surveys completed and diverse methods for inviting consumers to complete the survey process. However, results from 2018[28] and 2019[29] from the states of NSW, QLD, Victoria (2018 data only) and WA[30] shows:

- Higher proportions of YES Survey respondents rate their experience of service as ‘Good’, ‘Very Good’ and ‘Excellent’ when using community services as compared to hospital (admitted care) services.
- Higher proportions of YES Survey respondents rate their experience of service as ‘Good’, ‘Very Good’ and ‘Excellent’ when they have voluntary mental health legal status as compared to involuntary legal status.
- The lowest proportions of respondents reporting a positive experience of care are consumers using inpatient hospital services with an involuntary legal status (see Appendix 1 for more information)

YES Survey trends indicate that a very significant number of consumers do not feel they have positive experiences of care in involuntary contexts, especially when admitted to inpatient units.

Diversity of consumer and carer experience

One of the enduring challenges for large health services and systems is to effectively understand and respond to diverse community groups. This means that the planning and organisation of PCC or CDC needs to take a diversity approach as opposed to staying at a generalised level. Recognition is also needed towards established areas of lived experience and community leadership within specific communities, as well as representative organisations, services, programs, approaches and research. For example, Aboriginal and Torres Strait Islander communities have established networks of community-controlled health services, research, health leadership and lived experience leadership.[3] The frameworks of social and emotional wellbeing, intergenerational trauma, community engagement, cultural respect and cultural safety provide essential ways of offering mental health care that overlaps with the general principles of PCC and CDC.

Working from a diversity approach also requires an understanding of intersectionality, and how consumers, carers, families and kinship groups may be experiencing multiple and overlapping forms of discrimination and related trauma. This may include simultaneous experiences of racism, heterosexism, able-bodyism, religious intolerance or other forms of discrimination.[31] This is an important understanding when getting to know the wider needs of the person or group; for example, where a young person is from a refugee background, is same sex attracted, is homeless from family conflict and has learning disabilities. It is essential that therapeutic approaches attend to multiple experiences and layers of identity that are part of the persons context, and hence recovery journey.[31] It is also important from a planning perspective, in that planning services for specific groups needs to account for intersecting needs and service relationships among group members. Practically, this is a complex task, as we often focus on the needs and service interests of one identity group at a time, masking awareness of wider needs and experience.[32]

SECTION 2 METHODOLOGY FOR CONSULTATION AND CODESIGN

To achieve the aims of the report, the team decided to use interviews and focus groups with relevant stakeholders to understand how person-centred care and consumer directed care are being implemented in the Australian mental health care landscape. This was achieved by contacting service providers, consumers and peak bodies to invite them to participate in the consultation process. It was important to the research team that those participating provided diversity between practitioners and consumers, as well as across the country.

2.1 Consultation participants

The research team invited 39 organisations and over 20 individuals to participate in the consultation process. 20 organisations were able to connect with the project and contribute. Potential participants were sent a letter of invitation via email with information about the purpose of the consultation process. Those who did not respond to invitations were sent a follow-up email, and where possible, a phone call. Consultations occurred between November 2021 and March 2022.

Consultations for this project were conducted with consumers, carers, providers and peak bodies from across Australia. There were nine focus groups and 15 individual interviews completed, with 50 people participating in the consultation process. Participants represented the following groups:

- Perinatal mental health services
- Consumer advisors
- Carer advisors
- Peer work practitioners
- Child and adolescent mental health services
- Mental health nursing practitioners
- Office of the Chief Psychiatrist
- Psychiatric practitioners
- Aboriginal health services
- Clinical psychologists
- State-based Mental Health Commission
- LGBTIQA+ communities
- Youth work organisations
- Migrant and refugee communities
- Peer based services
- Drug and alcohol services
- Adult mental health services

A feature of this work was participants being able to provide practitioner and lived-experience perspectives in the consultation process. This allowed stakeholders to collectively contribute different perspectives and experiences and explain ideas about PCC and CDC. Some focus groups featured a mix of practitioners, peer practitioners and lived experience advisers. Breakdown of participants by state and role can be found in Tables 1 and 2

Table 1: Number of participants by state.

NSW	SA	TAS	WA	VIC	TOTAL
26	7	1	8	8	50

Table 2: Number of participants by affiliation.

PRACTITIONER	CONSUMER	PEAK BODY	CARER	PEER WORKER	TOTAL
13	10	8	12	7	50

2.2 Consultation structure

Consultations ran between 30 and 150 minutes, depending on the number of participants. All consultations were conducted over video conference due to the COVID-19 pandemic restrictions. During consultations, we aimed to understand:

- 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 barriers exist to the implementation of PCC and CDC.
- What shifts need to occur to allow PCC and CDC to be implemented.
- Examples of good practice PCC and CDC.

Participants were sent a background document explaining the concepts of PCC and CDC, and a copy of the consultation questions (see Appendices 2 and 3). Consultations were facilitated by one member of the research group, while another took detailed notes of the participant responses. Key phrases and quotes were recorded where points were emphasised by participants, rather than transcribing each consultation verbatim.

2.3 Analysis

At the completion of the consultations, notes were analysed into themes using a coding framework based on the topics discussed: CDC and PCC conceptually, barriers, shifts, and practice examples which produced positive outcomes. Sub-codes were then generated based on the data (see Appendix 4). Initially, notes were separated into lived experience groups and practitioners and policy makers to identify what aspects were similar and different between the two groups.

2.4 Role of literature

We did not undertake a formal literature review in the creation of this document. Instead, we used literature to contextualise the themes present within the consultation data with broader academic, lived experience and service provision understandings. This has been done in both Sections 3 and 4. Where possible, we have attempted to find systematic reviews that speak to the concepts discussed within consultations and the co-design process.

2.5 Codesign

After notes from the consultations were analysed, the project undertook a co-design process with 20 participants. 10 participants were invited from previous consultation networks, while 10 new participants were recruited, due to unavailability or limited capacity of earlier participants. The purpose of the co-design sessions was to guide thinking on barriers and possible shifts of practice and services to facilitate more consistent experiences of PCC and CDC. The outcome was the direction of the shifts described in the report, as well as key considerations about context, outcomes and good practice examples.

Co-design occurred over three 90-minute online sessions, with a facilitator external to the author team. Co-design employed a range of small and large group activities and open-ended questions regarding the language and concepts of PCC and CDC. The facilitator and author team recognised the diverse way that people contribute and provided necessary tools and resources to support this. The process involved seven consumers, four carers, six practitioners, two lived experience peak body representatives and two supporters which facilitated rich discussions and perspectives on the issues and shifts identified through the consultation process. Participants were from Victoria, South Australia, New South Wales and Western Australia. Detailed information about the co-design invitation and summary slides is available in Appendix 5.

SECTION 3 FINDINGS ON CONCEPTS AND CHALLENGES

Section 3 describes the findings from the consultation process. This is separated into three parts: 1) participant's understanding of PCC and CDC principles and outcomes; 2) participant's views of PCC and CDC within mental health services; 3) participant's experiences of challenges, issues and barriers in implementing PCC and CDC. The findings were generated by thematic analysis of participant interview transcripts, which identified the most significant and prevalent themes across 24 consultation interviews. Relevance of themes to the current literature are integrated throughout, and issues that need consideration outlined last.

3.1 Concepts of person-centred care and consumer directed care

One of the aims of the project was to identify how participants understand the concepts of PCC and CDC, and the connection to desired outcomes. From the analysis of consultation notes, the authors identified key themes for both concepts. Themes were then discussed within the co-design process which further refined the themes into a revised list for each concept.

All participants agreed that both PCC and CDC were important practice concepts for mental health service provision, believing that utilising these concepts will result in better outcomes for consumers, and carers. While there are similarities between the two concepts, it is important to recognise that these are two distinct approaches that lend themselves to different contexts. Conflating the two should be avoided. Overall, PCC is *provider driven* and most relevant within public health services, while CDC is *consumer driven* and therefore more orientated towards services provided through arrangements that maximise consumer choice and control (e.g., NDIS services). Table 3 provides a summary of the different themes within each concept.

3.1.1 Person-centred Care in mental health.

Key themes defining PCC in mental health were focused on a *holistic view of health* and *autonomy for individuals*. PCC takes a holistic view of health, recognising people in their social context, and seeing their interests, preferences, strengths and relationships. In most circumstances, this perspective is extended to include consumers, carers, kin and/or support people in health care decision making and planning. Successful outcomes are measured by what works for consumers, carers, families and practitioners. Recognising autonomy enables consumers to have power and agency to make decisions about their own care, integrating health literacy, learning and informed consent as important consumer experience outcomes. However, health systems are complex, and it should not be assumed that every person has the same capacity or health literacy to navigate different services in order to receive the care that they require. For care to be person-centred, people need information, choice and an equitable share of power. PCC also requires that services are coordinated, that effective communication occurs between different providers and that consumers and carers are at the centre of care.

3.1.2 Consumer Directed Care in mental health

Key themes from the findings used to define CDC were *choice* and *control*. Services have a customer service orientation, and successful outcomes are defined by what works for the consumer in meeting identified needs and wishes. Care services can be added, adapted, or ceased, based on the wishes of the consumer. Care quality is driven by market forces; care that does not meet people's needs will not be funded. A system based on CDC principles requires accessibility, capacity and choice to operate successfully. The sector should also provide a breadth of available options facilitating real choices that meet the diverse needs of consumers. It also requires supportive information and systems within funding organisations to adequately deliver CDC.

Table 3 summarises the themes associated with PCC and CDC according to areas of interest to the project. The team's analysis of themes for each concept are not exclusive to each other. Many of the themes overlapped across both concepts given how participants described each conceptual approach, and its associated outcomes. Our separation is based on what people emphasised as the main differences between each approach – for example, PCC emphasises individualised care, whereas CDC emphasises choice and control and builds on many key features of PCC.

Table 3: PCC and CDC themes and outcomes

AREAS OF INTEREST	PCC THEMES (PROVIDER DRIVEN)	IDENTIFIED OUTCOMES	CDC THEMES (CONSUMER DRIVEN)	IDENTIFIED OUTCOMES
1. Knowledge, power and decision making	Consumers are authors of their own story Person is the expert Care starts where people are Shared decision making	Self-determination Empowerment Inclusion	Led by consumers – choice and control Empowered to direct services Starts where people are Evaluates providers	Choice and control Empowerment
2. Service and systems design	Allows for flexibility Innovative and tailored Includes whole person life needs Includes carers or family centred	Meets identity related and psychosocial needs Family/carer inclusion	Breadth of service options – flexibility Supportive systems, coordination and relationships Includes or excludes carers based on consumer wishes	Meets identity related and psychosocial needs Access to wider range of services for recovery Improved service integration/

			Informed consent and information about services Access to funded plans (e.g., NDIS)	consumer navigation across services
3. Risk and consumer autonomy	Does not impose or coerce	Psychological and physical safety	Dignity of risk decision making	Psychological and physical safety
4. Service skills and capacities	Interpersonal skills, empathy and trust Time to build relationships	Improved respect, empathy and trust	Empathy and supportive relationships	Improved empathy and trust
5. Recognition, awareness, and diversity	Strengths, hopes and dreams Culture and kin recognised Includes social context	Hope Culture and gender identity valued Social roles and connections valued	Led by consumers – assumes capacity Services are available	Empowerment

3.2 Different concepts and different service contexts

Given the themes underlying PCC and CDC, observations were made by participants and the authors that there are certain service contexts where basing care on one concept or the other is more practical. This is because of the background origins of each concept, as PCC has been largely developed within clinical health care systems (sometimes still called ‘patient-centred care’), while CDC has been developed from a broader range of influences including market and insurance models. From conversations on this point, the authors observed that all care can be person-centred, but not all services are designed to enable CDC. For example, CDC has less utility in an acute/emergency setting where decisions are made relatively quickly and where consumers can not often choose their providers. In this context, it is more appropriate to help a person in crisis using a PCC approach. As PCC has been developed from a health provider context, it reflects the organisation of clinical care settings and is used across all levels of care.

3.2.1 Exploring identified outcomes

It was clear from the conversations with participants that most people had a good quality understanding of the outcomes associated with each concept. As in the literature, most of the outcomes identified related to service quality and consumer experience, rather than being directly linked to longer term mental health outcomes. As Table 3 indicates, the outcomes linked with PCC were about self-determination, empowerment and inclusion in decision making, having personal identity needs met through tailored, flexible services, and having safe and comfortable experiences via high quality relationships and communication. There was a significant overlap in these outcomes also being linked with CDC, but there was also stronger emphasis on CDC enabling a broader range of recovery needs met through accessing different services. Outcomes about service integration, coordination and navigation were also more present in conversations about CDC.

An observation on CDC was made by some practitioners that there is a tension between consumer choice and control and whether services are chosen based on effectiveness, not just that they propose to be able to meet the person's needs. This observation questioned whether there is enough emphasis on evidence of effectiveness as a basis for choice, and whether consumers are choosing services with available information on effectiveness.

The focus on service quality and consumer experience outcomes as described above is clear in the literature on PCC and CDC. This focus reflects the history and demand for improvements in these areas, and that these movements are strongly driven by advocates and professional leaders responding to poor quality care experiences. As such, the available research focusses on how the concepts improve service quality and consumer experience. At the present time, the levels of evidence directly linking these approaches to improved longer term mental health outcomes is limited. In the case of PCC, this reflects several factors, including that PCC has been mostly researched in broader health settings rather than in mental health settings, and that sophisticated study designs and resources are required to research the impact of shared decision making, collaborative relationships and other dimensions of PCC on long term outcomes.

For the participants of the project, it was evident that improving levels of service quality and consumer experience are intimately tied to whether services are going to be useful and have benefits for mental health. The key aspects of PCC were seen as facilitating collaborative relationships and continuity, so that forms of treatment had the best chances to be effective over time. Participants also highlighted how self-determination, hope and empowerment were central to recovery outcomes. Further, PCC was required to reduce the negative and harmful impacts of poor communication, coercion and other negative experience of care that contributed to people's distress and created ongoing barriers to care. CDC was also linked to longer term recovery outcomes, in that it proposed to offer a wide range of services that helped people with developmental needs, connections to community and gaining skills. It aimed to maximise self-determination and empowerment via a choice and control model.

While participants were clear on the need for PCC and CDC as guiding concepts in mental health, conversations quickly turned to a variety of tensions with traditional care models (for example, between the medical and biopsychosocial models), and other problems with putting these concepts into practice. These are explored in the following pages.

3.3 Experiences of person-centred care and consumer directed care

This section of the report details the various experiences, challenges, issues and barriers surrounding how well the concepts are put into practice across mental health services. We present 13 themes about various challenges and issues that have relevance for both person-centred and consumer directed approaches.

We asked people in the consultations about their experience, as practitioners, consumers, carers and policy leaders. Interview questions focused on how well both PCC and CDC are implemented in practice, revealing some separation of experiences in public mental health services, private clinical services, as well as in nonclinical psychosocial support services.

Across the consultations, the tone of most responses was to highlight problems in achieving person-centred and consumer directed principles in practice. This was particularly raised in the context of large health systems, and across specific sections of the public health sector. There were, however, positive examples of care experience that were shared highlighting how services can do better. The phrase of rhetoric versus reality was notable after it was used by several participants to describe the difference between policy commitments to PCC and what is commonly delivered or experienced. The participants (consumers, carers and many practitioners) reported an array of resource constraints, bureaucratic processes, legal requirements, practitioner skill variations, risk and safety processes and paradigm conflicts that limited the possibilities of consistently achieving person-centred ways of working and deciding together.

Participants, especially lived experience advisors, NGO service providers and policy leaders, were well able to describe comparisons between PCC and CDC based on how the concepts are aligned with service contexts such as NDIS funded services, or other psychosocial disability support programs (i.e., CDC), and with their experience of public mental health services (i.e., PCC).

Table 4 outlines the 13 themes and the connections with PCC and CDC themes described earlier in the section. The main aim of the table is to provide a summary of the aspirational aspects of PCC and CDC as well as the challenges to achieving them. The section then goes on to describe these challenges and how these are apparent in research and policy literature. There are many well-known tensions and gaps relating to achieving PCC and CDC in this literature.

Table 4: Themes of PCC and CDC and associated challenges, barriers and issues

AREA	PCC THEMES	CDC THEMES	THEMES ON CHALLENGES, BARRIERS, ISSUES
1. Knowledge, power and decision making	Consumers are authors of their own story Person is the expert Care starts where people are Shared decision making	Led by consumers – choice and control Empowered to direct services Starts where people are Evaluates providers	1. Paternalism and limits of the medical model 2. Professional knowledge can disempower lived experience
2. Service and systems design	Allows for flexibility Innovative and tailored Includes whole person life needs Includes carers or family centred	Breadth of service options – flexibility Supportive systems, coordination and relationships Includes or excludes carers based on consumer wishes Informed consent and information about services Access to funded plans (e.g., NDIS)	3. Lack of service flexibility 4. Funding and service parameters that limit service design 5. Lack of pathways for people with complex issues 6. Lack of information about services
3. Risk and consumer autonomy	Does not impose or coerce	Dignity of risk in decision making	7. Mental health laws and experiences of coercion 8. Too much focus on risk
4. Service skills and capacities	Interpersonal skills, empathy and trust Time to build relationships	Empathy, compassion and supportive relationships	9. Inconsistency of practitioner skills 10. Lack of true commitment and implementation 11. Resource/time limitations and practitioner burn out

5. Recognition, awareness and diversity	Strengths, hopes and dreams Culture and kin recognised Includes social context	Led by consumers – assumes capacity Services are available	12. Stigma and stereotyping about consumers 13. Need for accessible services for specific communities

3.3.1 Knowledge power and decision making

1. Paternal culture and limits of the medical model

> ***There are tensions in implementing PCC principles due to the paternalistic nature of treatment, with a heavy focus on diagnosis and medication. There is an over-reliance on ‘old fashioned’ treatments such as involuntary care and community treatment orders…mental health services find it difficult to release the paternalistic control of treatment…Ultimately, a ‘complete turnaround’ is needed to be able to effectively implement PCC in mental health care. (Clinical nursing leader)***

Paternalism was noted as both an overarching framework and experience which limited consumer and carers access to decision making and power within treatment encounters. This was seen in terms of ‘old culture’ of health professionals knowing best and not acknowledging the lived expertise and self-understanding of consumers, carers, families and kinship groups in assessing situations, problem solving and making shared decisions. Carers also spoke of the long-standing issue of being excluded from treatment planning, changes to medicines and decision making on transfer of care. Participants highlighted other care experiences where paternalism was absent. Here positive encounters were based on valuing consumer and carers preferences and practitioners acting on their recommendations.

2. Professional power and knowledge can disempower lived experience

> ***Professional objective measures that are used in assessments already start to take away some of the person-centred connections in the interaction. You’re saying that the objective measure is at least more important than the person’s own view of what's happening and what needs to happen. In my experience most services have some type of assessment intake which is basically saying ‘I will determine what that means for you, and what service is going to be appropriate’. (Peer work leader)***

This was a theme raised mainly by lived experience leaders and peer practitioners. This was a critique of how professional knowledge systems acting via objective assessments, measurements, and diagnostic models overshadow lived expertise and different viewpoints about a person's own health and wellbeing. This also included the approach of working in the person's best interests, as determined by professional knowledges and ethics, compared to corresponding approaches working from a person's expressed wishes/interests. Peers reported that aspects of personhood are often lost when distress or diverse experience is interpreted via the lens of psychological sciences and medicine.

Commentary on themes and literature relating to knowledge power and decision making

The team's analysis of these first two themes highlighted issues which are found in the literature on shared decision making, disability rights and recovery-orientated care. Our observations are that there are overlapping approaches and paradigms coming from each of these areas which shape the achievement of PCC and CDC and offer a critique of the medical model. These result in diverse expectations about how decisions are made, and what expertise is valued and influential in guiding care.

PCC requires a genuine partnership approach of valuing professional knowledge as well as the consumer's preferences, values and wishes about treatment. This recognises that lived experience accounts regarding care planning are essential, and that decision making is shared in a deliberate process.[9, 12] An older, custodial model of care relationships runs contrary to this approach.[33, 34]

Potential conflicts between professional and lived experience perspectives are recognised in the supported decision-making literature. Supported decision making makes a contrast between the 'best interests' model of substituted decision making, and an 'expressed wishes' model of the disability rights movement. This later approach is about recognising the legal capacity of people with disability to make life decisions and working together on this basis.[35] The disability rights movement is a key influence on CDC.

The recovery literature notes a contrast between the defining of clinical outcomes, as determined through clinical practitioner perspectives, and recovery outcomes, which are determined and evaluated by the consumer and family.[36] Australia's National Framework for Recovery Orientated Mental Health Services requests that practitioners maximise consumer self-determination and self-management of recovery.[37]

3.3.2 Service and systems design

3. Lack of service flexibility

> *More flexibility in policy and procedure is a must, and there's been times when the private sector has been flexible for me. My private psychiatrist had to fight my insurer pretty hard to get permission for a short admission without pharmaceutical intervention. And, they granted leave to allow me to be treated with traditional medicines and then return to the ward. A public acute service would never allow this. (Consumer advisor).*

Participants highlighted that the inherent nature of person-centred responses required innovation, creativity, problem solving and nearly always flexibility. This could be flexibility in accessing only psychological therapies rather than medicine-based treatments, flexibility in deciding about which medicines to use, flexibility in having CTOs reviewed at different points of time based on changes to a person's circumstances, or flexibility in using a consumers mental health advanced care directives to base treatment planning on the persons recorded wishes. It could be flexibility in choosing preferred practitioners or requesting changes.

4. Funding and service parameters that limit program design

> *Mental health consumers want safe and confidential areas to paint, yarn and weave, but services are not able to allocate funds to provide those services due to funding KPIs not allowing it, even though the guidelines say that care should be culturally sensitive. Structure of service provision and funding is dominated by psychology which doesn't recognise the collective kinship nature of Aboriginal People. There is cultural tension caused by this style of treatment because it makes Aboriginal People forget how treatment was done previously. Traditional care is about the individual and their kinship. What you do for one you do for the whole mob…sounds good on paper, but delivery is restricted by economic rationalism. These approaches don't work if they are not properly funded. (ACCHO leader)*

Some participants indicated frustration with funding and service rules which limit the types of services and programs that can be offered via funding programs. Often these have fixed key performance indicators which guide the activities of workers with consumers, families, communities and kinship groups in a specific direction, which may run counter to expressed wishes for client groups. Participants commenting on this level highlighted how CDC does mean having capacity for a service to move in flexible, innovative and uncertain ways, depending on the directions established in the consumers own care/service planning.

A further aspect raised by advisors working in the NDIS space, was that funding programs often have unrealistic expectations about change and recovery, which disrupt both people-centred, and consumer directed support. Personal and relational recovery reflects both small and long-term change, growth, connection, and healing from trauma. It is not a programmable linear experience. Working to support recovery requires a deep understanding of its lived experience.

5. Lack of pathways for people experiencing complexity

> ***Alcohol and other drug counselling see people who have significant trauma history, often with repeated traumas, and experiences of child sexual abuse. In rural settings, there are limited access to psychiatrists, people have to be more autonomous due to lack of services, only have access to two hospitals that are both two hours' drive, and services have to make riskier decision due to resource shortages. Current funding and allocation of resources in rural circumstances creates a tension with providing PCC. (Clinical leader)***

The key elements of this theme are gaps, barriers and absences of effective pathways of support for people experiencing comorbidities, and a range of psychological and social issues. This might be for people experiencing crisis who are homeless, on low incomes, have complex trauma, are estranged from family, or a part of child protection or criminal justice systems. Other scenarios could include young people going through gender transitioning and having issues with family conflict, homelessness, drug and alcohol use issues, or cultural identity conflicts.

Addressing the issue of limited pathways is about developing pathways within local health network services, as well as connecting with other community and lived experience organisations that have specialist knowledge and connection to the issues and communities. They need to reflect collaboration across and within services and teams. Part of the problem indicated by participants is that the paradigm underpinning collaborative pathways needs to be social, psycho, bio and lived experience. This enables different needs of the person to be heard and responded to with a wide range of practical supports. A psychiatric model of illness and treatment is a paradigm that is too narrow to be effective in helping consumers and families in complex distress and crisis.

6. Lack of information about services

> ***There are issues around transparency of decision making – people need to know who and what support they are being offered and have as much information as possible about their options. (Consumer advisor)***

Consumer, carer and practitioners speaking about psychosocial supports stated that CDC depends on high quality information about service availability, and how to use and access services. This was noted as a central challenge. This is further complicated by the large volume of services and programs that can be available, given the growth of providers under NDIS funding, and how consumers, carers and practitioners can access and keep up with information needs. Some participants pointed out that services should contain information about effectiveness or therapeutic value. The need for practitioners to know about the quality and quantity of service, so they make good quality referrals and build networks is vital

Commentary on themes and literature relating to service and systems design

In exploring these themes, the team noted that issues raised by participants are recognised and detailed in literature:

Professionals, consumers and carers regularly report various policy regulations and lack of resources which reduce flexibility and maintain barriers to PCC.[12, 38] In Australia, the experience of NDIS services indicate that a range of personal, program and market barriers limit choice and flexibility for consumers. Program barriers include NDIS lack of information about choice, communication and meeting processes that undermine choice and the limits of plans themselves. Market barriers include the quality of available programs and ability of providers to facilitate and honour choices.[39] Therefore, flexibility is about accessibility to diverse services within organisations and across the sector, and is an important aspect of health equity.

In terms of defining program outcomes, there is a tension between predefining service outcomes at the program level and how a range of personal, psychological and social outcomes are defined by consumers (individuals and groups). These tensions are well expressed by some population health planners indicating the need for local level planning, interpretation and co-design of outcomes.[40]

There is also complexity in defining recovery outcomes and includes social participation changes (e.g., connection to social supports, employment and participation), and psychological growth (discovery, feelings of agency and valued identity). Recovery also has process outcomes about the journey and impact of relationships,[41] recognising that change and progress is not always a linear journey. Meaning and reflection are important for defining what outcomes are to be valued.[42] These aspects of personal recovery have very significant implications for how programs are defined and evaluated as effective.

The CDC theme about providing a range of service options is also important when considering how services work together to offer co-ordinated care pathways for people with complexity. This focus is well recognised in the trauma-informed care literature where consumers, including young people, are experiencing multiple issues and have a high number of service needs.[43, 44] A fundamental challenge for larger health organisations is how well practitioner teams can recognise the diverse needs of the person and work together in transdisciplinary ways, where multiple professional perspectives are essential for providing all-inclusive care. Successful care requires successful interprofessional collaboration and coordination of time, resources and support structures.[45] Collaboration is also required across services and systems,[12] which often include mental health, drug and alcohol, homelessness services, income support, disability and family welfare supports.

The final theme about service information is a key aspect of how services are designed and accessible for consumer, carers and communities. The Productivity Commission report[46] acknowledges that it is a key challenge for consumer groups, carers and service providers to keep up to date with information on available providers, with consumers, carers, families and kinship groups often having very difficult experiences in navigating systems. Better service information and gateways are needed. Improved service, care and treatment information is essential for empowering consumer and carer decision making and lifting mental health literacy[47] which in turn improves help seeking experiences.[48]

Our understanding from reviewing these themes is that the service and systems design features of funding, defining outcomes, enabling flexibility and recognising the needs/preferences of the whole person are essential areas of development for progressing PCC and CDC. These are most evident when supporting people with complex needs and working from a recovery perspective on healing from trauma. Effective service and systems information is essential for care coordination and helping people to navigate and make the best use of services.

3.3.3 Risk and consumer autonomy

7. Mental health laws and experiences of coercion

> ***Safety is the biggest concern for people engaging with mental health services, and people often feel that current services are unsafe. (Consumer leader)***
>
> ***The Mental Health Act: clinicians often don't understand the principles. While you cannot let people with decreased capacity make decisions without support, that doesn't mean they have no capacity at all. Too often clinicians will take all control away from the person, when they instead should be talking and engaging with the person about decision making. (Policy leader)***

Part of the context that shapes decisions about care and treatment are Mental Health Acts in state legislation and CTOs. For example, in South Australia, the Mental Health Act 2009 provides principles and requirements for the treatment of people with mental health issues who are at risk. The Act gives trained health professionals limited powers to provide assessment, transport, custody and treatment to people who have, or appear to have, mental health issues and who are at risk of harm. The Act also provides rights and protections for consumers, carers and families.[49]

There were a range of views about the negative and positive impacts of treatment orders. Some consumers and clinicians indicated that orders such as Community Treatment Orders (CTOs) are contrary to achieving PCC, and enable coercions, iatrogenic harms and are re-traumatising. Yet other participants said that involuntary treatment can be delivered with compassion and valuing of the person, taking into consideration consumers' basic human rights. Some consumers also said that the shadow of laws and fears of risk management limit their sense of safety and disclosure. Some carers, consumers and clinicians said that having clinically directed care is sometimes necessary and a good thing. However, they said that it shouldn't come at the cost of dignity, but rather enabling the person's responsible autonomy and supported decision making, and that any restrictive orders need to be constantly reviewed.

8. Too much focus on risk

> *I am seeking help with self-harm and looking at 'am I safe here; is this another bad thing that's going to happen here; am I going to be let down'. (Consumer leader).*

> *Risk always trumps autonomy. Services have no time to be person-centred. (Clinical leader).*

> *Sometimes clinically directed care is required and the best thing when a person is really unwell. (Carer leader)*

Some consumer advisors reported that crisis encounters are too focused on risk assessment, including suicide risk assessment, which for them at times emphasises the latent power of mental health orders to limit consumer autonomy and safety preferences for comfort and support surrounding wellbeing and distress. This theme reflected the different perspectives on responding to risk. There are various sides, with consumers indicating that they often limit disclosure of their thoughts and feelings due to the need to prevent unwanted interventions, confinement and loss of control. They also can feel extra levels of distress about having to manage these potentially triggering/re-traumatising conversations and information sharing. A critical issue is that risk assessment and support is largely dependent upon on high quality shared decision making through person-to-person connection and therapeutic relationship, while those restrictive interventions can manifest and sometimes be repeated in a one sided and coercive way, which impacts negatively or can harm consumers and shape their subsequent reluctance to disclose deeply personal information for help seeking or response to help offering. Some advisors noted that a movement towards a broader crisis model framework should replace a singular medico-legal psychiatric model of consumer risk management.

Commentary on themes and literature relating to mental health orders and responding to risk in person-centred ways

These themes go to the heart of why PCC and CDC need to be reinterpreted from a mental health context. The differences in perspectives reported, reflect the well-known ethical issues surrounding mental health for people who are considered to be at risk of self-harm, harming others, or who need treatment for other wellbeing considerations. Our team noted how safety and risk is often seen differently between practitioner perspectives and lived experience perspectives. And we also acknowledged that people have had exceptionally difficult experiences in the mental health system, including iatrogenic harms and trauma that are not always recognised.

The literature reports that consumers, who are admitted to inpatient care, can experience coercion through use of sedation, restraint and seclusion. Human rights concerns occur due to lack of communication on consent, inadequate follow up on mental health advanced directives, and poor provision of information on medications. While studies show that consumers recognise that practitioner directed care can be necessary and can be achieved with dignity, coercive experiences undermine and are contrary to authentic PCC, informed consent and recovery.[9, 50] In community settings, consumers on CTOs report a lack of choice and control in treatment, experience an over emphasis on medicine-based treatment and worry about the threat of rehospitalisation. Recovery committed practitioners can feel their employing organisations lack genuine buy in for supporting personal recovery and use CTOs to manage risk.[37]

Our analysis identifies the tensions between recognising and supporting consumer autonomy and sense of safety and statutory responsibilities to manage a person's risk. Complex ethical dilemmas are well documented in terms of working through conflicts between risk management and self-determination for people experiencing suicidal crisis and in providing choice on medicines versus clinical evidence of effectiveness.[51] Practitioners wanting to facilitate recovery and positive risk taking in therapeutic work with consumers can face limits from embedded risk averse workplace culture which leads to set conditions for consumers to decide within. Practitioners can also face lack of strategic guidance from organisational policy as well as limited local practice support to work through dilemmas and decisions.[52] Given the diverse perspectives often involved in responding, practitioners are encouraged to work through complexities with consumers, and learn ways of identifying risk negotiation strategies and communicating about these with consumers, carers, families and kinship groups via a dignity of risk approach.[53]

The above issues of risk are complex and highlight various unintended impacts of mental health treatment orders for consumers, carers and practitioners. From the team's analysis there is an important need for the sector to discuss these challenges and differences in perspective, and work towards trauma-informed, connected and person-centred ways of responding to risk and ending coercion.

3.3.4 Service skills and capacities

9. Inconsistency of practitioner skills

> ***For other clinicians, when they have the skills and understanding, to align your values, and when ego is not in the way. This comes from a place whereby one identifies the needs of consumers and carers. (Clinical leader)***

Consumers and carers reported their experience of practitioners who have varying levels of skills and capability to enable PCC. Many reported that there would be no guarantee that the different practitioners they met over time would demonstrate the required skills base. The skills identified for

PCC and CDC included high-quality interpersonal communication and support skills, ways of including carers, managing information sharing appropriately and abilities to facilitate person-centred planning or decision making with consumers over time. Practitioner skills depend on familiarity and skills in using contemporary approaches, their level of experience and their level of comfort in facilitating care involving risk and safety issues.

10. Lack of true commitment and support for implementation

> ***Attempts to shift health care models to include PCC concepts must include everyone, as an approach that is not coordinated is unlikely to succeed. Tensions between individuals and disciplines will need to be worked out before effective change can commence. (Clinical leader)***

> ***PCC is an ideal. I haven't seen it embodied in the mental health world or the system...the mental health system is not well adjusted to make it efficient and plausible. It's very difficult. (LGBTIQA+ advocate leader)***

This theme was broad and related to focused development of PCC across organisational culture and into one-to-one care levels and within governance and service planning. Consumers and carers commenting from their experience, reported multiple reasons about a lack of implementation (as covered across these themes), but highlighted inconsistent implementation and not knowing whether the next level of service would be person-centred, or whether the next transition of care would work well. Clinical leaders highlighted that the public health system struggles to have the systems, resources and capabilities in place to provide nuanced PCC responses, to ensure tailored and innovative, responsive services for people going through complex mental health experiences. The need for stronger PCC leadership was closely connected to this topic.

11. Resource/time limitations and practitioner burn out

> ***In inpatient/acute settings - other cultural processes are at play. ‘High risk’ factors play out here – it is a barrier to seeing people as human beings, dehumanising - barriers to connection, working in that environment, if you feel unsafe this influences the perception that all consumers are risky. Rates of staff burnout and compassion fatigue occur here. (Clinical leader).***

> ***Services don’t allow people to practice PCC due to staff shortages, and subsequently a burnt-out workforce occurs. (Carer leader).***

Some clinicians highlighted that organisational requirements, documentation, prioritising diagnostic processes, often constrained their ability to spend time to build therapeutic relationships and facilitate person-centred planning, decision making and follow up. Time resources to attend to requirements, or guidelines for shaping decisions (e.g., a requirement for a referral to elicit a diagnosis that is not preferred by the consumer) can mean less time working and communicating with consumers and families. Consumers and carers highlighted a related issue. The fast-paced nature of service life and change fatigue produced burnt out workers who had lost the capacity for compassionate and committed care, and who now could not take that extra step of caring/supporting appropriately.

Commentary on themes and literature relating to service skills and capacity

The literature of PCC in health care settings readily identifies the importance of practitioner skills, effective organisational implementation and supports for the emotional self-care of practitioners. Our analysis saw these three areas as linked with effective leadership and the need for effective planning, and resourcing which aligned all staff practices within a framework of either PCC or CDC, depending on the context. How practitioners are supported through education, organisational supports and leadership is central.

Essential skills for interpersonal communication are appropriate, along with supportive information sharing, listening skills, validation, therapeutic relationships and supporting consumer and family involvement. Practitioners working in youth mental health settings in particular need specialist skills for supporting young people in care to have a voice while working within the family context. Training practitioners to be skilled and confident in person-centred approaches for information sharing and flexibility in tailoring services is a key need[12] as all aspects of high-quality consumer experience are facilitated through staff competencies. [9] [54]

Large health services are highly complex environments which present multiple challenges for implementing PCC and understanding outcomes in the persons lived context.[51] From a planning perspective, effective person-centred mental health care requires relevant, local and detailed data and analysis, more careful service planning and delivery, and better accountability and transparency through local co-production of programs and sought outcomes.[40]

One of the tensions noted in a review of care planning[8] is that consumers and carers consistently place highest value on the relational experience of care planning whereas professionals are required to emphasise service led outcomes and meeting KPIs. Organisational planning for improved PCC should define and validate time spent meaningfully with consumers. Organisations should also be aware that ritualised, task orientated processes, such as care planning, need to be a quality experience for consumers and carers as well as practitioners. There is an important emphasis on supporting practitioners to build high morale as both an outcome and driver of effective PCC partnerships.[8] The authors in this study acknowledge that tick box routines and drives toward administrative efficiency can undermine genuine relationships of care and practitioner fulfilment.[8]

In terms of health practitioner job satisfaction, burnout and the connection with PCC implementation, studies report positive associations between improved job satisfaction and PCC organisational environments.[54] However there are mixed results on whether PCC health environments are associated with less burnout among staff.[54]

3.3.5 Recognition, awareness and diversity

12. Stigma and stereotyping about consumers

> *Queer people are rarely forthcoming with their identities when receiving mental health care – having to 'out' themselves every time causes uncertainty towards how the service provider will react to their disclosure. Hospital experiences can be very difficult. I cannot guarantee that any staff have education of LGBTIQA+ issues and that any staff they come across can lead to upsets by saying horrible things. (LGBTIQA+ advocate leader)*

This theme reflected experiences shared by consumers and carers relating to stigma, patronising attitudes of staff, as well as assumptions that consumers have limited ability to shape decisions about their lives. Stereotyping or negative assumptions also related to experiences of discrimination relating to personal identity or culture. The main experience we heard was from LGBTIQA+ advocates sharing experiences on behalf of trans people experiencing ignorance, misgendering, or unsafe attitudes across health care encounters. Advocates indicated that trans and gender diverse consumers cannot predict that their next mental health care encounter would be via an informed, supportive and inclusive practitioner.

13. Need for accessible services for specific communities

> *Services are dominated by psychology which doesn't recognise the collective kinship nature of Aboriginal people. (ACCHO provider leader)*

The lack of care pathways and poor 'access to care', appose the key principles of PCC. Related to this is the observation from some participants that public mental health services struggle to develop and hold specific knowledge, expertise and working relationships with diverse community groups, or can adequately develop specific services to meet diverse local needs. As noted, LGBTIQA+ advisors reported that public mental health providers mostly struggled to develop workforce and service capability to know about, support and include young people or young adults transitioning and experiencing crisis. Poor access was also reported to occur in rural regions, where workforce shortages were occurring or where NGO programs were not funded to operate. Poor access to care occurs within services, at the organisational level, and on a sector level, where funding is not often directed to establish specific services for First Nations Peoples, culturally and linguistically diverse communities, regional, youth, or LGBTIQA+ groups. Participants highlighted those inequities. Some people have access to high incomes and private sector health care which can be more flexible, responsive and person-centred.

Commentary on themes and literature relating to recognition, awareness and diversity

The two themes above relate to multiple issues about how practitioners and services recognise and engage with diverse communities of lived experience. This includes the needs for addressing stigmatising attitudes relating to mental health, cultural background and sexual and gender diversity. It is also about the capability of services to develop effective engagements with community groups, in terms of better links, relationships with lived experience leaders, knowledge of specific social supports and local programs. A challenge for large providers is how to build these capabilities and links across multiple groups and maintain a focus on diversity and intersectionality.

Literature on discrimination in mental health identifies that stigma is often embedded in the attitudes and cultures of health services, including mental health services. This is commonly experienced by people in crisis that is related to personality disorders and self-harm.[55] Further, stigmatised beliefs about schizophrenia continue to be a feature within mental health professions regarding beliefs on dangerousness, incompetency, poor prognosis and desire for social distance, particularly among practitioners situated in acute care settings.[56]

Misgendering is a common experience in health care organisations as many professionals are not educated in gender affirmative care or inclusivity. Clinicians may lack skills for addressing people by their preferred identity, or may express negative judgements. Lack of supportive care can also be experienced by practitioners not knowing providers competent in gender affirmative care for referral.[57]

In terms of building improved community awareness and relationships, mental health programs face challenges in working beyond generic models of community need and often struggle to understand and meet real world requirements of specific community groups, culturally diverse, or people experiencing comorbidities.[51] This reinforces the need to recognise the valuable role that consumers, carers and community members with lived experience need to play in co-produced service planning. Accountability frameworks should honour these partnerships, and uphold PCC and CDC standards, rather than being transactional between providers and funders.[40]

3.4 Summary of section 3

The above section has described key findings of the project regarding participant understandings of PCC and CDC and associated outcomes. It also has provided findings on a range of challenges, barriers and issues that exist in health services environments, or are experienced by consumers, carers and practitioners. The section provided a commentary relating these findings to common issues found in relevant research and policy literature. This work highlighted tensions between competing cultures, paradigms and practices found in mental health that need to be addressed as well as potential strategies for change. Moving on to what needs to shift, and what actions are needed to better realise PCC and CDC across mental health services will be the focus on the next section.

SECTION 4: CREATING SHIFTS TOWARD PERSON-CENTRED AND CONSUMER DIRECTED CARE

This section of the report presents key actions that were developed via analysis of the project's consultations and then further refined through a co-design process.

4.1 Developing the Shifts

Throughout the consultation meetings, participants offered many thoughtful strategies for encouraging services and sectors to better meet the expectations for PCC and CDC. These were raised across many parts of the interviews as well as being detailed in response to our question about what shifts are needed in thinking and practices to overcome evident challenges and barriers.

At the end of the consultations, a thematic analysis was completed which included a focus on theming the various actions and strategies that were recommended by participants. This included identifying practice approaches (such as trauma-informed care) that participants highlighted in the consultations. From these, eight broad themes emerged. These span different topics and refer to various levels of action, including changes to practice, mental models and assumptions, organisational supports and the systems level of funding and commissioning.

Codesigning outcomes and considerations

We then presented these themes to participants and asked them to consider the value of these shifts, what was important about them and what things we need to consider if they were to be developed further or implemented. This was done while also summarising the challenges, issues and barriers (from last section) to participants, so that they could see the links between these issues and the recommended shifts.

The co-design meetings produced a lot of detailed information about preferred outcomes, and important areas of practice and experience that should be considered by governments, funders, service leaders and lived experience leaders (summary slides are available via the online Appendices). The shifts and sector leaders that should lead change are summarised in Table 5.

Table 5: Eight key system Shifts to enable better PCC and CDC.

PROPOSED SHIFTS AND ACTIONS	SECTOR LEADERS
1. Strengthen practitioner education and training on essential knowledge and skills.	》 Universities 》 Professional colleges 》 State/Territory Health Departments
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.	》 State/Territory Health Departments 》 Lived experience, ACCHO, NGO and clinician peak bodies
3. Create a national program for strengthening leadership and championing for organisational change in public mental health services. 4. Strengthen lived experience leadership in service governance and in the workforce.	》 Commonwealth and State Health Departments 》 Lived Experience peak bodies 》 Local Health Networks/Districts 》 Non-Government Services Sector
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. 6. Promote and fund crisis response models that emphasise dignity, personal safety and cultural safety.	》 State and Commonwealth Commissioning/funders 》 Lived Experience peak bodies 》 Aboriginal Community Controlled Health Services 》 Local Health Networks/Districts 》 Primary Health Networks 》 Non-government Services Sector
7. Fund lived experience organisations to co-design local mental health programs in partnership with specialist public mental health services. 8. Fund lived experience organisations to provide peer navigation services and develop better care pathways within health systems.	》 State and Commonwealth Commissioning/funders 》 NDIA 》 Lived Experience peak bodies 》 Aboriginal Community Controlled Health Services 》 Local Health Networks/Districts 》 Primary Health Networks 》 Non-government Services Sector

The results of the co-design work sets the direction of the following pages. Readers will see a description of each shift, a list of outcome areas, considerations about relevant models of practice and areas of innovation. There are also some links back to the literature as this content is described (see also Appendix 6). As this work was co-design we have used many of the terms and phrases shared by participants throughout.

As per the aims of this project, this work has been produced to encourage thinking, discussion and reflection for readers. Further development and implementation planning would be required for implementing action for each of these areas.

A service and systems focus

A focus on both services and systems has been evident during consultations, the analysis and co-design processes. This was because PCC and CDC need to be seen from the consumer journey perspective, from within organisations and from the communication and relationships between different services and programs. It is a complex scenario, with different services funded under their own mechanisms and programs, across health and disability and across State and Commonwealth sectors. Some of the organisations and groups essential to developing person-centred pathways and responses, are voluntary community and lived experience organisations. These groups should be recognised as helping to generate innovation and solutions regarding issues of service navigation, community literacy, information and education, advocacy, peer models of service, and building the learning and capacity of larger health organisations.

Many participant observations have encouraged the project to develop a systems focus. Participants talked about big picture patterns that are seen in the mental health sector, over time, regarding reform. These included a lack of accountability and uptake of existing recommendations made in the report, as well as a continuing lack of resourcing for community and crisis mental health services, given the evident demands. A third set of observations were concerns about accessibility and health inequalities between people with private health cover and those on low incomes. Or inequities based on rural/city location, on cultural background, or gender and sexual diversity. A fourth idea was that some people felt that incremental change in services has not worked to progress reform. Instead, these participants argued that an explicit system change focus is needed, including shifts to upscale innovation, create new funding streams and new workforce models. These ideas are reflected in the Shifts presented below.

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

> ***There has to be a cultural commitment and a culture in the organisation, not just policy and procedure, for PCC. We need a culture of being able to offer compassion and kindness. (Peer practitioner leader)***
>
> ***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 issues and build their capacity. Need to shift the culture from service-centred to person-centred, providing care that is safe, as defined by the person. (Practitioner leader)***

This Shift is about ensuring that universities, professional colleges and service providers strengthen practitioner education on key practice areas for PCC and CDC. This is in response to the collective observation that practitioners vary in their skills base for offering and facilitating PCC and CDC in the mental health services context. There is a cluster of education topics that have been identified as priorities for learning. These include shared decision making as a model to facilitate person-centred decisions about treatment, skills for trust and trauma-informed relationships and skills and practice strategies for supporting choice and autonomy. There is further description of the mental health specific research literature about these practice approaches and skills in our supporting documents (see Appendix 6).

Education and training are fundamental for action as all aspects of communication and decision making are facilitated via the effective skills and knowledge of practitioners. Lived experience perspectives and teaching, as well as established professional knowledge, can guide learning in each of these topic areas. Mental health practitioners need to be experts in building trust. This education approach should be intersectional involving inclusive decision making, empathy, interpersonal communication, LGBTIQA+ health and gender affirming care, cultural safety, carer involvement and trauma-informed care.

The educative process to achieve these shifts should be transformative in design, whereby stakeholders are encouraged to be critically aware and reflective about the possible implications of currently held views, divergent viewpoints, historical traditions and differences, and implications of differences for care. The context or setting of care is also important, recognising that different settings pose potentially diverse and interrelated opportunities for engagement with people in distress, psychological safety, shared learning and coming to a common understanding.

Identified outcomes from improved consistency of PCC knowledge and skills

During co-design, participants identified the following outcomes as important to pursue in terms of the skills of practitioners:

- Improved facilitation and experience of high-quality interpersonal communication and relational care, especially for staying connected, and finding tolerant ways to hear about and respond to risk and opportunity.
- Improved practitioner recognition of lived experience perspectives, feedback, recovery principles, and working across clinical and lived experience perspectives.
- Better practitioner skills for rebalancing power and knowledge sharing in decision making, enabling in turn, improved levels of informed consent, trauma awareness, validation of identity, experience and preferences, and agreed action plans.
- Increase consistency of self-compassion and reflection, helping more practitioners to be in touch with own hearts and self-care, and able to be genuine with consumers.

Other outcomes that participants identified were:

- Reduced experience of consumer distress and anxiety stemming from conflict with practitioners.
- More rewarding work experiences for practitioners.
- Improved staff retention over time.

Considerations for further planning and implementation

From the co-design meetings, we have identified the following considerations which relate to improving the consistency of PCC and CDC skills across the workforce.

- Learning and skills for understanding and enabling dignity of risk should be a central focus.
- Learning should challenge assumptions that consumers have deficits in capacity for making life decisions.
- Some settings such as emergency departments should be a priority for education as many staff are not mental health specialists and have lower levels of knowledge and skills.
- Rural and remote based practitioners face challenges that are unique to their contexts; education needs to be tailored to reflect communities and places and be easy to access for these practitioners.
- Local health service, or state government departments can also inform their PCC educational programs by drawing on consumer experience networks and partnerships to involve these lived experience leaders in education sessions.
- Local health services can support educational impact by having a PCC champions programs to encourage ongoing professional development.

- Mental health practitioner courses in universities should strengthen ‘experts by experience’ or consumer and carer led education in PCC and CDC. These methods show effective outcomes for reducing stigmatising attitudes and encouraging inclusion in care decision making.[58] [59]

4.3 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

> *People can have mental health issues and have insight and judgements about their own life - then that’s the starting point to engage in PCC. If you think they don’t know themselves, how can you trust them to make decisions. (Practitioner leader)*

This Shift encourages states and territory governments to consider implementing supported decision-making practices within their mental health legislation. It was formulated to reflect observations from participants that Mental Health Acts need improved ways of recognising human rights for people with disability and existing practices of substituted decision making can undermine personal autonomy. Strengthening a rights-based approach, through supported decision making, also promotes better recognition of mental health and planning, which express consumer wishes and preferences.

Supported decision making is a broad approach to empowering people living with disability to make life decisions in a way where decision making supports are put in place. The philosophical approach, as well as practices of advanced directives and consumer nominated decision makers align well with PCC and CDC, enabling wishes to be recognised and acted upon in times of crisis. There is a more detailed summary of the approach with links to literature in our supporting documents on practice approaches.

Identified outcomes from instituting supported decision making

In the co-design meetings, participants proposed the following as benefits from a legislated approach to supported decision making:

- Legal provisions embed practices which recognise, respects and affirms decision making capacity and strengths of people with psychosocial disability.
- Mental health advanced directives are more consistently used and acted upon in acute care settings.
- Consumers are provided with practices that promote being heard, understood and supported to make decisions.
- Mental Health Acts in each state and territory work to maximise informed consent and voluntary care.
- The tools and practices of supported decision making encourage improved literacy of disability rights for consumers, carers and practitioners.

Considerations for further discussion and planning

Participants in the co-design meetings identified a range of practice and planning considerations relating to promoting supported decision making. Beyond legislation, supported decision making can be promoted within organisations and models of care.

- Lived experience leaders and peer workers are well positioned for enhancing awareness and action about supported decision making within organisations and policy development. This includes within acute care and community care teams.
- The focus on legislative reform towards disability rights shines a light on how existing legislation creates obligations for practitioners to either empower or disempower consumers. Where is power embedded and with whom?
- There are significant conflicts to be worked through between the existing paradigm of assessing cognitive capacity and the supported decision-making approach.[35] Conversations are required on progressing the United Nations Rights of People with Disability in legislation.[60]
- Tribunals which review decisions under mental health legislation should ensure a balance of power between clinical paradigms and disability rights/lived experience approaches.
- Mental health crisis responses should encourage innovative ways of responding to crisis which avoid police attending first or ensure supportive peer/practitioner presence and least restrictive responses.
- Mental Health legislation reform needs to reflect recovery values, relational care and trust and facilitate high standards of practice.

4.4 Shift 3: Create a national program for strengthening leadership and championing for organisational change in public mental health services

> ***As a team manager, I can influence teams. How to use recovery focused language in MSE. [We need] education, training and individuals who are passionate about it. (Practitioner leader)***

> ***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' (Policy leader)***

This Shift was formed to reflect the consultation discussions on the need for improved leadership in guiding service and systems design. This is an area of development for consideration by various state governments, the Commonwealth Government and leaders of Local Health Districts/Local Health Networks (LHDs/LHNs).

Leadership plays a fundamental role in aligning the purpose, culture, strategies and behaviours of health service organisations.[61] There is need for strengthening and supporting mental health executive leaders and discipline leaders to make required shifts to adapt traditional mental models, practices, policies and organisational culture in a meaningful way. This should focus on addressing the issues relating to inconsistent resourcing and implementation of PCC identified in Section 4, including time available for improved relationships and practitioner/consumer ratios. This Shift also relates to participant observations that sustained leadership for PCC is required for long term change and consistent achievement. Mental health leadership in LHDs/LHNs is complex in that the wider organisational environment on safety and quality, budget allocations, involvement processes; policy and human resources subsequently constrains the autonomy of mental health services.

This Shift seeks a national program of leadership development on person-centred mental health care and systems change. There is a need to support the shared learning, activity, resourcing and adaptive leadership of mental health leaders as a unique and specialised form of health/disability/mental health sector leadership, recognising that PCC and safety and quality in mental health needs to reflect trans disciplinary approaches, social health, lived experience and disability knowledge bases. Mental health leadership also needs a co-production and systems change capability. A Champions program, for discipline based and lived experience leaders, should also be established.

An approach for encouraging nursing leadership at the service/unit level is evident is the Safewards program. This model aims at providing a safe, therapeutic environment for both consumers and staff in inpatient psychiatric services. This is achieved through ongoing meetings between consumers and staff to discuss mutual experiences and preferred ward routines. More about the literature on this approach is available in the supporting document on practice approaches (refer to Appendix 6).

Service design and cultural outcomes that can be strengthened through organisational leadership:

Participants in the co-design sessions collectively proposed these outcomes regarding the impact of improved leadership for PCC:

- Increased workforce commitment towards a supportive, caring, tolerant and recovery driven culture.
- Improved commitment and resource allocation towards consumer/carer engagement and co-production of services and programs.
- Improved cultural and operational practices regarding accountability, transparency and communications on service performance for PCC.
- Increased expectations of mental health leaders to embed PCC into organisational systems.

Specific outcomes relating to a National Leadership Program

- Better levels of shared learning and consistency at state/national levels for developing mental health PCC culture and organisational strategies.
- Improved networks of shared learning on service design and development, linking leaders of LHDs/LHNs nationally.
- Improved leadership at the professional level (Champions program) with an emphasis on power sharing and collaboration for trans discipline person-centred models of care.

Considerations for further discussion and planning

Participants in the co-design process highlighted the following points to be considered for further development of person-centred mental health leadership:

- It may be possible to build on and expand existing mental health leadership programs and networks to have an explicit focus on PCC.
- Leadership programs should focus on capability building to help leaders move in new ways, and lead innovation for new programs and services. An example of innovation is the philosophy and practice of the South Australian Urgent Mental Health Care Centre.[62] Increasing access to trauma healing services is also an important area for discipline-based and Aboriginal specific leaders to develop.
- There is a need to ensure that leaders champion PCC at every level of the organisation.[61]
- Leadership to transform paternal cultures will require legislative change as current mental health legislation obliges practitioners to step into substitute decision maker roles and take responsibility for consumers.
- Inclusivity of all cultural and leadership structures and governance requires the robust presence of lived experience leaders and diversity leaders.[61]
- Person-centred leadership culture encourages leaders to be ‘whole people’ including being ‘out’ with lived experience of mental health issues and using their skills for change without repercussions from AHPRA. We should encourage a culture of seeing the person, not just the separate role of consumers, carers, or practitioners.
- Encourage discipline leaders to develop PCC and CDC practice excellence, including core skills to co-work with lived experience leaders.

4.5 Shift 4: Strengthen lived experience leadership in service governance and in the workforce

> *Change comes from us carers and families it comes from us, and we can work together to raise interests working alongside consumers we will be the ones driving change and there are more and more people who want change. We should use the media to make change - it cannot go on. (Carer leader)*
>
> ***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)***

This Shift is about a systems level presence of lived experience leadership in service governance as well as creating peer practitioner senior leadership within mental health organisations and services. Participants raised this perspective in the context of discussing many of the challenges and issues detailed in Section 3. This includes issues relating to paternalism, increasing rights, involvement in decision making and helping the system become recovery focused.

Lived experience leadership provides critical, big picture insights on access issues, safety, risk tolerance, service gaps and impacts. The presence of leaders should be increased in numbers across LHDs/LHNs governing councils, safety and quality leadership committees and on boards of NGO and private providers. Within employed workforces, the numbers of senior peer leadership positions that promote recovery practice, and peer methodologies should be increased. A summary of the literature on the contributions of lived experience leadership is provided in our supporting document on practice approaches (see Appendix 6).

A national approach to funding lived experience leader development and integration within governance, including training for both lived experience leaders and other governance leaders is required. This can be supported at the Commonwealth level, via improved funding to support training and network development, and support for national peak bodies to coordinate policy development and the lived experience workforce.

Outcomes related to increasing the scale and presence of lived experience leadership

Participants in the co-design meetings proposed that strengthening lived experience leadership in governance and the lived experience workforce would result in:

- Increased profile, credibility and value of consumer, carer and kin perspectives in governance decision making, including integration of perspectives into funding agreements and KPIs.
- Improved recognition and response to consumer, carer and kin experience as generated through safety and quality outcomes data and feedback processes.

- Improved national development, increasing presence and numbers of the lived experience workforce.
- An up scaling of representation and recognition of lived experience in diverse communities, including through a diverse peer workforce.
- Improved integration and shared learning of peer workforces with other mental health disciplines, including the development of clear roles, and model of care responsibilities for peer work, non-clinical and clinical care practitioners.

Considerations for further discussion and planning

These considerations were related to undertaking further work to extend lived experience leadership:

- Lived experience can lead the way on conversations which promote humanity and inclusion, challenge stigma and ‘see the person, not label or work title’. There are numerous universities with lived experience led/involved education initiatives that guide recovery perspectives and PCC/CDC in clinician education.[63]
- It is important to ensure that peers in lived experience workforce and leadership positions have a justice orientation and are grounded in peer values, as distinct from clinical perspectives.[4] Specific peer skill sets will include supporting uniqueness, mutuality, acknowledging difference, emotional intelligence and self-care. Peers also need the skills to navigate different interests and conflicts within organisations and communities. They need to be clear on purpose for change.
- It is important to acknowledge intersectionality and multi-layered identities, where people have consumer, carer, worker and identity group connections. Further work is required to facilitate how lived experience can be expressed and acknowledged within clinical practice.
- Further efforts are needed to promote clear understandings of lived experience leadership value and purpose, and to support emerging leaders to gain skills and opportunities.[64] Effective valuing and gains from lived experience leadership requires all governance groups to learn and commit to co-design as a way of generating knowledge, planning and decision making.

4.6 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.

> *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)*

The focus of this Shift was developed out of participant’s perspectives on the issue and to incorporate a holistic focus for service responses. This was also related to raised issues on the lack of coordinated pathways for people with complex issues, the over emphasis on medicine-based care and the need for flexible service choices to meet a range of psychosocial, recovery and clinical needs. Many participants suggested that new program models which can meet these challenges need to be developed and funded. This is a Shift to be considered by commissioning groups within state and the Commonwealth governments as well as sector leaders generally.

Relational recovery is a term for seeing a person's recovery in the social context of personal development, family networks, relationships, life roles and connections. Service responses from this approach would offer supports and learning focused on social needs, wellbeing and inclusion, including helping people develop skills and capabilities. It is also about programs that address the experiences of trauma, disruption and lost development opportunities, that consumers, carers, families and kinship groups identify as needed for improving their mental health and lives. The connection to PCC and CDC is that service responses need to be able to respond to the whole person and the context of needs, preferences, strengths and interests. There also needs to be a system focus so that services can work together effectively to offer a coordinated care approach and have the strong external partnerships that facilitate this.

Open Dialogue was raised by several consultation participants as a promising program for this approach, despite having a limited evidence base. This approach features multi-disciplinary teams that support a focus on the consumer's social connections and identifying strategies to resolve issues across different life areas. More about this approach is available in our supporting documents (see Appendix 6).

Service design and system related outcomes from a relational recovery approach

Discussions within the co-design sessions identified these outcomes and benefits for improved PCC services:

- Services are designed to focus on psychosocial and wellbeing outcomes, and address issues that lead to distress and crisis.
- Needs are identified on a whole person basis, by the person as they see them, reflecting the social nature of mental health, and nuances of the person in their community.
- Services are multidisciplinary with a social health and relational recovery approach, inclusive of peer workforce and peer models.
- Services are funded for their communication and coordination functions across systems, enabling dedicated practitioner resources for collaboration, referral support and follow up.

Considerations for further discussion and planning

The following considerations and rationales for this approach were discussed in the co-design process:

- Taking this approach enables practitioners, consumers and families to focus on the root causes of crisis, what people experience as well as the well-known social determinants of distress.[5]

- This approach requires that service designs and contract agreements allow room for innovation, flexibility, and consumer/community driven outcomes. It should promote local, responsive and adaptable service models, rather than one size fits all – ‘cookie cutter’ models.
- This approach encourages services to work from an intersectional and diversity approach as a basis of mental health practice and recovery.
- Consumers, carers and families should be supported over the longer term to develop skills and connections. People need good quality care plans, effective flow and continuity of providers/care, supported by services which talk to each other.
- Funding coordination and shared communication functions across/between services can strengthen experiences of connection and being valued for consumers, carers, families and kinship groups. There should be an emphasis on reducing paternal and transactional ways of relating.
- Reaching into communities, mental health services can strengthen their work to promote inclusion and a compassionate society, and challenge stigma.

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

> ***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)***
>
> ***Leaders support group supervision as decision makers in this field can communicate and reflect with peers. This can build capacity of the individual and the service. Supervision provides validation to share struggles. Collaborative and supportive spaces, very useful to leaders. (Practitioner leader)***

This Shift is about improving consumer and carer experience and levels of care when seeking help for mental health and suicide related crisis. Many consumers are demanding change toward better levels of care, compassion, empowerment, respect and effective help when seeking help in crisis. Responses should focus on trusting engagement, genuine connection, emotional safety, strengths, dignity, belief and offer much more than risk assessment. Everyone should be offered an effective response and plan (see supporting document on practice approaches in Appendix 6).

Development needs to occur on the structural level, including the development and funding of alternative mental health crisis centres and improvement of Emergency Department capabilities for compassionate care and quality of service. On the practice level, development of more person-centred, compassionate and connected responses to personal risk are required to be more consistent across the sector. This can be enhanced by ensuring practitioners are supported and guided by high quality supervision, learning and clinical leadership while also valuing the contribution of peer led models. There is a fundamental importance in services learning from the consumer perspective on risk and safety, including the risks consumers feel in disclosing problems to practitioners when mental health orders can come into consideration.

This Shift is reflected in current innovations in crisis response models in Australia (see considerations below). We encourage state and Commonwealth governments, funding bodies and LHDs/LHNs leaders to support and resource this growth.

Outcomes from funding more crisis response models

The co-design meetings generated the following benefits and outcomes that would flow from increasing the scale of crisis response models:

- Increased availability and access to crisis response centres which use peer led or shared peer and clinical models for supporting people through crisis, and help them attend to life stressors (e.g., as occurs in the Urgent Mental Health Care Centre, SA).
- Reduced fear and increased psychological safety for consumers when explaining their difficulties and troubles and disclosing risk. Practitioners are more tolerant, accepting and reflective.
- An increase of safe and kinder service spaces which avoid retraumatising experiences for consumers, and work in connected ways to identify and decide on a range of safety strategies.
- Improved decision-making support, reflective supervision, organisational guidance structures and leadership for responding to risk in sophisticated ways[53] that are person-centred, or consumer led.
- Improved practitioner skills for empathy, compassion, collaboration, trust building and dignity of risk awareness.

Considerations for further discussion and planning

These considerations were provided about emerging or established approaches:

- Examples of established peer models for crisis conversations include Intentional Peer Support[65] and Emotional CPR.[66] Emerging models include *Suicide Narratives*.[67] *Alternatives to Suicide*[68] is a model of peer facilitated support groups rolling out in Australia. Other models being developed include warm telephone lines, drop in spaces and peer residential respite places.[69] There is specific significant learning/value for suicide prevention and crisis from peer led approaches to crisis, living with risk, disclosure and person-centred preferences.
- Examples of collaborative service and program development for crisis include Zero Suicide initiatives,[70] 4MentalHealth- Connecting with People, [71] Illawarra Shoalhaven Suicide Prevention Collaborative,[72] Safe Haven Models[72] and the Urgent Mental Health Centre, SA.[62]
- Effective and sustained training for practitioners, funders and peers in compassion, trauma-informed care, risk awareness and tolerance, safety strategies and after crisis support is required to ensure consumers receive consistent, person-centred responses.

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

> ***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 LGBTIQA+ community history and provides a wealth of experience that can be harnessed for good. (LGBTIQA+ advocate leader)***

This Shift recognises that PCC responses, and CDC-based programs need to be developed to meet local needs, preferences and wishes, and are meaningful to life context. Several participants in the consultation highlighted how Aboriginal Social and Emotional Wellbeing Programs reflect this type of development, as Aboriginal and Torres Strait Islander Health leaders have developed the SEWB approach and offer programs within community-controlled health service context (see supporting documents on practice approaches in Appendix 6).

Generalised models of care or support based on illness and treatment paradigms are seen as too narrow to understand, accommodate and facilitate meaning regarding a person's culture, identity, locality and interests. The assumptions of many services regarding accessibility and use can also skew effective access towards populations with higher incomes, private health cover, and access to urban centres. Many voluntary community organisations and networks operate which represent lived experience, offer support groups and educational opportunities or advocate for improved recognition and care pathways in larger health services.

This Shift encourages state and Commonwealth funding bodies, Primary Health Networks and LHDs/LHNs leaders to offer funding to assist lived experience organisations to either co-design or partner with established providers to design mental health programs with new parameters and KPIs that are in line with consumer/community preferences. Lived experience organisations working as NDIS providers are also well placed to develop in this manner, yet access for consumers should not only be limited to people on NDIS plans. Primary health care funding should also be considered.

Outcomes related to increased co-designed mental health support programs

Co-design participants saw value in this shift and identified the following outcomes:

- An improved range of accessible and flexible mental health supports which are grounded in the life context, needs, wishes and preferences of consumers. For example, wellbeing, social support and self-care programs.
- Increased mental health literacy, skills and support capabilities of local community organisations to provide programs or co-design and co-deliver programs with specialist mental health services.

- Lived experience and community organisations have improved capacities to advocate on behalf of members and share knowledge on access and inclusion with specialist mental health providers (see also Shift 8).
- Improved access for diverse consumer/community groups as they are supported to navigate and successfully access multiple services in the health/social sectors (see also Shift 8).
- Increased capacity of services to meeting consumer and carer needs through tailored programs and coordination, rather than being limited to what funding allows, or restricted to what KPI/parameter barriers present.

Considerations for further discussion and planning

Funding bodies looking at this Shift should consider the following key points and rationales:

- Consumer and community groups should be enabled to define and 'own' mental health care outcomes, such as, defining what is valuable and what success means.
- Importance should be placed on the ability of services to generate a sense of place and belonging. Achieving this can be guided by lived experience.
- Initiatives to develop programs with and tailored to the needs and preferences of diverse communities can be supported through good data collection systems, as well as creative ways of using data, consumer experience and communications.[73] [61]
- Funding can be used in creative ways to create new positions or co-locate positions and organisations in accessible places, e.g., community health centres and neighbourhood houses, or integration of support services alongside clinically focused services. This can enable a broader range of health and social outcomes for consumers.[74]
- Larger health services and NGOs need co-design capacity, time and skills, as well as consumer engagement practices and registers to effectively relate to diverse consumer groups.[61] An increase of capacity is required to be able to support community initiatives by ensuring friendly, accessible and useful facilities: meeting rooms, workshop venues, kitchens, and effective office space for peers.
- Community leaders and peer workers across diverse groups can be supported to develop skills that align with the mental health peer movement, especially in recovery, trauma-informed responses, mutual support and self-care.[75] The success of peer-based programs relies on high quality peer worker skills, supported through supervision and mentoring.[75]

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

> ***We need trans specific health services like we have in the Aboriginal Controlled Community Health Organisations. We could help provide peer navigation and support. (LGBTIQA+ advocate)***

This Shift is about improved funding to community and lived experience organisations to provide important functions for improving specialist mental health provider knowledge and the development of better care and referral pathways. Systems level advocacy, education to providers, and helping consumers and families/supporters navigate services and systems are all important ways of building PCC in larger health services for specific consumer groups. Priority groups for action include people experiencing complexity and trauma, trans and other LGBTIQA+ groups, Aboriginal and Torres Strait Islander communities, young people with Autism Spectrum Disorder, and asylum seekers and humanitarian entrants.

The literature describes the value that peer navigators can provide to help consumers, carers and families to access larger health services and other systems effectively. This includes functions of providing emotional and information support, helping to generate trust between consumers[76]and practitioners, and improving communication, coordination and referrals across services.[77] [78] At the systems level, lived experience leaders can provide education, advocacy and consultation to help develop inclusive practices and pathways within larger systems, as evidenced by the work of LGBTIQA+ health organisations.[79] Further information on these functions can be found in our supporting documents on practice approaches in Appendix 6.

This Shift can be supported through Commonwealth funding (e.g. Primary Health Networks), state government funding, or more local LHDs/LHNs funding initiatives. Funding agreements should recognise, define and align with consumer experience and defined outcomes.

Outcomes from increasing capacity of peer navigation/service access

Co-design participants proposed that following outcomes from undertaking this Shift:

- Improved access to and navigation within/across services, where consumers and families are supported with information and peer knowledge.
- Improved development of care pathways and service networks, encouraging coordination and communication between consumers/carers and the different practitioners/services.
- Increased capacity of specialist mental health providers to know and relate to the preferences, issues, culture and identity that is important to priority groups, including attending to the impact of social determinants on mental health.

- Further development of education and information resources which assist mental health literacy for specific communities.

Considerations for further discussion and planning

Funder bodies and service leaders should consider the following observations and rationales provided by co-design participants:

- Peer navigator and liaison roles are highly valued for creating supportive understandings within larger health services and helping consumers and carers to navigate these.[79]
- Coordination of care requires open communication between service providers and a willingness to work through barriers (e.g., mental health versus AOD issues).[45] Clarifying legal processes and improving information sharing agreements between agencies are also critical.
- Navigator services must be specifically designed to work across rural and remote settings, where access and equity issues, and lack of psychosocial care pathways are experienced.
- New models of care and pathways require inherent flexibility across therapeutic options e.g., deciding to only access psychosocial therapies and not medical treatments.
- It is important to ensure funding agreements recognise, define and fund responses to issues. For example, Complex PTSD is only emerging as a funded item for state hospital-based care.

4.10 Summary of section 4: shifts, practice approaches and outcomes

The focus of this part of the report has been in providing detail about eight proposed shifts in thinking, practice and funding for systems to facilitate better provision of PCC and CDC.

These shifts were identified through the projects consultation stage by choosing the most salient and prevalent strategies and practice approaches. We then used a co-design process to discuss these shifts with participants and collectively identify valuable outcomes. This work not only provided more depth and detail about outcomes associated with PCC and CDC, but it has also produced detailed considerations for sector leaders and funding bodies to discuss.

A map of the major themes and links between the findings presented in Section 4 is provided in Table 6. Here we have added a 5th column which lists key practice approaches and actions and proposed responses to the challenges, barriers and issues discussed in Section 3. This helps us to bring the main findings of the project together and provide a summary.

In the area of knowledge, power, and decision making, both supported and shared decision making have been identified as important practices for empowering consumers. Supported decision making enables recognition of disability rights across life choices including decisions about mental health services and recovery. Shared decision making is specifically about treatment choices, providing evidence-based information and increasing health literacy. Both approaches reposition the practitioner – consumer relationship in decision making power.

For service and system design, actions relating to improving service leadership have been identified in Shifts 3 and 4. These include developing leadership that enables consistent organisational development in PCC and improves accountability and transparency. This facilitates leadership that creates cultural shifts and improved resourcing, thus enabling more time for authentic therapeutic practitioner – consumer – carer relationships. The project identifies that lived experience leadership is an essential movement for improving design at service and system levels, through increasing leaders' presence at governance and workforce levels. Resulting cultural shifts are about improving the flexibility, tailoring and 'relational recovery' focus of services. Increasing the lived experience workforce and strengthening lived experience organisations (Shift 8) can result in improved service pathways, information, navigation and coordination for consumers and families.

In the area of risk and consumer autonomy, Shift 6 recommends crisis response models which are about maintaining connection, and achieving personal and cultural safety using a dignity of risk, rather than a risk averse approach. These are essential service experience outcomes for consumers.

Improving the education, resourcing and capacities of practitioners for PCC and CDC should be a strong focus of organisational and systems change. The project has highlighted key topics and skill sets for practitioner education and development. These focus on enabling family and carer inclusion, shared decision making, empathy, trust and trauma-informed care, as detailed in Shift 1. Improving PCC and CDC requires that services support practitioners to spend more time with consumers and carers in therapeutic relationship building, supporting choices and coordinated outcomes. These roles should be provided/experienced on a consistent basis.

Finally, the project emphasises that strengthening lived experience leadership and peer worker practice will result in improved levels of recognition and awareness of specific community needs and preferences. This occurs through better representation of interests and inclusion of diverse communities in co-producing and co-delivering services (Shift 7).

Table 6: Summary of shifts and practices approaches for promoting PCC and CDC

AREA	PCC THEMES	CDC THEMES	CHALLENGES, BARRIERS AND ISSUES	SHIFTS AND PRACTICE APPROACHES
Knowledge power and decision making	Consumers are authors of their own story Person is the expert Care starts where people are	Led by consumers choice and control Empowered to direct services Starts where people are	Paternalism and limits of the medical model Professional knowledge can disempower lived experience	Shift 1: Education for shared decision making and consumer health literacy Shift 2: Supported decision making, mental health

	Shared decision making	Evaluates providers		advanced directives and disability rights
Service and systems design	Allows for flexibility Innovative and tailored Includes whole person life needs Includes social context Includes carers or family-centred	Breadth of service options – flexibility, supportive systems, coordination and relationships Includes or excludes carers based on consumer wishes Informed consent and information about services Access to funded plans (e.g., NDIS)	Lack of service flexibility Funding and service parameters which limit service design Lack of pathways for people with complex issues Lack of information about services	Shift 3: Leadership and champions for organisational change Shift 4: Lived experience leadership Shift 5: Relational recovery – focus on social context Shift 8: Peer navigation, coordination and consultancy
Risk and consumer autonomy	Does not impose or coerce	Dignity of risk decision making	Mental health laws and experiences of coercion Too much focus on risk	Shift 6: Connected and risk tolerant crisis response models Shift 4: Lived experience leadership
Service skills and capacities	Interpersonal skills, empathy and trust Time to build therapeutic relationships	Empathy and supportive relationships	Inconsistency of practitioner skills Lack of true commitment and implementation Resource/time limitations and practitioner burn out	Shift 1: Education, inclusion, empathy, LGBTIQA+ health, cultural safety and trauma-informed care Shift 3: Leadership and champions for organisational change
Recognition, awareness and diversity	Strengths, hopes, and dreams Culture and kin recognised Includes social context	Led by consumers – assumes capacity Services are available	Stigma and stereotypes about consumers Need for accessible services for specific communities	Shift 4: Lived experience leadership and peer practices Shift 7: Co-design and partnerships for new services.

SECTION 5: SUMMARY AND RECOMMENDATIONS

Developing a Spotlight report on PCC and CDC is a challenging process. Both concepts have multiple dimensions and aspects and cannot be readily separated from the different service contexts of mental health care, or the different practices involved. At the centre of the topic is the consumer and carer experience. This focus on the consumer (and carer) journey is one of the most powerful aspects of these concepts, as it centres thinking evaluation and innovation from the perspective of what it is like to use services, and how they can be improved.

This report has documented the processes and outcomes of in-depth sector engagement and co-design with the academic team. Our aim was to generate a report which would promote discussion and improved understandings of PCC and CDC in the mental health context. Our work aimed to identify key points of tension and possibility between the implicit purpose of these concepts and the actual service environments experienced daily by consumers, carers, practitioners, clinical leaders, policy makers and community advocates. We aimed to identify possible ways forward in terms of practices and levels of change on organisational and system levels.

To this, we consulted with a significant group of organisational representatives, consumers, carers, practitioners and leaders, speaking with 50 people via individual interviews and group discussion. Our engagement explored perceptions and experiences relating to how these concepts are understood, how they are experienced as guiding service delivery and consumer experience, and what the challenges and issues were relating to each. From these conversations, participants highlighted key understandings and outcomes that are associated with the policy and principles defining these concepts.

Understanding Person-Centred Care in mental health

Collectively, participants described PCC in mental health as care that is orientated towards working from the persons own story, situation and beliefs about what is helpful, whereby they are an expert in guiding how care should be delivered. PCC is about sharing power and shared decision making, where services are flexible and care be tailored to the persons wishes, preferences, strengths, aspirations for the future and holistic needs. PCC includes a significant level of carer/family involvement and recognises the social context of relationships, roles and connections. PCC is offered through compassionate, trusting, empathic and safe relationships, where practitioner actions promote safety from multiple perspectives. This includes negotiating identified safety and risk issues with consumers and planning collaboratively without coercion.

The identified outcomes of PCC reported by participants are about quality of service and making the consumer journey easier and more supported. Participants identified self-determination, empowerment, inclusion in decision making as key outcomes. Services are better able to meet psychosocial and identity related needs and cultural values. There is improved psychological and physical safety, through better respect, empathy and trust in practitioner, consumer, and carer relationships.

These outcomes are well reflected in available peer reviewed literature on PCC in mental health. The literature adds that PCC improves consumer experience with medicines, and person-centred environments and facilities provide positive outcomes in comfort and safety.

Understanding Consumer Directed Care in mental health

In this project, participants describe CDC as an approach that builds on PCC principles by extending choice and control. Consumers lead decisions about care and about what services are required. Flexibility and having access to a range of services is important, and consumers also evaluate whether services are working for them, and whether to continue using them. In the mental health context CDC reflects dignity of risk decision making, where decisions should be supported by good quality information, informed consent and trusting care relationships. CDC assumes consumer capability to direct care that suits the recovery journey. Often there are different services required to meet wishes and needs on different aspects of life. In mental health, this means a stronger emphasis on supportive systems, coordination and communication is needed for consumers and carers.

The outcomes of CDC expressed by participants are similar to PCC but with a larger focus on experiencing choice and self-determination. A focus on recovery needs should enable people to have access to a wider range of services and programs that work for them. Psychologically safe services are also described as an outcome. The research literature in CDC is less developed than in PCC for mental health. Evidence from individual studies indicates positive outcomes in improvements in self rated recovery, autonomy, care experience use of wider support services, and connections with education and employment.

Challenges, barriers and issues

The consultations identified an extensive arrange of challenges, barriers and issues relating to the capacity of public health services and funded programs to facilitate PCC and CDC. These were identified through thematic analysis and described with 13 themes:

- Paternalism and limits of the medical model
- Professional knowledge can disempower lived experience
- Lack of service flexibility
- Funding and service parameters that limit program design
- Lack of pathways for people with complex issues
- Lack of information about services
- Too much focus on risk
- Inconsistency of practitioner skills
- Lack of true commitment and implementation
- Resource/time limitations and practitioner burn out
- Stigma and stereotypes about consumers
- Need for accessible services for specific communities

- Mental health laws and experiences of coercion

The themes highlight points of tension and possibility, and a connection to literature, in terms of evidence of key PCC and CDC practices, processes and outcomes.

Recommended shifts to thinking, practices and service models

The consultation and analysis process also resulted in eight Shifts that would benefit the capacity of services, organisations and communities to contribute to PCC or CDC experiences. The project then engaged in a series of co-design meetings with 20 participants to explore the context of challenges and importance of these areas of change. These discussions affirmed the directions of these Shifts, and produced detailed ideas on outcomes, key considerations, gaps in thinking and aligned practice approaches. It was notable that all the Shifts worked on during co-design point to key principles of the care concepts, and reflect that change needs to occur on multiple levels involving multiple stakeholders. These include workforce education and development, service delivery practices, organisational supports and administration, clinical, executive and lived experience leadership, models of care including crisis response and funding of community and lived experience organisations.

Each of these strategies should be interpreted within local contexts and work with different populations, communities and localities. While they are broad and general in nature, we believe each Shift responds to critical issues that limit or frustrate the capacity of services to delivery care via person-centred or consumer directed principles. As recommendations, they also identify ways practitioners can be better supported in their practice and learning to work according to key recovery orientated care practices and the expressed wishes and preferences of consumer and carer groups. This support includes ways of working through and reframing dilemmas and tensions associated with risk and safety in crisis situations, and taking a wider perspective on how risk, opportunity and support is carried by consumers, carers and providers over time.

The focus on leadership development highlights the need for sustained leadership development for executives, lived experience leaders and practitioners. This points to the need for continued leadership that links consumer and carer experience, service outcomes, recovery outcomes to co-design and effective and inclusive governance. This report notes the need to raise the profile and scale of lived experience leadership, as well for the broader health sector to acknowledge that mental health specific PCC and CDC leadership is needed and provide resources to support it.

Several of the Shifts relate to the need for improved accessibility, consumer led design and co-design of programs and service pathways. Funding and commissioning can be used to support the expansion of peer and community organisations and improve the capacity of these organisations to provide peer programs, education, advocacy and pathway development to/with public mental health services. Peer and community organisations can provide improved information and resources, peer/practitioner navigation support and increase awareness on the wider needs of the person. They can help consumers, carers, families and kinship groups step through the gaps in access, information, awareness and service models that frequently occur. They can help promote experiences of continuity, support and coordinated care.

Through the analysis and co-design processes, this report identifies eight Shifts:

1. Strengthen practitioner education and training on essential knowledge and skills: inclusion in decision making, empathy, interpersonal communication, LGBTIQA+ health and gender affirming care, cultural safety, carer involvement and trauma-informed care.

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.

3. Create a national program for strengthening leadership and championing for organisational change in public mental health services.

4. Strengthen lived experience leadership in service governance and in the workforce.

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.

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

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

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

Further work to define preferred outcomes from both PCC and CDC

The research team observed over the course of this project that there are many diverse outcomes associated with both PCC and CDC, as well as those expressed in the recovery movement. These cover many aspects of the consumer and carer journey and refer to quality of service indicators, experience and personal safety, psychological and social processes, decision making about therapies, use of services as well as longer term mental health outcomes. As consumers use acute care, community care and different psychosocial supports, there are various service sectors which also have different ways of defining outcomes.

There is a need to develop a framework of PCC and CDC outcomes and impacts. This would be a valuable contribution to support planning for programs and organisations and to promote consistent development at the national level. As such, we recommend funding quality research to co-design and evaluate development of a national outcomes and impact framework for PCC and CDC. This should be guided by lived experience and be applied at the program and service level, as well as the national level.

LIST OF APPENDICES

Appendix 1: Consumer and carer experience and perspectives

Appendix 2: Background discussion paper

Appendix 3: Interview schedule

Appendix 4: Coding framework

Appendix 5: The Story So Far - Codesign session notes

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

Plain language summary

Audio recording on Person-centred Care and Consumer Directed Care Principles

Invitation of codesign sessions for participants

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