University of South Australia

Background document: person-centred care and consumer directed care in mental health

Introduction: purpose and aim of the document

The aim of this document is to prepare background about the project and to provide an outline of the principles of person-centred care and consumer directed care. As we are seeking to involve a range of different groups in conversations about these care concepts, it is useful to provide an outline of the history of these principles in the health and social care areas, and how they are influencing the planning and delivery of mental health care.

Our key purpose is to define these principles so that it is easier to discuss them in the focus group conversations.

The aims of the project

The broader aim of the project is to assist consumers, carers, clinicians, providers, and policy makers to understand the two different care concepts and to look at the evidence about good mental health outcomes. This includes evidence in literature and from focus group discussions.

It also aims to identify and discuss points of tension and reconciliation across the concepts, as these relate to services, consumer preferences, coproduction, and governance. Our hope is that we raise more knowledge and awareness about what is occurring for people using and delivering services and have more clarity about the benefits of these approaches.

Person-centred care

History:

Despite a long history of personalised healthcare, person-centred care 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, person-centred care has been conceptualised in many ways, including patient-centred care, patient and family-centred care, relationship-centred care, and personalised care, among others. Initially included in the delivery of primary physical health care, person-centred care is increasingly being discussed in the context of mental health care, both in primary and specialist settings. Recently, the concept of person-centred care has been included in considerations of human rights to healthcare as facilitating safe and high-quality care which upholds consumer rights.

Definition and principles:

Person-centred care is about providing services and support that accounts for individuals' unique needs, preferences, circumstances, and goals. Here, the focus is on what is needed and what is effective for each person. Patients are viewed holistically, meaning their emotional needs are considered in healthcare delivery, as well as their physical needs.

Where appropriate, person-centred care 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 person-centred care is to deliver care that is respectful of—and responsive to—individual preferences, needs, and values. Specifically, person-centred care considers the individual in the centre of decision making, and is guided by the principles of:

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

Use in public mental health services

Person centred care principles have been introduced and developed across the wider public health system via the development of National Safety and Quality Heath Service (NSQHS) Standards. 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 very relevant for mental health services and encouraging person centred mental health care. These are:

- **Clinical governance** – helping opportunities for consumers and carers to be involved in governance committee, feedback and complaints management, and consumer centred leadership
- **Partnering with consumers** – services should involve consumers and carers 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 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 increasing level of supports.

Generally speaking, the NSQHS is a key framework guiding person centred health care in Australia, as all public health services are formally accredited using the standards. It is important to acknowledge that limits to person centred care and decision making occur due to mental health legislation, and the use of treatment orders or other restrictions on a consumer's autonomy and decision making.

Consumer directed care

History:

The concept of consumer directed care (CDC) has predominantly come from within the disability sector, where people with disabilities pushed for their rights to live more independently and participate in mainstream society. Since, consumer directed care principles have also been applied to aged care living 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 programmes 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 public mental health services

Consumer directed care in mental health mostly occurs via people using the National Disability Insurance Scheme (NDIS) for psychosocial disability. The scheme is directly designed by CDC principles and was developed to help people with a wide range of disability needs, and later included mental health. Consumers approved for an NDIS plan by the National Disability Insurance Agency (NDIA) are able to use the budget of their plan 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 support workers, recreational, 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 national funded scheme, some mental health services choose to have a philosophy of consumer directed care based on recovery principles of empowerment and peer support. These services also work from a framework of trauma informed care, which also is committed to consumer empowerment, choice and power sharing, trust and transparency. Examples are non-government services or consumer-based organisations. These services achieve a strong commitment to support consumers to find and receive the care and support they decide on, rather than what they are eligible to receive.

Taking a deeper look at care concepts

One of the aims of the project is to explore the benefits and limits of each care concept, and how they relate to each other. To do this it might be helpful to identify some values

and principles which are important to recovery and mental health care. Some of these we can cover in the focus groups include:

- Autonomy and choice
- Involvement in decision making
- Role of the consumer and health professionals
- How needs and care planning directions are identified
- Perspectives on safety, dignity and risk
- Range of different service options
- Transparency and accountability
- How effectiveness is understood and evaluated

In looking at these discussion points, it is important to acknowledge that public mental health care and services operate in a legislative context where care can be directed through treatment orders. Traditional clinical models of mental health are clinically directed care.

Consumer, carer and health practitioner perspectives

An important part of the discussion is to acknowledge that there are diverse perspectives about issues relating to autonomy, choice, responding to risk and evaluating care outcomes. As such, the consultation process aims to include a wide range of voices and perspectives on the issues discussed above.

From a consumer, carer, and community perspective, we wish to include:

- State-based peak consumer body
- A carer organisation/network
- State-based LGBTQI+ organisation
- Aboriginal and Torres Strait Islander People's lived experience perspective
- Aboriginal and Torres Strait Islander child and family health network
- Culturally and linguistically diverse communities and asylum seeker mental health network

From a practice perspective, we wish to include:

- Multidisciplinary acute care teams
- Psychosocial rehabilitation
- Peer-support provided services
- Safety and quality team representatives
- Infant and child mental health
- Nursing and midwifery
- State-based Mental Health Commission perspective

Using Co-Design to produce the report

The concept of Co-Design is about partnership between funders, service providers, and people using the service, who work together to design resources, new programs and new ways of organising services. In mental health codesign princples are used to have

balanced participation across consumer, carer and provider groups, with an emphasis on empowering consumer perspectives and enabling opportunties for leadership. This project aims to produce its main report via Co-Design, where a group of advisers will work together to define the principles and practices which best describe good practice in person centred and consumer directed mental health care. The project will convene a group of advisors early in 2022.

For further information about the project, please contact Joshua McDonough, Project Manager, Tel 08 8302 5988 or email: joshua.mcdonough@unisa.edu.au