







Foreword

Families are the foundation of a healthy community. Families provide support, guidance and direction to individuals as they aspire to reach their goals, to succeed, to learn and grow.

The Queensland Plan for Mental Health 2007–2017 outlines priorities for the reform and development of mental health care. The plan identifies strengthening consumer, carer and family participation as a key action priority area of 'improving and integrating the care system'.

Queensland Health recognises a shared responsibility for the delivery of quality mental health services to the community, working in collaboration with the non-government sector to further consumer, carer and family participation. Queensland Health is committed to being informed through its partnerships with stakeholders.

The Consumer, Carer and Family Participation Framework provides a guide to adopting a consumer-driven, recovery-oriented, and carer and family inclusive mental health service model. The framework provides direction to mental health services across the state regarding enhancing consumer and carer participation at a local level.

The development of this framework is only one step in the journey towards best practice with regards to consumer, carer and family participation in health services. The continued commitment and cooperation of consumers, carers, families, policy makers and health care professionals are essential.

I remain committed to facilitating access to a comprehensive, recovery-oriented mental health system that improves mental health for Queenslanders. I encourage you to embrace the guiding principles outlined in the Consumer, Carer and Family Participation Framework.

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2 Consumer, Carer and Family Participation Framework





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Background and principles

Executive summary

The Consumer, Carer and Family Participation Framework provides an overarching structure that links the Queensland Plan for Mental Health 2007–2017 to the National Standards for Mental Health Services (2010). Building on existing initiatives and guiding better practice, the framework will support Queensland Health mental health services enhance consumer and carer participation at a local level.

Key themes identified during consultation form the basis of the implementation strategies of the framework. Key performance indicators give a mechanism to assess and report success in implementing participation.

In addition to providing strategic direction, this framework iterates the importance of adopting a recovery-focused, strengths-based and empowering mind frame to guide Queensland Health's commitment to reform in the mental health service sector.

The framework has been divided into four components. The first three components (Parts A, B and C) guide mental health services on how consumers, carers and families can be involved and participate in all levels of service planning, delivery and evaluation. The fourth component (Part D) is an overview of resources that services can use to enhance consumer, carer and family participation.





Queensland Health is committed to ensuring that consumer, carer and family participation guides the planning, development, delivery and evaluation of mental health services. Implementation of the proposed framework requires commitment by the mental health sector to several founding principles:

- 1. Recognition that consumers, carers and families have an important role in the recovery journey.
- 2. Recognition that consumers and carers have separate experiences and participation requirements.²
- 3. Commitment by mental health service leaders to consumer, carer and family participation across all levels of service planning, development, delivery and evaluation.²
- 4. Commitment to change and recognition that mental health staff attitudes towards consumers and carers are a major factor in enabling participation.^{3, 4}
- 5. Commitment to the 'recovery journey'. Understanding that consumers are on a 'journey towards a new and valued sense of identity, role and purpose outside the parameters of mental illness, living well despite limitations of the illness'.⁵
- 6. Recognition of the importance of developmental milestones in adapting a model of consumer, carer and family participation to meet the changing needs and roles of parents and their children.⁶
- 7. Commitment to a 'strengths-based' approach. This requires separating the consumer from their diagnosis and appreciating the consumer's strengths.
- 8. Recognition that consumers and carers have the right to decline opportunities to participate.
- 9. Appreciation of the complexities of mental illness and its impact on consumers, carers and families, in particular the availability of people to participate.



Background and principles

Consultation and governance

Development of the Consumer, Carer and Family Participation Framework was informed by comprehensive statewide consultation with key stakeholders. The project team facilitated 45 consultations in 30 different locations across Queensland between January and March 2009. This consultation gave more than 200 consumers, carers, families, mental health staff and agency representatives an opportunity to describe participation, what it involves and what prevents it.

Key themes identified during the consultation (see pages 13–17) form the basis of the implementation strategies of the framework (Part B).

Development of the framework was coordinated by Queensland Health's Mental Health Directorate, with the support of a reference group including:

- consumers and carers
- Queensland Alliance
- Mental Health Carers Arafmi Queensland Inc
- Queensland Centre for Mental Health Learning (QCMHL)
- Executive Directors of Queensland Health mental health services
- staff from Queensland Health mental health services.





Consumer and carer participation has been increasingly highlighted as a national priority. This can be evidenced through the inclusion of consumers and carers at numerous national committees and working groups including the Mental Health Council of Australia. In January 1997, the Australian Health Ministers' Advisory Council's National Mental Health Working Group endorsed the National Standards for Mental Health Services 1996 (NSMHS). Subsequently, these standards have been revised and are now the National Standards for Mental Health Services (2010) (NSMHS). In this document, Standard 3 discusses Consumer and Carer Participation.

Work has also been undertaken at a national level to develop a set of six recovery principles. These are:

- uniqueness of the individual
- real choices
- attitudes and rights
- · dignity and respect
- partnership and communication
- evaluating recovery.

The principles of recovery-oriented mental health practice will guide the delivery of mental health services in a way that supports the recovery of mental health consumers.

Consumer, carer and family participation has been recognised as essential across all service levels at both the state and national levels since 1997. The Council of Australian Governments has highlighted the need to increase consumer and carer participation activities, and Queensland Health has responded with the development of the Consumer, Carer and Family Participation Framework.

Consumer and carer participation is the first of six principles underpinning the Queensland Plan for Mental Health 2007–2017 (QPMH).

The mental health system will support active participation of consumers, carers and families in all aspects of activity including policy development and implementation, service planning and delivery, and research to ensure mental health care is oriented to meeting the specific needs of individuals.⁷

A range of national and international policies, plans, practice standards and consumer and carer movement initiatives informed the development of this framework:

- Universal Declaration of Human Rights (1948) United Nations
- National Standards for Mental Health Services (1996) (NSMHS)
- National Standards for Mental Health Services (2010) (NSMHS)
- National Mental Health Strategy
- National Mental Health Policy 2003–2008

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- National Mental Health Plan 2003-2008
- Queensland Plan for Mental Health 2007-2017
- Queensland Government Carers (Recognition) Act 2008
- Queensland Government Carer Action Plan (2006–2010)
- Queensland Government Carer Recognition Policy (2007)
- Sharing Responsibility for Recovery: creating and sustaining recovery-oriented systems of care for mental health (2005)
- Consumer and Carer Participation Policy: a framework for the mental health sector (2004)
- Towards Consumer Centred Services: Queensland Health action plan for consumer and carer participation in Queensland mental health services (2003)
- National Practice Standards for the Mental Health Workforce (2002).

From 2006 to 2009, the Mental Health Directorate contracted project officers Michael Burge and Kath Reid to design and develop a statewide framework for consumer and carer participation in Queensland mental health services. After several versions of the framework were reviewed, a new project team and reference group was formed in 2009 under the guidance of the Mental Health Directorate. Forty-five consultations took place at 30 locations throughout Queensland with consumers, carers, mental health unit staff and other relevant stakeholders. Following these consultations, the document was renamed to reflect the important role families play — Consumer, Carer and Family Participation Framework. The Mental Health Directorate wishes to acknowledge the following people for their involvement and commitment:

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Consumer

A person who is accessing or has previously accessed a mental health service. Within a child and youth mental health context, both the parents and the child or young person may be described as consumers.8

Carer

A person who voluntarily provides ongoing care or assistance to another person who, because of disability, age, frailty, chronic illness or pain requires assistance with everyday tasks. Carers include, for example, parents, partners, children, grandparents, aunts, uncles, siblings and/or friends of the consumer. 7

Accountable, responsive, quality services

Accountable and transparent mental health services involve consumers and carers at every stage of planning, service delivery and evaluation. Active consumer and carer participation results in mental health services that are responsive to community mental health care needs.^{4, 2, 9} Representatives who are responsible for advocating on behalf of consumers and carers have a mandate to 'ensure that the body being represented is kept well informed of activities, processes and outcomes'.2

Choice

Choice is about consumers being involved in decision-making processes and setting their own goals of recovery alongside their carers and family members.

Consumer and/or carer participation

The process by which consumers and carers assume a key role in planning, delivery and evaluation of services they use and influence the way in which their service needs are met.

Hope

Holding on to hope requires the belief that change and recovery are possible. It is about focusing on and appreciating the strength and resilience of consumers and carers.⁵

Key performance indicator

A measure of performance currently used to help an organisation define and evaluate its progress towards organisational goals or achievement of identified standards.

Leadership

Participation means consumers and carers are recognised as leaders within mental health services, playing a central role in service planning, development and evaluation. 10 Leaders in mental health services play a key role in supporting and implementing consumer and carer participation. Consumer leaders strive towards the achievement of a mental health service that provides clear opportunities for consumers to participate in mental health service delivery. 10 Carer leaders give voice to the shared experiences of carers and work to gain further recognition of the importance of carer and family involvement.

Background and principles

Mutual respect

Respect means recognising each consumer as an expert in their own lives. Consumers' lived experiences of mental illness give them unique insight into its effects and helpful ways to respond. Respect also means acknowledging the significant contribution made by carers and families in supporting consumers on their recovery journey.

Partnership

Partnership requires engaging consumers and carers as active participants and recognising that carers and family play a significant role in the lives of consumers. Partnership requires services to consciously work with consumers, carers and families in a proactive manner.¹¹

Recovery

Recovery acknowledges that having a mental illness does not necessarily mean life-long deterioration. People with a mental illness are recognised as whole, equal and contributing members of our community, with the same needs and aspirations as anyone else. As a result, when working to facilitate recovery, the basic elements of citizenship need to be considered, such as ability to live independently, form social relationships and access employment opportunities. In doing this, it is important that relevant stakeholders adopt and are supportive of recovery-oriented service provision. 1,5

Resilience

Resilience is the ability to recover quickly from illness, change or misfortune; to recover strength, spirit and good humour quickly; the ability to spring back into shape or position; buoyancy.

Social justice

Social justice relates to the equal and fair distribution of social values such as freedom and the opportunity to take part in society; the process which seeks to ensure the maintenance of a fair, equitable, egalitarian and generally harmonious society.

Standard

An established requirement.

Trust

To have confidence in something, a sense of certainty that is based on experience. When consumers, carers and families are trusted and open to trust, participation becomes possible.

Uniqueness

It is important to recognise the diversity of consumer and carer experiences. This means recognising that consumers and carers have different experiences and needs. It involves creating a diversity of consumer and carer participation initiatives that are inclusive of the appropriate consumer and carer participatory needs and interests.¹²

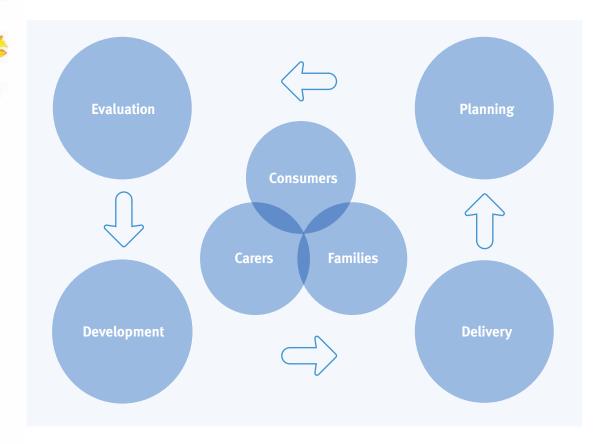


Defining participation

Participation has different meanings for everyone. It is a range of processes in which consumers, carers and family members are engaged to have their say at both individual and system levels and in the planning, development, delivery and evaluation of services. Participation (Figure 1) means consumers, carers and families being involved in the full spectrum of health care, from policy development and legislation, through to delivery and evaluation of services.

Consumers, carers and families have the right to participate individually and collectively in all areas of decision-making that impact on their mental health and to be offered choices about their care. 13

Figure 1: Forms of participation



In addition to the various forms of participation, there are a variety of mechanisms that services can use to engage consumers, carers and families (Figure 2). It is expected that a mental health service would employ a variety of these mechanisms throughout the service. For example, a service may involve consumers, carers and families in the design and planning for a new service by providing information, gathering information and consulting. Alternatively, a service may use consultation and partnership mechanisms to involve consumers and carers in developing the care plan.

Through participation, consumers, carers, families and clinicians work in partnership; sharing responsibility for making decisions. Participation is an opportunity to demonstrate respect for the expertise of consumers, carers and families.

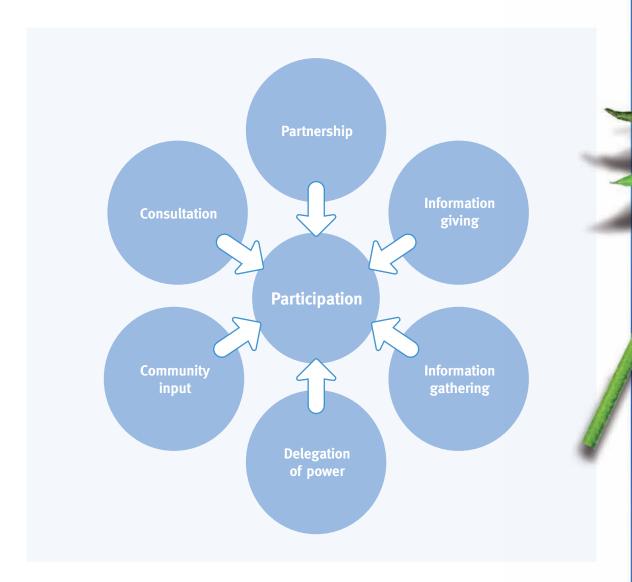
Background and principles

Being an active participant in one's health care can positively impact the recovery journey.

For the carer, an improved understanding of mental illness is thought to reduce stress levels, increasing their overall sense of wellbeing. 14 Furthermore, positive involvement of carers is understood to contribute to 'improved family functioning, increased periods of wellness and improved "quality of life" for the carer. 14, 15

Consumers whose family are informed, supported and encouraged to participate are more likely to have positive outcomes. 3, 4, 5, 8, 14, 16

Figure 2: Mechanisms of participation



Feedback from consultations

Key themes for consumers

Respect and compassion

Consumers stated how crucial it is to be treated like a person in their recovery journey. For consumers this meant being taken seriously and for staff to value the consumer's insights. For some consumers this involved 'starting the process where people are at'. Consumers described what a difference it makes when 'staff value what we say and they want us to be a part of implementing change'.

'Participation gives me the opportunity to voice my opinion. It doesn't matter where we come from, we have different colours to contribute. By putting the colours together we create a rainbow.' (consumer worker)

Inclusion and information

Consumers spoke clearly about how essential it is to have their own say about their treatment and that being central to their own care planning processes is essential for their recovery. Consumers across Queensland raised the issue of the importance of being given information about medications that are prescribed and any potential side-effects. They also mentioned the need for this information being provided in a language they can understand.

'Being heard and valued has been hugely empowering. It has transformed me as a person. Being able to be included has helped me feel accepted and comfortable. It has empowered me to think that my voice is valuable. It has given me back control, to be able to give back.' (consumer)

Cultural safety

Consumers articulated the importance of feeling comfortable to participate, to feel a sense of cultural safety. Some Indigenous consumers spoke about the importance of having a person, such as an Aboriginal health worker, with them during appointments. Some consumers from culturally and linguistically diverse (CALD) backgrounds spoke about how useful it is to have staff who are welcoming, and friendly, as well as having open and inviting spaces. Suggestions included employing more Indigenous and CALD staff members and 'staff going out and learning about other cultures, to introduce themselves to communities'.

Peer support

A number of consumers referred to the importance of peer support and how it helps participation. Consumers explained 'meeting informally with other consumers helps reduce stigma and increases comfortability' and 'through sharing our experiences and stories with other consumers and carers, we can help each other'.

'It has been a chance to work towards overcoming the stigma related to mental illness in the community.' (consumer and carer worker)

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Youth-friendly services

Young consumers spoke about how important it is to feel comfortable and to have youthfriendly environments. Suggestions included having 'informal and open communication' during assessment and planning processes 'that are not intimidating for young people who are not familiar with "formal" interview processes'. Young consumers also said how crucial it is to be asked what they think, for staff not to assume that 'young people are without an opinion or the capacity to intellectually respond'.

'When you are a young person, you don't feel like your voice is as valuable. When we are included, it is an honour to be engaged, to be given the opportunity to have your say. We want our experiences to be used. We have lived through something; we have skills from this. We want to use these.' (young consumer)

Support during a crisis

Consumers drew attention to the importance of being listened to when they are reaching out for help or when they are presenting to the emergency department. They also spoke about how crucial it is to have their crisis plans passed on to the staff at the emergency department, so consumers do not have to constantly repeat their stories.

Advocacy

Most consumers referred to the importance of independent advocacy being available. Several consumers indicated that they did not know of any available advocacy services available and that advocacy was another way of being supported to ensure that they were heard.

'It is a chance to be a part of changing organisational cultures, offering our contribution has brought hope and assisted us in our journey of recovery.' (consumer worker)

Staff education

Consumers spoke about the need for staff education about what participation is and what it could involve. Consumers also spoke about how important it is to have staff with facilitation and counselling skills working with other staff and psychiatrists 'who then know what they are dealing with'.

'For me, participation has been an opportunity to improve services. It has been important for me to know I am contributing to the knowledge of what works for consumers and carers in mental health services, to know I am playing a role in achieving the best possible outcome.' (consumer worker)

Continuity of staff

Consumers explained how staff turnover brings frustration for them and affects rapport and trust. Consumers said that 'changing case managers puts you back a step'. Consumers described that 'when you have the same case manager, they get to know what works and doesn't work for you'.

Representation, communication, information and dissemination

A few consumers spoke about how they would like their local consumer advisory group (or other mechanism) to have two-way feedback processes with consumers and carers at



the regional and statewide levels. Consumers identified how useful it is when there is a broad range of consumer representatives sitting on working parties and looking at various service development activities.

'By having a collective voice you realise you are not alone.' (consumer)

Key themes for carers

Respect

Carers spoke about how important it is for them to be respected in their role as carers. For carers, respect meant recognition that they have important knowledge to share about their loved one that could benefit assessment and planning processes. This involved clinicians 'trusting that carers know what they are talking about'. Some carers even raised the possibility of being seen as consumers of the mental health service.

The importance of being listened to

Carers observed that participation starts with being listened to. Some carers mentioned that staff sometimes see carers as 'adversarial'. They also spoke about how much difference it makes for them to be listened to and to be taken seriously.

Training for staff regarding confidentiality in practice

Many carers spoke about times when they have been excluded from participating in their loved one's care due to 'the misuse of the confidentiality card'. Carers have sometimes felt shunned or left out of care planning processes. They pointed out how crucial it is for staff to have a broader and more accurate understanding of confidentiality. Some carers acknowledged that they have been involved at times, were able to speak to a staff member and were given general information and support even when the consumer had not consented to their involvement.

Information and education

Across Queensland, carers repeated the need for more information and education for carers and the importance that information be in easy-to-understand language. Some suggestions included training on specific diagnoses/illnesses, support strategies, warning signs and information packages/resources.

Carer involvement during assessment and planning

Carers discussed the importance of being involved in decision-making about medication, optimum dosage for functioning and information regarding side-effects. Several carers shared stories of their loved one being discharged without their knowledge or consultation, and explained the enormous difference it makes for them and their loved ones to be seen as a part of the treating team.

Recognising the different needs of carers

Carers noted the importance of ensuring that there are a range of times (particularly some after-hours times) and days available for carers to participate. The importance of separate

Background and principles

forums for consumers and carers, offering carers after-hours forum options, was also raised. Carers indicated that this can involve recognising the diversity of carers (parent, partner, sibling, friend, foster carer and their potentially different participation needs).

'Participation has empowered me to assertively ask questions to get the best care for my son. It has enabled me to inform other carers and consumers how to do this.' (carer worker)

Respite options

Some carers expressed concerns about being tired and worn out, and how this undermined their ability to participate. Carers articulated the importance of flexible respite options to ensure they are more able to participate.

Support during crises

Carers agreed on the importance of having contact with a case manager and/or other staff for support during crises. Carers also suggested further training for police, to more sensitively respond to their loved ones during a crisis. Carers recognised how useful it is to streamline assessment processes.

Representation

A few carers felt that current consumer and carer advisory mechanisms don't adequately represent carers. Carers raised the importance of carers' interests being considered in service planning, delivery and evaluation. A clear communication path is needed to ensure carers' input and feedback are dealt with in a timely and appropriate manner.

'Participation enables a responsive relationship, as opposed to a reactive relationship, between the consumer, carer and mental health service.' (carer)

Key themes for staff

A shared responsibility

Many staff recognised the importance of mental health services understanding that participation is everyone's responsibility.

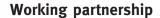
Service delivery

Staff confirmed the importance of cooperation between services to ensure positive experiences for consumers and carers. They also acknowledged the importance of consistency in information and reporting, to avoid consumers having to tell their story over and over again. Other suggestions included the mapping of local services and key workers to research best models of care.

Recruitment and retention of staff

Staff agreed that it is useful to have an emerging consumer and carer workforce within mental health services to support consumer and carer participation. The issue of having a full complement of staff was also raised, particularly in rural and remote areas, and the specific challenges they face with recruiting and retaining personnel. The challenge of providing services over large geographical distances, especially in the context of understaffing, was also acknowledged.





Staff spoke about the importance of a sense of trust between consumers, carers and the mental health service. They explained that 'with trust comes hope — with hope recovery is possible' and identified that partnership means open communication between all stakeholders. Staff also observed that working together involves ongoing 'shared' learning and identified 'the need for joint education to skill staff, consumers and carers for participation'.

Working with carers and families

Staff drew attention to the need to give consumers and carers information and support. Some staff mentioned how the role of a case manager should include 'to actively involve carers to maintain the consumer's family relationships'. It was clearly recognised that carers have collateral information that is useful for assessments. The importance of including carers in consumer's discharge planning was also discussed. It was also acknowledged that (with the consumer's permission) the carer should be informed of any changes to medication, treatment and the *Mental Health Act* status of the consumer.

Staff education

It was recognised that most staff understand the importance of participation, but some may not know how to go about it. The suggestion was that chairpersons of committees should be offered education on how to include consumer and carer representatives to enhance the chairpersons' skills of being inclusive, without being intrusive or tokenistic.

Strengths-based and recovery-focused planning

Staff recommended more education for mental health staff to work with consumers and carers in a way that is client-centred and collaborative to create strengths-based and recovery-focused plans.

The value of a multi-disciplinary team in care planning was also reiterated.

'Consumer participation discourages me from adopting bad habits with regards to care. It ensures that I do not dehumanise a person as a problem but rather a human being suffering unpleasant symptoms.' (nurse unit manager)

Workload balance

Mental health staff acknowledged that while they are committed to consumer and carer participation, they still need to be supported to enable them to balance their workloads.

Consumer and carer representation

Staff identified the importance of matching the skills of individual consumer and carer representatives to the relevant participation opportunities. They recommended that mental health service staff should make the effort to get to know the available consumer and carer representatives, their experience and interests. Many staff members also agreed that the provision of education, training and support to consumer and carer representatives is essential for meaningful participation.

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