

Consumer, Carer and Peer Worker Lived Experience CAPTURE Framework



Developed by the Queensland Centre for Perinatal and Infant Mental Health (QCPIMH), Children's Health Queensland Hospital and Health Service.
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Queensland Centre for Perinatal and Infant Mental Health - Consumer, Carer and Peer Worker Lived Experience - CAPTURE Framework

Aim: Embedding contributions of lived experience perspectives across the Perinatal and Infant Mental Health continuum of care in Queensland.

Service Development ↔ **Workforce Development** ↔ **Promotion, Prevention and Early Intervention** ↔ **Research** ↔ **Advocacy**

C	A	P	T	U	R	E
Codesign	Action	Principles	Timeframe	Utility	Reach	Evaluation
People with lived experience of perinatal and infant mental health (PIMH) issues are involved at every level of PIMH service design and implementation.	Consumer, carer and peer worker contributions are documented and put into action, with clear communication about what is done and why.	<ul style="list-style-type: none"> Put people first Create safety Be authentic Be flexible Pay and credit people fairly for the work they do. 	Tasks and activities have clear timeframes with a beginning, middle and end.	Activities focus on practical benefits for consumers and carers.	Service improvement is sustainable, transferable and scalable, aiming to benefit as many families as possible.	Consumers, carers and peer workers are involved in evaluation at all levels including design, methods, data collection, analysis, reporting, and translating results into service improvement.

	What is this level?	Who is involved?	Consumers, carers and peer workers are.....				
			Informed	Consulted	Involved	Collaborated with	Leading
Family Level	Clinician and consumer/family work together to achieve improvements in the mental health of the parent and/or child, and improvements in family functioning.	<ul style="list-style-type: none"> PIMH clinician Parent(s) Child Family 	Clinician explains reasons for treatment approaches, recommendations and decisions. Clinician provides information to help build the family's health literacy.	Clinician consults with the parent(s), child and family about how best to support them.	Clinician actively seeks feedback from parent(s), child and family about how treatment is progressing, and modifies approaches based on this feedback.	Clinician works with parent(s), child and family to create safety and trust, putting the family's treatment goals first, and working collaboratively to achieve these.	Parent(s), child and family feel safe to suggest new ways of working, to improve their experience of care and help them achieve their goals.
Clinical Team Level	The clinical team and consumers/families work together to ensure all aspects of service delivery are informed by lived experience perspectives.	<ul style="list-style-type: none"> PIMH clinicians Parents Children Families Consumer and carer representative(s) PIMH Peer Worker(s) Team Leader Service Manager(s) 	The clinical team provides information to parent(s), child and family about what they can expect from the service, in ways that build health literacy. Consumers and carers understand how to provide positive feedback or make a complaint.	The clinical team consults with consumers and carers using formal mechanisms like feedback surveys.	The clinical team involves consumers and carers in service improvement projects on an ad hoc basis (e.g. reviewing a new consumer resource).	The clinical team's governance includes regular formalised representation from the lived experience perspective, for example through a consumer and carer committee and/or dedicated consumer/ carer representative positions.	Consumers and carers are actively engaged, resourced, supported and encouraged to initiate and contribute to the clinical team's quality improvement processes and projects.
Services Network Level	The perinatal and infant mental health service system, across sectors, is informed by the lived experience perspective.	<ul style="list-style-type: none"> Parents, children, families and community members PIMH Team Leaders PIMH Service Managers Funding agencies Primary Health Networks Non-Government Organisations Private PIMH providers Commissioning and co-ordinating bodies such as MH AODB, QMHC Consumer and carer organisations 	Parents, children, families and community members can easily access information about PIMH services and supports in their local area.	Parents, children, families and community members are formally consulted about the need for PIMH services, existing gaps and access barriers, to inform network-level planning and investment.	Parents, children, families and community members are involved at the network level in planning and making decisions about investment in PIMH services.	Formal mechanisms such as a Community Advisory Council support parents, children, families and community members to collaborate in network-level planning about investment in PIMH services.	Parents, children, families and community members are actively engaged, resourced and supported to initiate and contribute to quality improvement processes and projects, including making decisions about investment in the PIMH service system at the network level.
Strategic Level	Lived experience contributes to improvements in PIMH policy, planning and implementation at state-wide, national and international levels.	<ul style="list-style-type: none"> All of the above plus national and international bodies 	Parents, children, families and the broader community can easily access information about PIMH health services and supports across the state, nationally and internationally.	Parents, children, families and the broader community have opportunities to participate in formal consultations about state-wide and national policy development, planning and investment decisions regarding PIMH.	Parents, children, families and the broader community are involved in state-wide and national policy development, planning and investment decisions regarding PIMH.	Parents, children, families and the broader community are formally represented as collaborators in state-wide and national policy development, planning and investment, through mechanisms such as state-wide and national PIMH Consumer & Carer Networks.	Lived experience organisations and formal bodies such as Consumer & Carer Networks are actively engaged, resourced and supported to initiate, contribute to and lead quality improvement processes and projects at state-wide and national levels.

Glossary

Advocacy – promoting and protecting the rights and interests of an individual or group. May include educating the group or individual about their rights, helping them make informed decisions to address discrimination and unfair treatment, and building their capacity to advocate for themselves.

Carer – person who provides care, support or assistance to someone with a mental health challenge. In this document the term refers to a family member, partner or friend, not a professional employed to provide care.

Children’s Health Queensland Hospital and Health Service – a state-wide provider of hospital and health services for children and young people across Queensland and northern New South Wales.

Clinician – a health professional involved in assessment and treatment of a consumer. A consumer and carer may meet several clinicians who form part of their treating team.

Codesign – service improvement through co-operation among service providers, consumers and carers. To engage in codesign, all parties need to be curious, non-judgemental, prepared to work with ambiguity, and willing to learn by doing. Codesign may require specific processes to invite and support the participation of consumers and carers with diverse lived experience perspectives.

Consumer – person who uses a mental health service (may also be referred to as a client or patient).

Continuum of care – a system of healthcare that provides for the consumer’s changing needs in a continuous and integrated way through a range of service models and settings e.g. general practice doctor, community mental health service, inpatient mental health service, telehealth service.

Health System Areas of Engagement – is the level of engagement within and/or across the Perinatal and Infant Mental Health continuum of care when engaging consumers, carers or peer workers at an family level (individual), clinical team level (service), services network level (network) or strategic level (system).

Hospital and Health Services – independent statutory bodies responsible for delivering public health services in geographic areas of Queensland. Hospital and Health Services are governed by a Hospital and Health Board and managed by a Health Service Chief Executive.

Infant mental health – mental health and emotional wellbeing of children from conception to school age.

Level of influence – the degree to which a person or group has power over a decision or course of action. For example, a health service may simply ‘inform’ consumers about a change to services. This differs from codesign, in which a group of consumers exercises a higher actively participates in creating the change, demonstrating a higher level of influence.

Lived experience – personal lived experience of mental illness and/or service use and recovery, from a consumer or carer perspective. Some people have both consumer and carer experiences.

Mental Health Alcohol and Other Drugs Branch – a branch of Queensland Health that provides system-wide clinical, policy and planning leadership to support the delivery of safe, high-quality, evidence-based mental health alcohol and other drug services across Queensland.

Not-for-profit organisation – an organisation that does not operate for profit or for the benefit of specific people (such as its members, directors, or their friends or relatives).

Perinatal mental health – mental health and emotional wellbeing of parents from conception to two years after the end of a pregnancy.

Peer worker – person employed in a role that requires them to identify as having lived experience as a mental health consumer or carer.

Peer workforce – the body of people employed in mental health services for their lived experience expertise as consumers or carers.

Primary Health Networks – organisations funded by the Australian Government to:

- Improve the range of medical services available, including primary and community-based mental health services, particularly for those at risk of poor health outcomes.
- Commission health programs that will be effective in meeting local community needs.
- Improve links among health services, so that patients receive the right care, in the right place, at the right time.

Promotion, Prevention and Early Intervention – the area of healthcare that educates the community about health and wellbeing, supports people to maintain their health and prevent illness, and provides early treatment for health problems before they get worse.

Queensland Centre for Perinatal and Infant Mental Health (QCPIMH) – Queensland’s state-wide hub of expertise in perinatal and infant mental health. QCPIMH supports parents, caregivers and communities to have the confidence, knowledge, skills and resources to support their own wellbeing and raise emotionally healthy and resilient children. QCPIMH works across sectors to support service development, workforce development, research and evaluation, advocacy, and mental health promotion prevention and early intervention, in perinatal and infant mental health.

Queensland Mental Health Commission – a statutory body established by the Queensland government to drive ongoing reform towards a more integrated, evidence-based, recovery-oriented mental health system.