

## Contents

Contents	
List of Figures	i
Disclaimer	ii
Acknowledgments	iv
Glossary and Abbreviations	v
Guiding principles	1
Consumer-Led	1
Co-Designed	1
Information sharing and communication	1
Collaboration	1
Comprehensive and recovery oriented	1
Continuity of care	2
Executive Summary	
Background	1
Purpose	1
What is care coordination?	2
Why is care coordination important?	2
Coordination in specific population groups	2
Summary of Recommendations to improve care coordination	3
About the Guidelines	g
Background	g
Context	g
Purpose	S
Aims and objectives	10
What is severe and complex mental illness?	10
What is care coordination?	13
How the guiding principles can support care coordination	14
What are the benefits?	15
What are the enablers?	15
What are the processes required for good care coordination?	16
Rights and responsibilities	17
Care coordination across the health and social system	17
Culturally safe care coordination	18
Care coordination across the life domains	19
Overview	

Recom	mendation 1. – Clarify the function and role of each stakeholder	23
	mendation 2. – Ensure there is a care coordinator to navigate and coordinate support for ners	24
Recom	mendation 3. – Ensure multiagency care planning is consumer-led and recovery oriented	27
	mendation 4. – Develop and implement practices that support communication and informa	
Recom	mendation 5. – Establish and support safe transitions of care	33
Recom	mendation 6. – Ensure Aboriginal and Torres Strait Islander services are involved and availa	ble
Recom	mendation 7. – Promote and strengthen innovative leadership	39
	mendation 8. – Ensure workforces are equipped to deliver effective coordination	
Recom	mendation 9. – Commit to improve and increase the use of data and technology in care nation	
	nges and transitions	
	inal and Torres Strait Islander people	
_	ally and linguistically diverse	
LGBTQ	IA+	51
Person	s living with a disability	53
	living in regional, rural and remote communities	
Impleme	nting, evaluating and maintaining the Guidelines	55
Comm	unication and education	55
Review	of these Guidelines	55
Gayaa Dl	huwi (proud spirit) declaration	56
Reference	es	57
Appendi	x A: Principles underpinning Aboriginal and Torres Strait Islander holistic health	62
List	of Figures	
Figure 1	Some of the services and sectors a person with severe and complex mental illness, their cand community may engage with	
Figure 2	Processes involved in coordinating treatment and supports for people with severe and complex mental illness	17
Figure 3	The three main levels of integration across the health and social system	18
Figure 4	Determinants of Aboriginal and Torres Strait Islander social and emotional wellbeing	50

## Disclaimer

These Guidelines were funded by the Australian Government Department of Health and developed by Health Technology Analysts (HTAnalysts) to support health and non-government or other community services and organisations and workers achieve better coordination of the various treatments and supports of people with severe and complex mental illness. These Guidelines do not claim to reflect all considerations. As with all guidelines, recommendations may not be appropriate for use in all circumstances and professional judgement in each individual case should be followed. These Guidelines are aspirational and should be strived for by all government and non-government agencies, service providers, health care and welfare professionals, peak bodies representing people with a severe and complex mental illness, caregivers and lived experience groups.

While the Guidelines are considered to be true and correct at the date of publication, changes in circumstances after the time of publication may impact the accuracy of the Guidelines. The Guidelines have been prepared and presented with all due care; however, HTAnalysts do not warrant or represent that the Guidelines are entirely free from error or omission. They are made available on the understanding that HTAnalysts and its employees shall have no liability (including liability by reason of negligence) to the users for any loss, damage, cost or expense incurred or arising by reason of using or relying on the Guidelines.

Best practices have been provided where possible to guide system, organisations, services and workers in developing and implementing change. Care has been taken to provide a wide selection of best practices; however, the Guidelines do not represent all possible best practices and it is the responsibility of the users to make their own investigations, decisions and enquiries about ways to meet the recommendations and suggestions of the Guidelines.

Although the Guidelines have been prepared following extensive review of literature, stakeholder consultation and review by an expert advisory committee, the authors do no bear any clinical responsibility for actions undertaken based on the information in the Guidelines.

A copy of the full Guidelines is available at Department of Health's, Fifth National Mental Health and Suicide Prevention Plan webpage.

## Acknowledgments

The Department would like to express appreciation to the Action 9 Working Group, membership of which included:

- Mark Roddam: Chair, Mental Health Principal Committee representative, Australian Government,
   Department of Health
- Daya Henkel: National Mental Health Consumer Carer Forum, Consumer representative
- Hayley Solich: National Mental Health Consumer Carer Forum, Carer representative
- Dr Vanessa Lee: Aboriginal and Torres Strait Islander Mental Health Project Reference Group
- Professor Tim Carey: Aboriginal and Torres Strait Islander Mental Health Project Reference Group
- Glen James: Primary Health Networks representative
- Australian Capital Territory, ACT Health
- New South Wales, NSW Ministry of Health
- Queensland, Queensland Health
- South Australia, Department of Health
- Tasmania, Department of Health
- Victoria, Department of Health and Human Services
- Western Australia, Mental Health Commission
- Senior Officials Working Group, Mental Health Interface Sub-Working Group representative
- Local Hospital Network representative

The Department would like to express appreciation to the key stakeholders and all other individuals who have contributed information, expertise and ideas to this important document. These include:

- Agency for Clinical innovation
- Attorney-General's Department, South Australia
- Austin Health, Victoria
- Australian Government Department of Health
- Australian Capital Territory Department of Health
- Brisbane North Primary Health Network
- Child and Adolescent Mental Health Services, North West Tasmania
- Child and Family Mental Health Services, New South Wales
- Community Mental Health Australia
- Consumers Health Forum of Australia
- Consumers of Mental Health Western Australia
- Department of Attorney-General and Justice, Northern Territory
- Department of Communities and Justice, New South Wales
- Department of Education, Northern Territory
- Department of Education, South Australia
- Directions Australian Capital Territory
- Equity Rights Alliance
- Flourish Tasmania
- Forensic Mental Health Services, New South Wales
- Gold Coast Primary Health Network
- Justice and Community Safety, Australian Capital Territory
- Lived Experience Australia
- Mental Health Australia
- Mental Health Commission, Western Australia
- Mental Health Community Coalition, Australian Capital Territory
- Mental Health Coordinating Council, New South Wales

- Mental Health Council, Tasmania
- Mental Health Families and Friends
- Mental Health Victoria
- Mental Illness Fellowship Australia
- Mind
- National Disability Insurance Agency
- National Indigenous Australians Agency
- National Mental Health Commission
- National Mental Health Consumer and Carer Forum
- New South Wales Ministry of Health
- Northern Territory Department of Health
- Northern Territory Primary Health Network
- Office of Chief Psychiatrist, South Australia
- Office of Chief Psychiatrist, Western Australia
- One Door Mental Health
- Orvgen Australia
- Phoenix Australia
- Queensland Aboriginal and Islander Health Council
- Queensland Alliance for Mental Health
- Queensland Department of Health
- Queensland Department of Housing
- Royal Australian and New Zealand College of Psychiatrists
- Selectability
- South Australia Department of Health
- Tasmanian Department of Health
- Tasmanian Health Service
- University of Sydney
- Victorian Department of Health and Human Services
- Western Australia Association for Mental Health
- Western Australia Mental Health Commission
- Western Victoria Primary Health Network

## Glossary and Abbreviations

**Access:** The ability of any person to obtain required or available services when needed within an appropriate time frame.

**ACCHOS:** Aboriginal Community Controlled Health Organisation and/or Service.

AMS: Aboriginal Medical Service.

**CALD:** Culturally And Linguistically Diverse.

**Care coordination:** The process of working with and for the person with severe and complex mental illness, their carer and community to help them plan care and access a range of different health and social care services and sectors.

**Carer:** Refers to persons that provide care and support to a person with severe and complex mental illness. Carers can be formal or informal and include family, friends or community members. The role of carer can vary over time depending on the needs of the person and the carer.

**Consumer:** A person who has or has had a personal lived experience of severe and complex mental illness and who is accessing or has previously accessed mental health and social care services.

**Consumer-led:** Coordination of supports is directed by the person with severe and complex mental illness they have a right to make their own decisions. These decisions should be respected and supported by carers, communities, services, sectors and professionals.

**Communities:** Refers to any persons involved in the consumer's life. This includes families, friends, aunties, uncles, cousins, teachers, colleagues and neighbours.

**Cultural safety:** Determined by Aboriginal and Torres Strait Islander individuals, families and communities. Ensuring respect for cultural and social differences in the provision of health and social care services.

**Culturally safe:** Practices that include ongoing critical reflection of health practitioner knowledge, skills, attitudes, practicing behaviours and power differentials in delivering competent, appropriate, safe, accessible and responsive care that is free from racism.

**Information sharing:** Refers to the sharing of appropriate clinical and nonclinical information between professionals, services, consumers, carers and communities.

**Kinship:** The kinship is based on direct blood lines through family such as grandparents, parents and child(ren); and/or there is also traditional kinship systems which include nations and clan groups who have ties across extended families, such as grandparents (and their siblings), aunties, uncles, cousins, parents (siblings) and child(ren).

**Leadership teams:** Refers to persons who lead services and workers to adapt and improve the way services are developed and delivered to consumers, carers and communities.

**LGBTQIA+:** Refers collectively to people who identify as lesbian, gay, bisexual, transgender, intersex, bodily diverse, gender fluid, queer, pansexual, sister-girls, brother-boys and other sexually and gender diverse populations.

MOU: Memorandum of understanding.

**Multiagency:** Refers to a number of different services working together with and for the consumer, carer and community.

NDIS: National Disability Insurance Scheme.

**Organisation:** Group of people with a particular purpose such as a business or government department.

**Peer worker:** Refers to a person employed specifically from either their personal lived experiences of mental illness and recovery, or their lived experience of supporting family or friends with mental illness, along with their professional experience, training, strengths and abilities.

**Person-centred:** Involving the person, their carer and community in planning, designing and delivering of services.

**Recovery oriented:** Refers to the practice of supporting people to recognise and own their recovery journey. People should be supported toto define their goals and desires.

**Sectors**: Refers to different departments and services of care, including health, psychosocial, housing, justice, education and employment.

**Services:** Refers to a person, business or organisation who carries out actions or work that help people with severe and complex mental illness, their carers and communities.

**Severe and complex mental illness:** Encompasses severity (reflected through diagnosis and episodic nature of illness), persistence (reflected through duration of illness or service needs) and complexity (reflected by impact to daily living, comorbidities and/or trauma).

**Shared decision-making:** Involves collaboration and discussion between the person, their carer, community and the service provider. The person should be supported to make decisions, exercise their legal capacity, make day-to-day choices, and draw upon their personal strengths and support networks to reach the most appropriate decision for that person.

**Social and emotional wellbeing:** A whole-of-life view that is multidimensional and intrinsically connected to all aspects of living, including family and kinship, culture and spirituality, connection, sense of belonging, reciprocity and the land.

**Trauma informed care:** Practices that understand and recognise the widespread impact of trauma for people with severe and complex mental illness, carers, communities, workers and others. Practices that respond by integrating trauma informed knowledge and principles into policies, procedures and practices.

## **Guiding principles**

The Guidelines are underpinned by six guiding principles, outlined below. These principles emphasise a person-centred, recovery oriented and trauma informed approach to coordination and improving the mental wellbeing of a person with severe and complex mental illness



#### Consumer-Led

- Coordination of treatment and supports is consumer-led and directed.
- The rights and responsibility of consumers to make decisions regarding their lives and the support they need is respected and supported.
- Coordination of treatment and supports is culturally safe and appropriate.

### Co-Designed

- The way the coordination of treatment and supports are designed, delivered and monitored, at the systems and delivery level, is consumer-led and co-designed with providers, carers and community.
- Consumers and carers have a direct and active role in all processes that affect their lives including:
  - Identifying and creating an entirely new plan, initiative or service, that is successful, sustainable and cost-effective and reflects the needs, expectations and requirements of all those who participated in, and will be affected by the plan.
  - Implementing, delivering and evaluating supports, systems and services, where consumers, carers and professionals work in an equal and reciprocal relationship, with shared power and responsibilities, to achieve positive change and improve outcomes.

#### Information sharing and communication

- Coordinated delivery of treatment and supports is driven by the professional and consistent use and sharing of information among providers.
- Only relevant information about a consumer should be shared with their consent and involvement where possible.
- Communication with the consumer should be according to their preference and align with trauma informed care and culturally safe practice.

#### Collaboration

- Interaction among providers is defined by trust, a shared understanding of goals and roles, effective communication and shared decision-making.
- There are clear lines of accountability where providers are responsible for working together with the consumer and their supporters to deliver consumer centred and directed treatment and supports.
- Interaction among providers is underpinned by a clear understanding and consistent application of respective roles and responsibilities, including areas of shared responsibility ensuring a central point of contact for consumers and carers is available where possible.

### Comprehensive and recovery oriented

- Treatment and supports will complement each other to support optimum clinical and personal recovery.
- Treatment and supports effectively meet all of the health care (including physical health, mental health and co-occurring conditions), psychosocial and other support needs of consumers according to their goals and wishes.









- Providers demonstrate a recovery oriented holistic approach to service delivery, culture and practice, which supports and builds the capacity of consumers on their recovery journey.
- Providers are committed to ensuring the workforce has the skills, competencies, culture and mindset to work in a coordinated way with other providers.
- Treatment and supports that place relationships, families and kinship<sup>1</sup> groups at the heart of
  mental health recovery to ensure families/carers are included in comprehensive care with the
  consumer's consent.

Continuity of care

Timely and uninterrupted treatment and supports are delivered across providers over time.

<sup>&</sup>lt;sup>1</sup> Kinship in these guidelines are defined as either (a) the kinship is based on direct blood lines through family such as grandparents, parents and child(ren); and (b) there is also traditional kinship systems which include nations and clan groups who have ties across extended families, such as grandparents (and their siblings), aunties, uncles, cousins, parents (siblings) and child(ren)

## **Executive Summary**

Endorsed in 2017, the *Fifth National Mental Health and Suicide Prevention Plan* (Fifth Plan) builds on previous National Mental Health Plans and reform efforts.

The Fifth Plan identifies several priority areas and actions to improve the provision of better integrated mental health and related services in Australia. Action 9 of the Fifth Plan focuses on the coordination of treatment and supports for people with severe and complex mental illness.

As a part of Action 9, The Australian Government Department of Health has commissioned the development of National Guidelines to improve coordination of treatment and supports for people with severe and complex mental illness (the Guidelines).

## Background

In Australia, approximately three per cent of the population have a severe mental illness and their needs are often not the same. Understandings and definitions of severe and complex mental illness vary. We acknowledge that the below definition may not fully represent consumers and carers experiences, preferred language, recovery journeys and path to re-claiming their citizenship.

Severe and complex mental illness as defined in this document encompasses:

- Severity (reflected through diagnosis and episodic nature of illness)
- Persistence (reflected through duration of illness or service needs) and
- Complexity (reflected by impact to daily living, comorbidities and/or trauma).

For Aboriginal and Torres Strait Islander people, social and emotional wellbeing should be included in any diagnosis, support and treatment plan.

People with severe and complex mental illness often require access to and support from various health services and professionals. These supports are commonly delivered in combination with a range of other services including housing and community services, alcohol and other drugs services, psychosocial support services, education, employment and justice. In addition, the physical, emotional and social health and wellbeing should always be considered when working with people with severe and complex mental illness.

Despite ongoing efforts by services and sectors to improve outcomes, many people with severe and complex mental illness still do not receive the treatment and supports they need. This is, in part, due to a lack of coordination among the network of services and sectors that exist to support this population group.

Throughout the Guidelines, people with severe and complex mental illness may be referred to as consumers. We acknowledge that not everyone will identify as a consumer. In these Guidelines, consumers refer to people with severe and complex mental illness who are engaged or engaging with various services and sectors to support their mental wellbeing and recovery journey.

## Purpose

The Guidelines are aspirational and intended to inform stakeholders on areas associated with the improvement of coordination of treatment and supports for people with severe and complex mental illness. Stakeholders include government and non-government health, social care and community services, providers and program managers, consumers, carers and communities within Australia. The Guidelines do not outline implementation strategies. Implementation plans will need to be developed separately and individually tailored.

Implementation of these Guidelines will vary depending on the audience (e.g. Primary Health Networks, community managed organisations, private professionals) and jurisdiction. Gaps, improvements or delivery of services or programs are out of scope of these Guidelines.

## What is care coordination?

Care coordination is the process of working with the person as well as their carer and community, to help bring a range of health and social care services and sectors together. Ensuring smooth access and coordination between services and sectors will help the person meet their needs, achieve their goals and work towards recovery.

To achieve the best outcomes for people with severe and complex mental illness, a coordinated approach is needed. Coordination is a complex task and requires ongoing concerted effort and commitment to ensure treatment and supports are person-centred and appropriate to meet the unique needs of each individual.

Coordinating treatment and supports for people with severe and complex mental illness requires an array of health and social care services and sectors to work together with and for the person. It is essential that coordination is consumer-led, person-centred and integrated. This will allow each person to access and receive the most appropriate treatment and supports and enable better navigation and understanding of a complex system.

## Why is care coordination important?

The benefits of effective coordination are significant. It can improve consumer, carer and community experiences, quality of life and family engagement. Good care coordination will also reduce hospital admissions, improve clinical outcomes, increase productivity and provide economic benefits. Coordinated care increases the likelihood that the person will feel supported and safe to access and receive support where and when it is needed.

The needs of a person change over time, so it is vital that coordination efforts focus on the person receiving care. Individual goals and basic needs, including physical health, housing and employment, need to be understood and met in order to help improve overall health and wellbeing.

## Coordination in specific population groups

There are some key considerations when working with specific population groups. Some of these are outlined in these Guidelines. Services and sectors must commit to the ongoing learning and understanding of the needs of various population groups, including those not identified here.

#### Life stages and transitions

Supporting people through significant life stages and transition points requires additional attention and coordination. These include adolescence to adulthood, older age and prison release. These stages can be challenging times for people, and opportunities to engage appropriate treatment and supports can be missed. Services need to work in collaboration to ensure that people who are moving through significant life stages or transition points are adequately supported and connected with the right treatment and services to support recovery and wellbeing.

### **Aboriginal and Torres Strait Islander**

Providing well-coordinated care for Aboriginal and Torres Strait Islander people requires active engagement with culturally safe services. Equally important is recognising and listening to the unique voice of the person and their identified support networks (e.g. family, Elders, etc.). Services, sectors and professionals should ensure all treatments and supports are coordinated through a social and emotional wellbeing approach.

### **Culturally and linguistically diverse**

Services and sectors should develop and maintain partnerships with local culturally and linguistically diverse (CALD)-focused organisations to enhance service accessibility and delivery of care for consumers. Recognition of the need, value and importance of family and community in mental health and wellbeing for CALD persons is needed when coordinating care.

#### **LGBTQIA+**

Services and sectors need to establish trusting, safe and confidential relationships and environments. It is important that professionals are aware and sensitive to the various cultures, needs and diversity of LGBTQIA+ communities. Working with LGBTQIA+ specific services can improve the delivery of appropriately coordinated care.

### Persons living with a disability

Services and sectors should seek to maximise the involvement of the individual, their carer and community when coordinating treatment and supports. A willingness from services and sectors is required to adapt approaches when coordinating care to accommodate any physical or intellectual support needs.

### People living in regional, rural and remote communities

Consideration of the variations between community needs is required as no two geographical locations will have access to the same supports or services. Additional support for the carers and communities of people with severe and complex mental illness within regional, rural and remote locations may be needed. This is because many carers and communities have added burden to fill potential gaps in care. Services and sectors should seek to promote and maintain confidentiality and trusting relationships within small communities where everyone knows each other. Digital technology should be offered to support consumers, carers and communities where appropriate, particularly when services may be located far away.

## Summary of Recommendations to improve care coordination

Improving the coordination of treatment and supports for people with severe and complex mental illness will require unity and commitment from all stakeholders. The Guidelines outline nine recommendations that, when implemented, will support and improve the coordination of treatment and supports for people with severe and complex mental illness.

Successful implementation of these recommendations will need strategies. Implementation plans will need to be developed by the various services and sectors and tailored to the specific state and territory.

## Recommendation 1. Clarify the function and role of each stakeholder

Recommendation 1.1: Ensure that all functions, roles and responsibilities are designed and developed with and for the consumers, carers and communities and are clear, transparent and understood.

- Functions and roles will vary depending on the involvement and needs of the consumer, jurisdiction, level of care, care team, carers and communities.
- Governments must meet consumer needs with minimum confusion and duplication. Services must
  be delivered in collaboration with other health and social care services and sectors. The role of care
  coordinators is to partner with consumers, carers and communities to develop care plans and
  identify and navigate services.

Recommendation 1.2: Clearly outline the requirements and expectations of each role for all stakeholders to understand, including consumers, carers and communities.

• Determine what the role will achieve.

- Define how the roles and responsibilities will contribute to or support coordination with and for the consumer, including collaboration with other health and social care services and sectors.
- Detail what activities are expected to be carried out and how this will be evaluated and monitored.
- Determine what skills and experiences are needed to fulfil the functions and roles.

# Recommendation 2. Ensure there is a care coordinator to navigate and coordinate support for consumers

Recommendation 2.1: With consumer consent, engage a care coordinator to identify needs and support the coordination and navigation of services and sectors.

- One person should act as the central point of contact for the person, their carer and community. In some situations, it is desirable for a person to have a care coordinator for example, under an involuntary treatment order.
- There should be a specific role for someone to be the care coordinator. The peer workforce could
  also be employed to carry out this role. If a care coordinator is not available, depending on where
  the person enters the system, the care coordinator may be identified as being their general
  practitioner or work within a service or sector.
- The care coordinator must work in partnership with the person to develop a care plan, help navigate the health and social care system, and engage the appropriate services and sectors. Care coordinators will also advocate with and for the person.

Recommendation 2.2: Provide care coordinators with appropriate support, resources and authority to oversee and ensure the multiagency care plan is being implemented.

• Skilled and knowledgeable people are required to act as care coordinators. Adequate time and resources are needed to support the role of a care coordinator including funding and item numbers.

# Recommendation 3. Ensure multiagency care planning is consumer-led and recovery oriented

Recommendation 3.1: Establish processes to develop multiagency care plans with and for the consumer.

- All services and sectors should develop processes that enable them to initiate and participate in multiagency care planning. These should be planned, designed, developed, measured and evaluated in partnership with consumers, carers and communities.
- There must be shared decision-making with the person regarding which services and sectors are best suited to meet their needs.

Recommendation 3.2: Services, sectors, carers and communities should collaborate and work alongside each other according to an agreed single multiagency care plan to meet the consumer's needs.

- Consumer goals, beliefs, preferences and culturally safe supports.
- Assessment of physical, mental, emotional and social health and wellbeing as well as escalation pathways and risk management details.
- Open communication, transparency and accountability between consumers, carers and services must be achieved. This requires regular discussions as well as ongoing evaluation and feedback mechanisms.
- Shared and common understanding of the consumers support needs, goals and wishes is critical. Shared tools and languages should be used to support this.

Recommendation 3.3: Ensure the consumer is an involved decision-maker and participant in their multiagency care plan.

• Care plans must be consumer-led and carried out in a person-centred, trauma informed approach.

• Consumers must be supported to be present at all multiagency meetings. Rescheduling should occur if the person is not available.

# Recommendation 4. Develop and implement practices that support communication and information sharing

Recommendation 4.1: Develop information sharing protocols that are underpinned by principles of consent and confidentiality.

- Consent and confidentiality must underpin any information sharing protocol. Consent to share information should always be gained where possible and reviewed regularly.
- Sharing information without consent should only occur in certain situations depending on the circumstance, local legislations and professional and ethical standards.

Recommendation 4.2: Develop information sharing protocols in collaboration with health and social care services and sectors, and across states and territories.

- Information sharing protocols should be developed between health and social care services and sectors to support coordination and timely information sharing. Protocols should be co-designed with consumers, carers and communities and include (but is not limited to) what information can be shared across services and sectors and how it will be shared and stored safely.
- States and territories should adopt a mutual recognition principle within mental health legislation so that each state or territory legally recognises mental health orders made under the legislation of all others. Information sharing protocols, similar to that described between health and social care services and sectors, should be developed to safely share information across states and territories.

Recommendation 4.3: Ensure all professionals have access to education and resources on how to gain and document informed consent, the legislation in each state and territory and how to communicate information.

- Regular training should be provided (at least once a year) to all professionals' working with people with severe and complex mental illness.
- Training should include (but not be limited to) what informed consent means, what the information sharing protocol means and in what situations consent is not needed.
- Consumers, carers and communities should be involved in training sessions with professionals.

Recommendation 4.4: Ensure consumers, carers and communities have access to education and resources on consent and information sharing processes.

- Consumers, carers and communities have a right to access appropriate education and resources that allow them to understand why some information may need to be shared.
- There should be increased communication with consumers, carers and communities to improve understanding of why information is shared, how and with whom.

## Recommendation 5. Establish and support safe transitions of care

Recommendation 5.1: Improve or develop formal pathways with shared agreements between health and social care services and sectors.

- Shared agreements should be developed between health and social care services and sectors to define formal pathways for safe transitions.
- Agreements should be co-designed with consumers, carers and communities. The agreements should define the roles and responsibilities of each service involved in the transition, promote warm referrals, define follow up and evaluation processes, and outline escalation pathways.
- The original service must maintain contact with the individual their carer and community as well as the service they are transitioning to until all parties agree that the transition has been successful.

Recommendation 5.2: Clearly define and clarify the roles and responsibilities of those involved in the transition of care.

The services and professionals involved in the transition should be clearly defined in the
multiagency care plan. This includes an agreement to engage with the person, what service they
will provide and when. This will ensure the services are held accountable to fulfil their role in the
multiagency care plan.

Recommendation 5.3: Identify a coordinator to support the consumer and assist in ensuring safe and effective transitions.

As per Recommendation 2, a care coordinator should be identified and involved to support the
consumer, their carer and community in the transition. If a care coordinator is not available,
another key person must be identified to support continuity of care and ensure the transition is
safe and successful.

## Recommendation 6. Ensure Aboriginal and Torres Strait Islander services are involved and available

Recommendation 6.1: Ensure Aboriginal and Torres Strait Islander services, professionals and social and emotional wellbeing teams are embedded across government and non-government health and social care services and sectors.

 Commitment from governments to invest in Aboriginal and Torres Strait Islander services, professionals and social and emotional wellbeing teams.

Recommendation 6.2: Develop strong culturally safe partnerships that enable coordination with health and social care services and sectors, as well as communities, to meet the social and emotional wellbeing needs of Aboriginal and Torres Strait Islander consumers.

- Aboriginal and Torres Strait Islander community services should be involved in the development and delivery of culturally safe and responsive care coordination, including the training of staff.
- Services and sectors should foster partnerships with Aboriginal and Torres Strait Islander community services.

Recommendation 6.3: Continually consider and assess the social and emotional wellbeing and needs of each individual, offering access to culturally safe treatment and supports that include the kinship family.

- The National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing is available and should be utilised by services and sectors.
- Services and sectors should work with and for Aboriginal and Torres Strait Islander consumers, carers and communities to best understand their culture, value and beliefs. It is also important to be able to understand how this influences their social and emotional wellbeing and treatment and supports.
- All Aboriginal and Torres Strait Islander consumers should be given the opportunity to access
  cultural services such as Elders, traditional healers, cultural healers or storytellers to support
  their care coordination.

## Recommendation 7. Promote and strengthen innovative leadership

Recommendation 7.1: Develop and support internal system and organisational leadership to facilitate effective communication and care coordination.

Governments should develop leaderships teams that foster effective relationships across health
and social care services and sectors and facilitate the negotiation and mobilisation of resources and
networks.

- Services and sectors should invest in strong leadership that facilitates seamless integration with
  other health and social care services and sectors and supports frontline staff in providing effective
  coordination.
- Evaluation, monitoring and feedback mechanisms must support strong leadership.

Recommendation 7.2: Support consumers, carers and communities to develop independent life and leadership skills that will assist in their recovery journey.

• Services and sectors should connect consumers, carers and communities with mentors or educators who can provide guidance in life and leadership skills.

Recommendation 7.3: Establish, build and maintain trusting relationships and partnerships with other services, professionals, carers and communities.

- Regular networking events should be scheduled to facilitate relationship building across health and social care services and sectors.
- Leadership teams should relay relevant care coordination information and practices to staff in a timely manner.

## Recommendation 8. Ensure workforces are equipped to deliver effective coordination

Recommendation 8.1: Ensure services and sectors are trained to provide culturally safe and effective coordination.

- Governments, services and sectors need to commit to investing in adequate time and resources that support the delivery of culturally safe coordinated care.
- Training should support staff to understand and overcome various barriers to coordination including discrimination, service eligibility and service availability.
- Training should also educate and support services and sectors on the value and importance of the peer workforce, carers and capacity building in consumers.
- Proper evaluation, monitoring and feedback is crucial and must be ongoing.

Recommendation 8.2: Ensure peer workers are treated as valued members of the workforce.

- Services must promote and support the peer workforce.
- Training and professional development needs to be available to peer workers.
- Training and resources should be developed and delivered by peer workers to ensure relevance.

Recommendation 8.3: Build the capacity and confidence of consumers, carers and communities to engage in their own health and wellbeing journey.

- Services and sectors should work to build capacity and confidence so that consumers, carers and communities can fully participate and take control of their own health and wellbeing.
- Capacity building training and resources should be co-designed with consumers, carers and communities.

# Recommendation 9. Commit to improve and increase the use of data and technology in care coordination

Recommendation 9.1: Ensure electronic information sharing platforms are compatible across government and non-government services and sectors.

- Information sharing platforms should be improved or developed to assist the workforce to share the appropriate information in a safe and timely manner.
- Consumers should have access to their own information and data.

 The platform should also have the ability for professionals and consumers to access and update the care plan, identifying as a minimum, the care coordinator and the services and professionals involved.

Recommendation 9.2: Collaborate with consumers, carers and communities in the development and implementation of electronic platforms.

- To develop a new system or improve on the interoperability of existing systems, consumers, carers and communities should be involved throughout.
- Time and dedicated resources by Commonwealth, state and territories are needed to develop, improve, implement and evaluate the platform.

Recommendation 9.3: Ensure consumers have the opportunity and choice to use digital technology (i.e. telehealth) to supplement face-to-face contact for remote monitoring and consultations.

- Telehealth and internet-based support services should be available for consumers to increase access, particularly for those in rural, regional and remote areas, however should not replace faceto-face consultations
- Consumers have a right to choose how they access and receive the service.
- Governments have an ethical responsibility to ensure that a regulative body is established to ensure consumers and services can safely use artificial intelligence.

## About the Guidelines

## Background

Endorsed in 1992, the National Mental Health Strategy has provided the overarching policy framework that has guided extensive mental health reform in Australia [1]. Over the last 20 years, the strategy has evolved to encompass the various national policy and planning documents relating to mental health reform. This includes the first four five-year National Mental Health Plans covering the period between 1993 and 2014 [1]. Endorsed in 2017, the *Fifth National Mental Health and Suicide Prevention Plan* (Fifth Plan) builds on the foundations established by previous National Mental Health Plans and reform efforts. It is the first mental health plan to recognise the devastating impact of suicide and outline future direction and actions to address this public health issue [2].

The Fifth Plan is underpinned by several targeted priority areas, supported by actions intended to set the direction for change and provide a foundation for longer-term system reform [2]. Action 9 of the Fifth Plan focuses on improving the coordination of treatment and supports for people with severe and complex mental illness, identifying the need for National Guidelines.

The Australian Government Department of Health engaged Health Technology Analysts (HTAnalysts) to assist in the development of *National Guidelines to improve coordination of treatment and supports for people with severe and complex mental illness*. HTAnalysts carried out extensive stakeholder engagement to identify and collaborate on a variety of key barriers and issues associated with the coordination of treatment and supports for people with severe and complex mental illness, seeking to identify culturally safe and mutually agreed upon solutions.

## Context

Mental health conditions are widespread and can have a significant social and economic impact. The Fifth Plan is the culmination of extensive consultation to establish a national approach for collaborative government action to improve the provision of better integrated mental health and related services in Australia [2]. An important element in achieving this is the smooth and effective coordination and communication within and across relevant services and sectors.

In Australia, approximately three per cent of the population live with a severe mental illness and their needs are not often homogenous [2]. Some people have episodic illness. Others have more persistent illness which can reduce their ability to function and participate in daily activities. Some can be supported through time-limited primary care clinical services while others may require hospital-based services and community support [2].

People with severe and complex mental illness often require access to and support from various health services and professionals. These supports are commonly delivered in combination with a range of other services including housing and community services, alcohol and other drugs services, psychosocial support services, education, employment and justice [3]. Literature highlights a fractured mental health system, hindering the effective coordination of treatment and supports for people with severe and complex mental illness [3-5]. Commonly reported barriers include inefficient information sharing and communication, nonstandard referral pathways and difficult navigation of and between services.

Despite ongoing efforts to break down these barriers, many people with severe and complex mental illness still do not receive the treatment and supports they need [2].

## Purpose

The Guidelines are aspirational and intended to inform government, non-government and community health and social care services, providers and program managers, consumers, carers and communities

within Australia on areas associated with the coordination of treatment and supports for people with severe and complex mental illness.

The Guidelines do not outline implementation strategies. Implementation plans will need to be individually tailored and developed separately. Implementation of these Guidelines will vary depending on the audience (e.g. Primary Health Networks, community managed organisations, private professionals) and state or territory. Gaps, improvements or delivery of services or programs are out of scope of these Guidelines.

## Aims and objectives

The Guidelines have been developed to improve the coordination of treatment and supports for people with severe and complex mental illness. The Guidelines address various issues relating to coordination including roles and responsibilities, information sharing and navigation, which may hinder effective coordination. They aim to highlight fundamental components vital to supporting successful coordination, identifying and guiding improvements within and across health and social care services and sectors. The Guidelines:

- Clarify roles and responsibilities across the health and community support service sectors.
- Are consistent with the Council of Australian Government's Mainstream Interface Principles (which
  determine the responsibilities of the National Disability Insurance Scheme (NDIS) and other service
  providers).
- Specify criteria to guide the targeting of service delivery to consumers, including identifying pathways for culturally competent services.
- Promote the roles of multiagency care plans, care pathways and information sharing protocols.
- Identify opportunities for the use of digital mental health and electronic health records in coordinating care.
- Highlight the role of data in supporting these activities.

## What is severe and complex mental illness?

Understandings and definitions of severe and complex mental illness vary. We acknowledge that the below definition may not fully represent consumers and carers experiences, preferred language, recovery journeys and path to re-claiming citizenship. For the purposes of the Guidelines, the definition of severe and complex mental illness encompasses the following elements:

- Severity encompasses clinical severity (including episodic) and is reflected in diagnosis, acuity of symptoms of the primary mental illness, recent hospital admissions and/or the presence of functional impairment.
- Persistence is reflected in the duration of illness and/or service needs.
- Complexity in severe mental illness arises from three main sources and their interaction with each other. The first is the impact on activities of daily living and role dysfunction due to the severity of the illness. This may include disengagement from occupational, social/community or family connections, and the requirements of support, such as self-care, self-management, accommodation and vocational assistance, to achieve and sustain maximum independence and quality of life. Second, complexity arises when the person with mental illness also experiences comorbid intellectual, developmental, personality or substance use disorder, and/or physical illness (connection to body) or disability. Third, complexity arises when a person with mental illness experiences: social exclusion, abuse, neglect or other trauma (including intergenerational trauma); homelessness; or involvement with the criminal justice system.

For these Guidelines, the target group is considered to comprise of three subgroups of people with severe and complex mental illness and complexities primarily relating to:

- 1. Significant disability arising from their mental illness
- 2. Multimorbidities which impact upon and are exacerbated by their mental illness
- 3. Social adversity factors which impact upon or are exacerbated by mental illness

For Aboriginal and Torres Strait Islander people, social and emotional wellbeing should be included in any diagnosis, support and treatment plan. Social and emotional wellbeing is a multidimensional concept that encompasses a person's connection to family, ancestors, community, culture, spirituality, and belonging to 'land' or 'place' (see Figure 4). This is a whole-of-life view, and when one or more connections or cultural assets are broken or disengaged a person can become mentally unwell resulting in the need to have strategies to address trauma or sometimes a clinical diagnosis is required.

Throughout the Guidelines, people with severe and complex mental illness may be referred to as consumers. The Guidelines acknowledge that not everyone will identify as a consumer. In these Guidelines, consumers refer to people with severe and complex mental illness who are engaged or engaging with various services and sectors to support their mental wellbeing and recovery journey.



An exploration of what care coordination is, how it is defined, why care coordination is needed, the key enablers that help achieve effective coordination, and understanding how culture and life domains influence care coordination.

This section highlights processes involved in care coordination, and their key elements, in a simple visual summary.



## What is care coordination?

Care coordination is the process of working with and for the person, their carer and community to help them plan their care and access a range of different health and social care services and sectors. In these Guidelines, carers refer to those who are directly involved with providing formal or informal care to the person (e.g. spouse, family). Community refers to other people in the person's life such as friends, neighbours and other support networks.

There are six key components of care coordination that are vital to the successful coordination of treatment and supports for people with severe and complex mental illness. These include:

- 1. Whole of person Consider the person's physical, mental, emotional and social wellbeing, as well as their goals and desires, when planning treatment and supports.
- 2. Timely and targeted care Consumers receive the right treatment, support and care at the right.
- 3. People with severe and complex mental illness, carers and communities Practices are trauma informed and designed with and for the person, their carers and communities.
- 4. Navigation and leadership Invest in consumer, system and organisation capacity to support access to and coordination of care.
- 5. Culturally safe Culturally safe pathways that support people to access and receive appropriate treatment and support.
- 6. Information and data sharing Open communication and a shared knowledge and understanding of the care plan, including the person's consent.

The aim of care coordination is to support each person to plan and access care in a timely manner to achieve their personal health, wellness, and recovery goals [6]. Care coordination and planning therefore requires holistic and trauma informed, recovery oriented practices whereby services and the workforce seek to identify and integrate services reflective of a person's broader needs [7].

Figure 1 outlines some of the services and sectors a person may need or want to engage with and should be incorporated into a coordinated approach. This could include access to stable housing, mental health services, alcohol and other drug services, employment, income support, social and family support, education, community and justice services. These services and sectors should work together to support the consumer, their carer and community as well as promote positive outcomes and facilitate sustained recovery [7].

The dynamic nature of severe and complex mental illness makes achieving smooth and effective care coordination challenging. Bringing multiple services and sectors together to achieve a common goal requires flexibility and mutual understanding [8]. It is critical that appropriate consideration is given to the needs of each person, as well as their carer and community. This means that the range of health and social care services must reflect the individual and their needs. Where appropriate, for long-term support, support to gain access to the NDIS should be included. For Aboriginal and Torres Strait Islander people, coordination of services needs to be appropriately integrated into a culturally capable model of care widely recognised as enhancing effectiveness of treatment and maintaining positive outcomes for the individual [7].



Figure 1 Some of the services and sectors a person with severe and complex mental illness, their carer and community may engage with

Source: informed by stakeholder consultations

## How the guiding principles can support care coordination

Effective care coordination for people with severe and complex mental illness requires all services to follow the six guiding principles (see Guiding principles). If the principles are not taken into consideration, good care coordination is not achievable.

The consumer-provider relationship is crucial for achieving person-centred outcomes and recovery. Care plans need to reflect the person, their strengths, needs, desires and goals. Consumer perspectives highlight the value and importance of strong positive relationships when developing person-centred care plans [9]. At times, a consumer may feel overwhelmed and isolated. This can make it hard for the consumer to know where to start or to identify their goals and desires. Strong consumer-provider relationships can help consumers identify what they want to achieve.

Being heard and understood is vital for building rapport, partnerships and for recovery. Service commitment is also vital in care coordination. People need to feel confident services are proactively following through with actions and working towards a common goal.

Information sharing is thought to enable better coordination. Information sharing and communication between services was found beneficial for reducing unnecessary repetition and providing all

professionals with access to appropriate consumer records [10]. Language can hinder effective information sharing and communication, impacting the way people understand and perceive information sharing [3]. It is essential that information sharing and communication is carried out in consented and mutually agreed upon ways.

Coordinating care requires a holistic and comprehensive approach to ensure adequate and appropriate services are engaged throughout a person's journey. When identifying and collaborating with services, consideration of the person's needs, goals and expectations are important.

## What are the benefits?

Efficient and effective care coordination can improve outcomes for all stakeholders: the person with severe and complex mental illness, carers, communities, services and sectors [6]. For the individuals, carers and communities this includes improved experiences, quality of life and outcomes. For services and sectors this includes enhanced service delivery and economic benefits [6, 7]. Coordinated care also increases engagement with the person, their carer and community and the likelihood that each person will access and receive support where and when it is needed.

Coordinated care improves the experience of people with severe and complex mental illness, as it reduces confusion, a sense of isolation, and effort required to gain access to the services needed in a timely manner [11].

There is growing evidence that collaborative service delivery provides the best quality primary mental health care and services [8]. Improved clinical outcomes include symptom reduction, reduced severity, better treatment response and improvements in physical and social functioning [12]. This is because coordination between services ensures that those services who are best equipped to support the persons' needs are engaged at the earliest possible opportunity after the need arises.

These benefits also translate to improved service delivery, reflected in more targeted referrals, and reduced hospitalisation rates  $[3, \underline{6}]$ . Additionally, care coordination typically improves engagement, reflected in increased use of, and self-efficacy with appropriate medication and treatment  $[3, \underline{6}]$ .

An approach that increases partnerships between health and social care services and sectors has clear benefits that extend beyond mental health. Improving care coordination for people with severe and complex mental illness can also generate cost savings as a result of clinical outcome improvements (such as reduced hospital admissions, reduced relapses and crises) and improved efficiency of service delivery (such as reduced service duplication) [13]. Although there is an initial cost to deliver collaborative care, the return on investment per person is significant in the long-term. For example, using a collaborative care approach with 50 000 people with severe or complex mental illness may cost \$63 million but generate cost savings of approximately \$187 million [13]. Reinvesting savings back into the health and social care services and sectors to support people with severe and complex mental illness would yield further benefits.

## What are the enablers?

For effective care coordination, key enablers and qualities that should be demonstrated is [14-16]:

- trauma informed and recovery oriented
- person-led
- respecting the persons values and goals
- information sharing and open communication, with consent
- multiagency care planning
- defined purpose and goals
- engagement with various stakeholders
- strong relationships and networks
- productive, diverse multidisciplinary care teams

the use of technology to support care coordination.

Engagement with a wide range of consumers, carers, communities, services and sectors is a core component to enabling and sustaining care coordination [16]. For people with severe and complex mental illness, innovative approaches to engaging these stakeholders is necessary to ensure that care coordination remains relevant, person-centred, trauma informed and recovery oriented.

Relationships and networking continually emerge as key enablers for successful coordination and are equally important in facilitating positive engagement [15]. When developed and maintained, good relationships and networks between key stakeholders open opportunities to expand alliances and resources.

To meet the needs of people with severe and complex mental illness, developing trusting relationships within and across health services, and learning who has the knowledge and abilities to assist in various situations, is key to effective care coordination [15]. These relationships and networks should span across social care services as well, including psychosocial, emergency, justice, housing, education and vocation services [15]. These relationships and networks should seek to be diverse with representation from various population groups including Aboriginal and Torres Strait Islander, culturally and linguistically diverse (CALD) and LGBTQIA+ as well as establish cultural, religious and community connections.

Coordination consists of services coming together for the purpose of meeting the needs of consumers [16, 17]. Striving for broader, more diverse multidisciplinary care teams, will increase the likelihood of meeting the complex needs of people with severe mental illness. Individuals working within care teams should comprise clinical and nonclinical professionals such as peer workers and Aboriginal Mental Health workers. Building and maintaining strong working relationships within care teams is equally important to ensure effective communication and coordination.

## What are the processes required for good care coordination?

Each person's mental health journey is unique, and no two people will follow the same recovery journey. The processes involved for good, coordinated care are dynamic and require adaptation to ensure each person's needs are met. The level of support or services they need to access may change as their needs, desires and goals vary throughout their life and recovery journey.

Figure 2 illustrates the various processes involved in effective care coordination. There are critical points that require additional support to ensure continuity of care. These include, but are not limited to:

- Transition between services or care settings
- Significant changes in consumer needs, desires, goals or life stage
- Structural changes to services.

These critical points may occur at several times throughout the persons' journey. To ensure the best outcomes for the consumer, carer and community, services must ensure appropriate processes are in place.



Figure 2 Processes involved in coordinating treatment and supports for people with severe and complex mental illness

## Rights and responsibilities

There are various resources available to support people to understand their rights and responsibilities when accessing and receiving assessment, treatments, care and support for people living with a mental illness. Some key consumer and carer rights include:

- The right to receive timely and appropriate treatment, care and support
- The right to their privacy and confidentiality
- The right to be an active participant in decision-making
- The right to have their lived experiences taken into account
- The right to have families, carers and support persons involved to the extent requested by the consumer
- The right to have kinship family involved to the extent requested by the consumer
- The right to be advised by the treating clinicians or services of events affecting the consumer

The Mental Health Statement of Rights and Responsibilities aims to ensure that consumers, carers, support persons, service providers and the community are aware of the relevant rights and responsibilities and can be confident in exercising them [18].

State and Territory *Mental Health Acts* also provide guidance and information regarding consumer and carer rights and responsibilities. There are also federal laws that exist to protect people from discrimination and breaches of human rights.

People with severe and complex mental illness, as well as carers and communities, should be supported to understand and exercise their rights.

## Care coordination across the health and social system

Care coordination occurs across three main levels of the health and social system (see Figure 3):

- System (macro) refers to a holistic approach that places people's needs first to meet the population being served.
- Organisation and professional (meso) refers to the extent that services are produced and delivered and the partnerships between professionals both within and between organisations.
- Individual (micro) refers to the delivery, access and interaction between services and people.

There has been global recognition of the importance of person-centred care. This means care is provided according to the person's needs rather than the system, organisation or professional needs. This can lead to consumer-led care. Its importance is highlighted in various reports, and in some countries considered a core principle for health care [16, 19]. Maintaining person-centred care requires mechanisms that supports integration across all three levels [20].

System level integration needs to occur across health and social care services and sectors to improve coordination and counteract the current fragmentation of services [21]. Cross-sectorial collaboration aims to improve the overall health of people and populations. Integration across the sectors is necessary to ensure organisations work together and deliver appropriate treatment and supports [21].

Organisational integration is particularly important for people with severe and complex mental illness who require a broad spectrum of services and professionals. Achieving integrated care at the organisation level requires unison and flexible networks [21].

At the individual level, integration of clinical and nonclinical professionals with organisations and systems is necessary. Clear communication with individuals interacting with organisations, services and professionals is also required for successful coordination of care [22]. Challenges can arise if there are differences between organisational and individual level cultures. Adequate education and professional development can support integration at the individual level and improve coordination [22].

SYSTEM INTEGRATION

8 PROFESSIONAL INTEGRATION

9 PROFESSIONAL INTEGRATION

9 PROFESSIONAL INTEGRATION

1 PROFESSI

Figure 3 The three main levels of integration across the health and social system

Source: adapted from [21]

## Culturally safe care coordination

Health care and services in Australia are embedded in western science and medicine. Yet Australia is one of the most multicultural societies and home to the oldest continuous cultures on the planet [23]. Culture is about how we think, interpret and understand the world around us. Various factors influence culture and culture can influence the way we define, express, approach and respond to health and wellbeing [24, 25].

For example, at the foundation of Aboriginal and Torres Strait Islander mental and physical health is social and emotional wellbeing. This whole-of-life view encompasses the physical, emotional and cultural wellbeing of individuals and their communities [26] (see Figure 4).

Social and emotional wellbeing is multidimensional and intrinsically connected to all aspects of living, including family and kinship, culture and spirituality, connection, sense of belonging, reciprocity and the land [27]. Similar holistic concepts can be seen in other cultures [24, 25, 28]. Therefore, understanding

the various cultures and cultural nuances is integral to understanding a person's mental health and wellbeing [25].

Cultural safety is a fundamental human right for all people and delivering culturally safe care is everyone's responsibility [29]. Cultural safety is not just reflected through the person and how it is experienced by the person, but also through the space and environment in which the services are provided. Only the individual accessing and receiving care can determine if cultural safety has been achieved [30]. Working towards cultural safety requires services and sectors to achieve cultural awareness, cultural sensitivity and cultural competency. Given Australia's multicultural landscape, there may be some services and professionals who are not confident in providing culturally safe support [31]. To overcome these gaps, services and professionals have a responsibility to network and engage with culturally appropriate services to ensure the provision of care that is safe and approachable.

There is increasing recognition that improving culturally safe care for Australia's diverse cultural population can improve access to health care, the quality of health care and overall health outcomes [30, 32]. To coordinate culturally safe treatment and supports, we first need to recognise and better understand the person's culture and needs [25, 26, 32]. It is also necessary that services and professionals acknowledge how their culture or understanding of culture can influence the way they coordinate care for people with severe and complex mental illness [24].

Actively engaging and collaborating with Aboriginal and Torres Strait Islander workers, consumers, carers and communities in the care coordination process is crucial for improving the social and emotional wellbeing of Aboriginal and Torres Strait Islander people [26]. Proper consideration of Aboriginal and Torres Strait Islander social and emotional wellbeing in the development and coordination of treatment and supports is crucial to protect their culture and way of life [26]. Investing in diverse workplaces and including the voices of CALD populations at the various levels of care coordination will help to improve the health, wellbeing and outcomes of CALD populations [32]. Ensuring services and sectors are appropriately connected with LGBTQIA+ services will support the culturally safe coordination of treatments and supports for LGBTQIA+ communities.

## Care coordination across the life domains

Various theories have been proposed to better understand the complexities of mental wellbeing and life satisfaction [33, 34]. The dynamic relationship between mental and physical wellbeing is becoming increasingly acknowledged but it is still not well understood [35]. There are some shifts towards measuring population changes and improvements using objective wellbeing data, with countries such as Canada and Scotland assessing wellbeing against economic growth [36, 37].

The subjective nature of a person's wellbeing makes measuring changes and improvements challenging. The World Health Organisation [38] defines quality of life as "an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns." There are a variety of domains used to assess wellbeing. Commonly identified broad domains include physical, psychosocial, cognitive, social, economic and environmental [38, 39]. These domains include aspects of self, culture and spirituality, relationships and social networks, the family unit, communication and practical skills, housing and security, education and occupation, and food and nutrition [38, 39].

Domains are unique to the individual and assist to identify the relevant needs and supports necessary to improve the mental wellbeing of the individual. Life experiences, interests and preferences influence our current and future wellbeing.

It is important to remember that our understanding of and our preferences related to health and wellbeing are fluid and can change with age and experience. It is equally important to remember that everyone has the right to change their mind about how they view and approach their health and wellbeing. This is the same for people with severe and complex mental illness.

Coordinating culturally safe treatment and supports requires recognition of not just the mental and physical wellbeing of individuals, but also their core life domains which impact upon mental and physical wellbeing. It is essential that the basic human needs – housing, security and employment – of people with severe and complex mental illness are also met to improve their mental and physical health and wellbeing.



## **OVERVIEW**

This section outlines the National Guidelines.

There are nine recommendations detailed in the following pages.

Each recommendation provides direction for stakeholders to improve coordination. If implemented, these actions will improve and support the coordination of treatment and supports for people with severe and complex mental illness





### Overview

In these Guidelines, the nine recommendations, listed below and detailed in the following pages, are for government and non-government health and social care services and sectors. When implemented, these recommendations will enhance the coordination of treatment and supports for people with severe and complex mental illness.

These recommendations are the product of extensive consultation and consensus-based processes. These recommendations are aspirational, and services and sectors should work together to achieve them. These recommendations do not provide implementation strategies. These will need to be individually tailored and developed according to the stakeholder and jurisdiction involved in providing treatment and supports to people with severe and complex mental illness. See the section on implementing, evaluating and maintaining the Guidelines.

As previously mentioned, the term consumer refers to people with severe and complex mental illness engaged or engaging with health and social care services and sectors to support their mental wellbeing and recovery journey. The recommendations refer to consumers in this context.

#### The nine recommendations are:

- 1. Clarify the function and role of each stakeholder.
- 2. Ensure there is a care coordinator to navigate and coordinate support for consumers.
- 3. Ensure multiagency care planning is consumer-led and recovery oriented.
- 4. Develop and implement practices that support communication and information sharing.
- 5. Establish and support safe transitions of care.
- 6. Ensure Aboriginal and Torres Strait Islander services are involved and available.
- 7. Promote and strengthen innovative leadership.
- 8. Ensure workforces are equipped to deliver effective coordination.
- 9. Commit to improve and increase the use of data and technology in care coordination.

# Recommendation 1. – Clarify the function and role of each stakeholder

- 1.1 Ensure that all functions, roles and responsibilities are designed and developed with and for the consumers, carers and communities and are clear, transparent and understood.
- 1.2 Clearly outline the requirements and expectations of each role for all stakeholders to understand, including consumers, carers and communities.

### Why this is a priority?

Supporting people with severe and complex mental illness requires contribution from and access to a myriad of services and sectors. Coordinating treatments and supports requires involvement within and across the various levels of health and social care services and sectors (e.g. system, organisational structure and service delivery). Ensuring everyone is engaged and informed is vital for achieving optimum stakeholder participation and performance.

Clear roles and responsibilities that are understood by all stakeholders, including consumers, carers and communities, keeps services and sectors accountable when coordinating treatment and supports for consumers. Roles and responsibilities that are understood by everyone means that the consumer, carer, community or other stakeholders will know which services are the most appropriate to engage with at various stages throughout a person's recovery journey. This assists services and sectors to coordinate appropriate and safe care with and for the person.

It is critical that everyone has a clear understanding of their own roles and responsibilities and the roles and responsibilities of other stakeholders involved.

#### About the recommendation

#### **Recommendation 1.1**

Everyone will have a different role to play when coordinating treatment and supports for people with severe and complex mental illness. The functions, roles and responsibilities of each stakeholder will vary depending on the person, their life stage, needs and wants, the jurisdiction, the level of care provided, the organisational structure and the care team, carers, families and communities involved.

Commonwealth, State and Territory governments must clearly define, outline and commit to the different functions and roles to minimise confusion and duplication of services as well as enhance coordination of appropriate services to meet the consumers' needs.

Services have a role to promote and work in a collaborative manner with other services within and across sectors. This involves developing and maintaining partnerships with local services and understanding the roles and responsibilities of other services and sectors.

The role of the care coordinator is to assist in developing a plan of care in partnership with the consumer, their carer and community. They help people navigate and access services that support their needs, desires and recovery goals. For care coordinators to achieve their role, see <a href="Recommendation 2">Recommendation 2</a>.

Consumers, carers and communities are key stakeholders. Consumers have a role as active participants and decision-makers in the planning and coordinating of treatment and supports. Services and sectors should ensure they work with and for the consumer to facilitate consumers fulfilling their role. Carers and communities have a role as valued and respected contributors in the coordination and delivery of support for people with severe and complex mental illness. All functions, roles and responsibilities should:

- Be clearly communicated with and understood by other stakeholders, including consumers, carers and communities.
- Identify and outline how the role will support care coordination.

#### **Recommendation 1.2**

Functions, roles and responsibilities must be described simply, in sufficient detail and without the use of jargon. To assist in clearly outlining requirements and expectations to fulfil the functions, roles and responsibilities, services and sectors should:

- Determine what the role will achieve.
- Define how the roles and responsibilities will contribute to or support coordination with and for the consumer, including how the role will coordinate with other services and sectors.
- Detail what activities are expected to be carried out and how this will be evaluated and monitored.
- Determine what skills and experiences are necessary to successfully fulfil the roles and responsibilities.

For example, a community mental health service has identified that their purpose is to provide care to consumers with severe mental illness who are experiencing homelessness. They intend to work with the local hospital and therefore will establish relationships which supports seamless coordination.

All stakeholders should have a shared understanding of their role and responsibilities and what is expected from them when coordinating treatment and supports for people with severe and complex mental illness. This will mean that services and sectors will know who they need to work with to provide coordinated care.

Consumers, their carers and communities should feel confident that they understand which stakeholders are involved and how care will be coordinated and supported. For consumers and their community, this means they know and understand which service provides what in the individuals recovery journey. For carers, this means they know how coordination should be delivered and can identify what aspects of care coordination may be missing.

# Recommendation 2. – Ensure there is a care coordinator to navigate and coordinate support for consumers

- 2.1 With consumer consent, engage a care coordinator to identify needs and support the coordination and navigation of services and sectors.
- 2.2 Provide care coordinators with appropriate support, resources and authority to oversee and ensure the multiagency care plan is being implemented.

### Why this is a priority?

People with severe and complex mental illness require support from multiple services and sectors. Having one person to assist in care planning and coordinate the integration of different services needed and wanted by the consumer, reduces the probability that they will experience gaps in care.

The care coordinator is not a case manager but is instead a facilitator to empower and assist the person to meet their needs, desires and goals. Across all elements of care coordination, care coordinators improve the consumers' experience and overall health outcomes by advocating with and for the consumer, carer and community. Care coordinators identify gaps in service needs, facilitate educational requirements, increase access to services, oversee the care plan and ensure it is being implemented. The care coordinator can prevent duplication and repetition of services, which benefits both the consumer and the health system.

#### About the recommendation

#### **Recommendation 2.1**

All consumers should have the opportunity to access and receive support from a care coordinator. The consumer should consent to engaging a care coordinator. In some situations, it is essential for a consumer have a care coordinator. For example, under an involuntary treatment order.

There should be a specific role to carry out the responsibilities of a care coordinator. The peer workforce could be employed to carry out the care coordination role. A well trained and supported peer workforce are valuable. They bring unique skills, experiences and empathy which will improve coordination and overall outcomes. If there is not a specific care coordinator role, the person should still have one point of contact. This may be their general practitioner, worker within the specialist mental health service, community managed organisation or primary health care service.

The role of the care coordinator includes but is not limited to:

- Collaborating with the consumers, carers, community, professionals (or clinical coordinator) and services and sectors to identify the service needs and develop a plan of care.
- Connecting and providing access for consumers, their carer and community with the services they need and desire.
- Promoting and sharing decision-making.
- Involving the individual's carer and community as appropriate.
- Acting as a central point of contact between services and sectors.
- Be consumer-led.
- Assisting consumers to access NDIS supports if they are eligible and choose to use it.
- Engaging the appropriate services and sectors.
- Supporting the consumer at key transition points and ensuring a safe transition.
- Identifying and communicating the process for a structured and timely escalation if responding to deterioration.
- Advocating with and for the consumer.
- Acting in the best interests of the consumer to ensure their health, safety and welfare. In some situations, this may not be consistent with the person's wishes.
- Developing partnerships with services and referral pathways that increases access to services and sectors.

The aim of a care coordinator is to coordinate care alongside the person through the development of a trusting relationship with the consumer, their carer and community. To support the development of this relationship, it is recommended that the care coordinator remain with the consumer throughout their recovery journey. This gives the person a consistent and familiar point of contact with someone who has an understanding of their preferences, goals and desires as well as the time to assist the person.

It should also be recognised that the care coordinator may need to increase and decrease the level of support provided depending on the person's needs. For people with severe and complex mental illness who have been admitted into hospital should be linked with a care coordinator during the hospital discharge planning to provide continuity of care. For some people who may require an increased level of support, the care coordinator should be bringing together the services and sectors the person needs, develop a detailed multiagency care plan and ensure that it is implemented.

#### **Recommendation 2.2**

The care coordinator requires skills and knowledge of the local services available and should have authority to ensure the care plan is being implemented. The care coordinator must therefore have access to the multiagency care plan and the ability to share appropriate information to achieve safer and more effective care.

The complexity and difficulty of coordinating treatment and supports for people with severe and complex illness means that adequate time and resources are needed to support the role of a care coordinator. This may include additional funding or appropriate item numbers. Efficient and effective care coordination would also reduce duplication of services, replace the ad hoc coordination of care and lead to cost savings in the health system (see <a href="What are the benefits?">What are the benefits?</a>).

### How could this look in practice?

#### **Queensland Nurse Navigators**

#### Queensland, Australia

Nurse navigators in Queensland assist patients with complex chronic health conditions who require treatment and supports from several services. Nurse navigators work across system boundaries and in partnership with several services and sectors. They help to coordinate services for the patient and ensure that the right care is received at the right time and place.

Nurse navigators provide a single point of contact for patients and they oversee and ensure that optimal care is provided. They work alongside the patient throughout their whole journey, they can monitor them and identify any unmet needs. With their knowledge and skills, nurse navigators can also assist in making decisions about a patient's health care by providing information and support, improving their overall health outcomes.

Source: Queensland Health [40]

#### Whānau Ora

#### **New Zealand**

Whānau Ora is a culturally informed, holistic approach which is person and whānau (family) centred. Whānau Ora Kaiārahi (navigators), community partners and service providers collaborate with each other, the person with a mental illness and their family to coordinate personalised supports that are culturally sensitive.

Kaiārahi support the individual and their whānau to identify specific needs and goals, then connect them with the services (health and social) they need to achieve their goals. This may include education providers and employment services. Kaiārahi are valuable as they have cultural and local knowledge required to understand whānau and build relationships of trust and confidence. They also have a role in building trusting relationships between service providers and whānau through culturally informed care and support.

The Whānau Ora Kaiārahi approach has been identified by the Productivity Commission in New Zealand as an example of an integrated whānau centred approach supporting collaboration and access within and between health and social services

Source: Te Puni Kokiri (Ministry of Maori Development) [41, 42]

## Recommendation 3. – Ensure multiagency care planning is consumer-led and recovery oriented

- 3.1 Establish processes to develop multiagency care plans with and for the consumer.
- 3.2 Services, sectors, carers and communities should collaborate and work alongside each other according to an agreed single multiagency care plan for the consumer's needs.
- 3.3 Ensure the consumer is an involved decision-maker and participant in their multiagency care plan.

#### Why this is a priority?

No single service or person can deliver all aspects of care and support that a person with severe and complex mental illness needs. Coordinating the various treatments and supports for people with severe and complex mental illness requires all stakeholders to agree to and understand one common approach. Additionally, it is important that appropriate services and sectors are identified and engaged in a timely manner to ensure effective coordination and seamless continuity of care.

Multiagency care planning provides a platform for services and sectors to share information, develop comprehensive assessments and understandings, and plan strategies to mitigate potential risks. The process of coming together, discussing and agreeing on one approach to consumer care creates transparency and accountability between all services and sectors about their roles and responsibilities in responding to and meeting the consumer's needs. This increases trust between services and sectors as well as with consumers, carers and communities.

Multiagency care planning improves clarity of stakeholder roles and responsibilities. It increases trust between stakeholders and knowing that each stakeholder can and will deliver the agreed upon care. For services, multiagency care planning contributes to strengthening and broadening partnerships with and across a range of health and social care services. The efficient use of resources and mutual support between services and sectors reduces duplication and improves the referral process. For consumers, multiagency care plans provide continuity of care and enables them to experience increased service satisfaction and improved health outcomes.

#### About the recommendation

#### **Recommendation 3.1**

All services should develop processes that enable them to initiate and participate in multiagency care planning with other services, sectors, carers and communities to meet the needs of each consumer. These processes should be planned, designed, developed, measured and evaluated in partnership with consumers, carers and communities.

The consumer must be involved and included in deciding which services and sectors are best suited to meet their needs.

In instances where consumers have an NDIS package, the National Disability Insurance Agency should develop and support processes that enable NDIS providers to engage and connect with other services that may be relevant to supporting the consumer.

In acute crisis situations, if the consumer is unable to be involved in deciding which services to invite, the engaging service should follow any advanced directives or involve the carers, family or other nominated support.

#### **Recommendation 3.2**

Multiagency care planning requires a commitment from all services and sectors to participate in a single consumer-led care plan. There should be a shared and agreed upon approach that all services follow to appropriately support and meet the individual's physical, mental, emotional and social needs.

The process of multiagency care planning must identify and outline various aspects, including but not limited to:

- Consumer goals, beliefs, preferences and culturally safe supports.
- Assessment of consumer's physical and mental health, emotional wellbeing and social care needs.
- How each service or sector will be involved in the consumer's care plan and relevant key contacts.
- Key lead coordinator or person to support the consumer in identifying, navigating or accessing services
- Escalation pathways and risk management.

Care plans must reflect the individual's needs, goals and desires. For Aboriginal and Torres Strait Islander people, there should be consideration of kinship responsibilities. Care plans should be created, reviewed and updated at agreed time points accordingly (e.g. in acute situations, reviews may be needed more frequently). The decision of who oversees these reviews and updates will vary for each individual consumer. The nominated person should be agreed to by the consumer and other stakeholders involved the multiagency care plan.

Mechanisms must be in place to support open communication, transparency and accountability between the consumer, carer and members of the multiagency care plan. This may include regularly scheduled meetings (virtual or face-to-face) and notifications to communicate any changes. Care plans should be available to and shared with the consumer, carer, family or other nominated supports without the need to ask for access. Sharing of the care plan between participating services and sectors should align with Recommendation 4.

There should be shared language and shared assessment tools across services and sectors to enhance communication and coordination. These should be discussed during the process of multiagency care planning and mutually agreed upon. Tools used need to be appropriate, relevant for each consumer and should encourage individual self-assessment. All services must have a shared understanding of the person's diagnosis, treatments, supports, preferences and needs.

Digital technology should be utilised to facilitate multiagency care planning where appropriate. This may be through virtual meetings and web-based collaborative platforms. Consideration of legislation, privacy and consent in sharing and storing information is needed. The multiagency team, including the consumer, carer and community, must discuss and formally agree on mechanisms used to facilitate multiagency care planning.

Consumer, carer and community satisfaction tools should be utilised by services to evaluate and improve the delivery of multiagency care plans.

#### **Recommendation 3.3**

Multiagency care planning must be person-centred and consumer-led. Meetings should be made in collaboration with the consumer, carer and community to ensure full participation from everyone involved. This should include kinship family for Aboriginal and Torres Strait Islander people. Where possible, the consumer must be present at all discussions and meetings. Where appropriate, and with the consumers consent, carers, family members and/or other nominated support persons should also be present. Services should work alongside the consumer as an active participant in their recovery journey, empowering them to be involved decision-makers.

If a consumer is unable to attend a meeting, the meeting should be rescheduled. If the meeting cannot be rescheduled, a nominated person to represent the consumer (e.g. family member, carer) should be present. This person should have the authority to speak on behalf of the consumer.

Consumer's should feel safe and supported to raise any emerging concerns or unmet needs. Services should work with the consumer, carer and community to build safe environments that facilitate open communication and active responses.

#### How could this look in practice?

#### **Housing and Accommodation Support Initiative**

#### **New South Wales, Australia**

The Housing and Accommodation Support Initiative (HASI) is a successful demonstration of effective partnerships between Housing New South Wales, New South Wales Health, Non-government Organisation Accommodation Support Providers and community housing providers.

Evaluation identified various enabling factors that contributed to successful and effective partnerships. These included clearly communicated direction; open communication lines and strategies; commitment to the consumers and each other; sound governance processes including regular meetings, shared policy priorities, and senior staff involvement; and mutual understanding of purpose, goals and roles and responsibilities of all stakeholders.

HASI demonstrated that with appropriate, consistent and supported mechanisms, multiple agencies across various health and social care services can work effectively and efficiently together to coordinate and meet the needs of people with severe and complex mental illness.

Source: Bruce, McDermott [43]

## Recommendation 4. – Develop and implement practices that support communication and information sharing

- 4.1 Develop information sharing protocols that are underpinned by principles of informed consent and confidentiality.
- 4.2 Develop information sharing protocols in collaboration with health and social care services and sectors, and across states and territories.
- 4.3 Ensure all professionals have access to education and resources on how to gain and document informed consent, the legislation in each state and territory and how to communicate information.
- 4.4 Ensure consumers, carers and communities have access to education and resources on consent and information sharing processes.

#### Why this is a priority?

Consumers, carers and communities may interact with many health and social care services and sectors in their day-to-day life. To support good care coordination, data and information should be shared and done so in a timely manner.

When underpinned by consumer consent and confidentiality, good information sharing practices can improve the quality of the service and support provided to the consumer, their family and carer. When services know and understand what information should and should not be shared with other services or sectors, it improves service satisfaction and health outcomes.

In addition, if the information sharing protocol is trauma informed, it can reduce the risk that a person is reminded of their trauma when interacting with a new service. For some people, retelling details of trauma can cause them to experience emotional or biological stress. For professionals, knowing extensive detail of someone's trauma is not usually necessary to work and support them in their recovery journey. Having a clear understanding of what information should be shared, and what the person wants shared, can assist in creating a safe environment for the person, their carer and community.

Information sharing across states and territories should also be supported to improve care coordination and continuity of care. People who are placed under an involuntary mental health order in one state or territory should be able to receive the appropriate treatment and supports if they travel or move to another state or territory.

All health and social care services and sectors have their own local policies regarding information sharing. By developing an information sharing protocol between health and social care services and sectors, as well as across states and territories, local policies are not replaced, rather they are enhanced by facilitating a shared cross-boundary dialogue and understanding.

Developing a protocol in collaboration with various sectors at the local, state and territory level will enable the development of a shared language and understanding on how to gain and document consent.

Additionally, the process of developing protocols for information sharing between services and sectors not only provides a gateway for information sharing but also secures buy-in from key stakeholders. This helps develop the partnerships and relationships required to agree on a shared aim and outcome.

#### About the recommendation

#### **Recommendation 4.1**

Consent to share information must be gained wherever possible. Gaining an individual's consent for information sharing and communication must underpin any information sharing protocol that is developed.

Information sharing, without the consumer's consent should only occur in certain situations. For example, if the person disclosing the information believes, on reasonable grounds, that the person is at risk of harm to themselves or others. Some people may also be under an involuntary treatment order which enables some service professionals to share certain information without the need for consent and without breaching confidentiality laws or professional ethics and standards.

#### **Recommendation 4.2**

#### Between health and social care services and sectors

Information sharing protocols between health and social care services and sectors should be developed at the local level to align with the various state and territory information sharing principles, guidelines and legislation. The protocol should also be co-designed with consumers, carers and communities.

The protocol developed should support professionals in sharing information in a safe, timely and effective manner. As far as possible, the consumer's preferences regarding disclosure of information should be respected.

The protocol should include (but not be limited to):

- A shared aim and understanding of why information sharing needs to occur.
- How to gain informed consent.
- What information should be shared between services and sectors.
- How communication and information sharing will be carried out to maintain the individual's privacy, confidentiality and needs.
- How the information will be appropriately stored.
- Communication strategies that align with trauma informed care and culturally safe practice.

The protocols should be co-designed and regularly reviewed in collaboration with services and sectors involved as well as with consumers, carers, communities and those with lived experiences. The use of technology, including the development or improvement of an information sharing platform (see <a href="Recommendation 9">Recommendation 9</a>), will support the protocol and issues of platform incompatibility between current information sharing systems.

#### **Across states and territories**

When people with severe and complex mental illness cross state or territory borders, ensuring the continuity of their care is a common challenge. Each Australian jurisdiction has its own mental health legislation. This means that mental health orders made under the legislation of one state or territory may not have effect under another. This also contributes to difficulties in the sharing of an individual's information between services and sectors and their counterparts in other states or territories.

To facilitate the sharing of an individual's information to support care coordination, states and territories should take two primary steps:

- Adopt a mutual recognition principle within mental health legislation, so that each state or territory legally recognises mental health orders made under the legislation of all others.
- Develop a Memorandum of Understanding, which sets out the principles for the sharing of consumer information between services and sectors in different states or territories.

This can in turn provide the framework to enable services and sectors to develop information sharing protocols with their counterparts in other states or territories – similar to those described for information sharing between services and sectors within the same state. For example, if a person under a mental health order moved from one state to another, the health department in their new state could be alerted to the existence of the mental health order, as well as request other information to more proactively provide care and supports.

#### **Recommendation 4.3**

When developing and disseminating the information sharing protocols, professionals involved in coordination should be provided with ongoing support and education. Consumers, carers and communities should be included to provide training as well as share their experiences. The training should be at least once a year, tailored to the state or territory and include:

- What informed consent means.
- How to gain informed consent to share information.
- When informed consent is not needed.
- How to document when consent has been gained.
- Processes of reviewing and regaining informed consent.
- What the information sharing protocol means and what information can be shared with various organisations and services.
- What the information sharing laws and principles are according to the state or territory they are in.
- Strategies to effectively communicate information with the consumer, their carer and community and ways to ensure they understand.

Regular training will provide professionals with a strong understanding of how to gain consent and what the information sharing protocols, laws and principles are in their state or territory.

#### **Recommendation 4.4**

Consumers, carers and communities have a right to be provided with appropriate and adequate information. This means having access to education and resources to understand and provide informed consent. Consumers, carers and communities should also have access to resources to understand their rights and ability to participate in the consumer's care. Open communication is also needed between consumers, carers, communities and professionals. Service level improvements should include but are not limited to:

- Increased communication about what information needs to be shared with who, when, how and why it may need to be shared.
- Provision of resources, for example web-based or pamphlets.
- Access to translators if required.

The resources must be easy to understand, available and accessible in different languages. Resources should be co-designed and developed with and for consumers, carers and communities.

## Recommendation 5. – Establish and support safe transitions of care

- 5.1 Improve or develop formal pathways with shared agreements between health and social care services and sectors.
- 5.2 Clearly define and clarify the roles and responsibilities of those involved in the transition of care.
- 5.3 Identify a coordinator to support the consumer and assist in ensuring safe and effective transitions.

#### Why this is a priority?

The most vulnerable period for people with severe and complex mental illness is when they are transitioning through various care episodes and/or settings. This includes from child and adolescent services to adult and older adult services, as well as forensic or inpatient services transitioning to or between community-based services. The transition may also be from a service back into the care of the person's carer or community.

The constant in any transition is the consumer. The transition should therefore be reflective of the individual's needs, strengths and choices. They should feel safe and supported throughout the transition which will ensure that the person receives timely and appropriate care, reducing hospital readmissions and improving health outcomes and overall quality of life. Carers and communities will also experience higher satisfaction with care when transitions are managed effectively.

#### About the recommendation

#### **Recommendation 5.1**

Shared agreements for formal pathways within and between health and social care services and sectors, should be improved or developed for streamlined and safe transitions. There should be a focus on shared agreements between hospital and community services which are co-designed with consumers, carers and communities. These agreements should:

- Clearly define agreed roles and responsibilities of each service and sector in the transition.
- Define how information will be shared at transition (in line with Recommendation 4).
- Promote warm referrals— in person or over the phone with appropriate documentation.
- Promote culturally safe transitions.
- Have clear, effective and timely documented communication between stakeholders.
- Have flexibility in service provision during transition.
- Define follow up and evaluation processes.
- Develop and define local escalation pathways.

Follow up is needed to make sure the person has engaged with the receiving service. If the person has been unable to engage with the receiving service, the original service and coordinator should work with and support the consumer, their carer and community to make alternative arrangements. This may involve using the escalation pathways developed to ensure consumers do not deteriorate while waiting to receive the appropriate treatment and supports. With the person's consent, the original service must maintain contact with the consumer, carer and community as well as the receiving service for a period of time after transition. When all parties agree that the transition has been successfully completed, the original service can cease contact if no longer required.

Monitoring and evaluation processes will ensure consumers, carers and communities are supported in providing feedback about the transition process. Their experiences can then be used to inform and improve future transitions. Both the original and receiving service should undertake monitoring and evaluation. The data collected should be used to inform service development and future transition processes.

#### **Recommendation 5.2**

The transition process will ensure that services are informed and responsive to the needs of the consumer. Planning for transition should begin as early as possible and is built around the consumers' needs and goals. The consumer should always be involved in all aspects of the transition process. Other key stakeholder such as the carer or community should be included as appropriate.

When providing effective transitional care planning and processes, the roles and responsibilities of each service and professional in the transition of care should be clearly defined. This should be defined in the multiagency care plan to ensure a level of accountability. This should include:

- An agreement to engage and support the consumer, carer and community.
- What supports each service, organisation and professional will provide and when.

If the consumer is being transitioned back into the care of the carer or community then it is essential that the service or organisation engages with them. As long as this is the consumer's choice, the communication process with the consumer and carer or community should be clear. This includes, but is not limited to, discharge processes with a simple summary of the discharge papers, follow up appointments and any next steps. This will ensure continuity of care.

Consideration for the diverse needs of any consumer, carer or community in the transition process must be respected. For more information on the diverse needs of specific populations, see <a href="Specific Populations">Specific Populations</a>.

#### **Recommendation 5.3**

If supported by the consumer and in consultation with their carer and/or community, a care coordinator should be identified. The care coordinator will support the consumer, their carer and community throughout the whole transition. If a care coordinator is not available, a key person should be identified who is responsible for ensuring a safe transition. The care coordinator or key person should have the authority to ensure that all treatment and supports needed for the consumer are engaged and involved (see <a href="Recommendation 2">Recommendation 2</a>).

#### How could this look in practice?

#### **Transitional Care Program**

#### New South Wales, Australia

The Transitional Care Program enables people with a mental illness who have been admitted into hospital to be provided with support from a mental health nurse.

The mental health nurse is engaged with the consumer from the hospital for up to 12 weeks to support their transition from tertiary care back into the community. The nurse ensures the consumer has access to a regular general practitioner, psychologist or other services that can assist and support them to reach or maintain their recovery goals.

The program provides the consumer with a single point of contact to help coordinate services for them and ensure they receive timely and appropriate care.

Source: Central Coast Primary Care (CCPC) [44]

#### The Peer Supported Transfer of Care

**New South Wales, Australia** 

The Peer Supported Transfer of Care (Peer-STOC) initiative offers support via a peer worker to consumers during the difficult transition between inpatient care and community-based care. Consumers are connected with peer workers who have lived experience of recovery and managing their wellbeing.

The peer workers provide support by helping consumers navigate the various services and sectors and connect them to the information, knowledge, resources and services they need to live well in the community. They empower the consumer to be active participants in their recovery journey and act as a beacon of hope for the consumer, their carer and community.

Source: New South Wales Mental Health Commission [45]

## Recommendation 6. – Ensure Aboriginal and Torres Strait Islander services are involved and available

- 6.1 Ensure Aboriginal and Torres Strait Islander services, professionals and social and emotional wellbeing teams are embedded across government and non-government health and social care services and sectors.
- 6.2 Develop strong culturally safe partnerships that enable coordination with health and social care services and sectors, as well as communities, to meet the social and emotional wellbeing needs of Aboriginal and Torres Strait Islander consumers.
- 6.3 Continually consider and assess the social and emotional wellbeing and needs of each individual, offering access to culturally safe treatment and supports that include the kinship family.

#### Why this is a priority?

Aboriginal and Torres Strait Islander people have a significantly increased risk of experiencing psychological distress and suicide compared to other Australians. Services and sectors must have support available to connect Aboriginal and Torres Strait Islander people with culturally safe treatment and supports.

Aboriginal and Torres Strait Islander people have a deep-rooted, holistic approach to mental health. Social and emotional wellbeing is fundamental and encompasses the physical, emotional and cultural wellbeing of the individual and their community.

Connecting Aboriginal and Torres Strait Islander people with culturally safe services will empower Aboriginal and Torres Strait Islander people when engaging with and receiving treatment and supports. The partnerships and networks services make with Aboriginal and Torres Strait Islander community-controlled services will increase professional awareness and understanding when providing coordinated care to Aboriginal and Torres Strait Islander consumers and communities.

#### About the recommendation

#### **Recommendation 6.1**

Effectively coordinating treatment and supports for Aboriginal and Torres Strait Islander people requires leadership, engagement and partnership in the planning, delivery, management, monitoring, evaluation and measurement of services and programs. This is crucial for developing and fostering greater involvement, trust, connectivity and culturally safe care and for achieving better outcomes for Aboriginal and Torres Strait Islander people and communities.

All services and sectors must contribute to bridging the gap and coordinating culturally safe treatment and supports for Aboriginal and Torres Strait Islander consumers, carers, communities and kinship families. Aboriginal and Torres Strait Islander professionals and, where possible, social and emotional wellbeing teams, should be included and involved in health and social care services and sectors. To support this, there must be commitment from governments to invest in Aboriginal and Torres Strait Islander community-controlled services, professionals and social and emotional wellbeing teams.

Aboriginal and Torres Strait Islander people and communities should have the option and opportunity to connect with Aboriginal and Torres Strait Islander community-controlled services, professionals and teams.

Where Aboriginal and Torres Strait Islander professionals and teams are not available within a service, agreements and partnerships with Aboriginal and Torres Strait Islander community-controlled services should be in place to connect Aboriginal and Torres Strait Islander consumers, with appropriate treatment and supports.

#### **Recommendation 6.2**

Aboriginal Community Controlled Health Organisations and/or Services (ACCHOS) and Aboriginal Medical Services (AMS) are a wealth of knowledge. ACCHOS are primary health care services initiated and operated by the local community, delivering culturally safe care to the community controlling it. AMS are funded services addressing the needs of Aboriginal and Torres Strait Islander people. ACCHOS and AMS should be involved in the design, development and delivery of culturally safe and responsive coordination training. Robust partnerships with ACCHOS should be developed across various health and social care services and sectors, including but not limited to:

- Commonwealth, state, territory and local governments
- Primary Health Networks and Local Health Networks
- Mental health and alcohol and other drug services
- Psychosocial services
- Community mental health services
- Education and vocation services.

Developing strong partnerships in health and social care services and sectors will help to forge new directions and mental health outcomes for Aboriginal and Torres Strait Islander populations.

#### Recommendation 6.3

The National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing [26] is available to guide and support services and professionals when working with Aboriginal and Torres Strait Islander people (see Appendix A).

Aboriginal and Torres Strait Islander people and communities must be included in all decision-making when coordinating treatment and supports – 'nothing about us without us.' Services should consider the individual's needs, understanding of their diagnosis and, wherever possible, connect with appropriate Aboriginal and Torres Strait Islander community-controlled services to support the communication and coordination of care.

Aboriginal and Torres Strait Islander consumers should be empowered as active participants and involved decision-makers in their treatment and recovery journey. Providing culturally safe coordinated care should include the opportunity to access services including, but not limited to:

- Elders
- Traditional healers
- Cultural healers
- Interpreters.

Culturally safe treatment and supports must resonate with the person as well as their carer, community and kinship family.

#### How could this look in practice?

#### Wadamba Wilam (Renew Shelter)

#### Victoria, Australia

Working in a holistic way, Wadamba Wilam provides outreach support to Aboriginal and Torres Strait Islander people who are experiencing homelessness and require support around their social and emotional wellbeing.

The service is a partnership of organisations including Neami National, the Victorian Aboriginal Health Service, Uniting Care ReGen and the Northern Area Mental Health Service.

Wadamba Wilam works with consumers from intake and throughout their journey, helping to ensure sustained long-term housing. The service also works to provide support to consumers in areas including mental health, housing, physical health, social and cultural wellbeing, substance use, employment and education.

The team have diverse skills and capacity to work intensively with consumers which reduces the need for referrals and minimised the chance of consumers not receiving the care they require

Source: Neami International [46]

## Recommendation 7. – Promote and strengthen innovative leadership

- 7.1 Develop and support internal system and organisational leadership to facilitate effective communication and care coordination.
- 7.2 Support consumers, carers and communities to develop independent life and leadership skills that will assist in their recovery journey.
- 7.3 Establish, build and maintain trusting relationships and partnerships with other services, professionals, carers and communities.

#### Why is this a priority?

Bringing people together and working towards one common goal is a key component of achieving and providing effective and coordinated care for people with severe and complex mental illness.

Strong leaders, or leadership teams, help to direct and inspire services, sectors and staff when working towards a common goal. Having strong leadership keeps everyone person-centred and recovery oriented when coordinating treatment and supports. Building strong leadership across services will assist to build and maintain robust networks that will benefit service productivity as well as consumer outcomes.

#### About the recommendation

#### Recommendation 7.1

Leaders, or leadership teams (i.e. a group of leaders within an organisation), need to be developed thoughtfully and strategically. Leaders will bring unique skillsets that initiate and cultivate strong relationships both within the services and across services and sectors. Services should strive to select leaders who are innovative thinkers, outward looking, courageous, creative and, open to change.

Adequate resourcing and time must be made available to ensure that there is capacity to build and foster lasting leaders, or leadership teams.

All governments should develop leadership teams that support the integration of systems and services. This will influence how a consumer, carer or community receives coordinated care. Leadership teams should:

- Build effective personal relationships with other health and social care services and sectors.
- Negotiate and mobilise resources and networks to achieve the desired outcomes.
- Undertake performance reviews and reflective practices to measure changes and maintain accountability.

All community, public and private services should develop leadership teams. Not all leaders will work directly with consumers and carers, but their work can affect how consumers interact with, receive and experience care. Peer workers should be taught leadership skills. Consumers, carers and communities should also be included in leadership teams. Leadership teams need to:

- Facilitate seamless integration with services and sectors.
- Develop and maintain strong relationships and networks with other leadership teams.
- Support frontline staff in providing coordinated care for consumers.

All leaders, or leadership teams, should:

- Be developed to withstand any workforce changes.
- Be developed to ensure longevity and sustainability.
- Include reflective practices that assess leadership performance and maintain accountability and focus.

#### **Recommendation 7.2**

Consumers, carers and communities should be provided with resources and support that develop their own leadership skills. Where possible, services should connect consumers, carers and communities with Elders, mentors or educators who can support the development of life and leadership skills. Resources and supports must be co-designed and developed with consumers, carers and communities. They should assist consumers to understand how they can take control of their health and wellbeing journey and assist carers to understand and overcome barriers to accessing services (e.g. language, technology, health literacy).

#### **Recommendation 7.3**

Leaders and leadership teams are responsible for developing trusting relationships and partnerships with various services. Leaders and leadership teams must maintain regular contact with other leaders and leadership teams through various channels, including email, phone calls and face-to-face meetings (virtual or physical).

Networking events should be scheduled at regular intervals throughout the year that support the relationship and partnerships between services and sectors. This includes, but is not limited to, mental health and alcohol and other substance use services, community services, hospitals, psychosocial, housing, education and justice.

Leaders and leadership teams are responsible for ensuring staff members are supported when coordinating care. This means relaying relevant information and practices that will enable staff to connect people with appropriate services. Leaders ensure nobody gets left behind.

#### How could this look in practice?

#### **Transformational leadership**

#### **Australia**

One Australian project strived to improve the culture and practice of an acute mental health inpatient setting. Using person-centred principles, the project aimed to align the working culture with that of management and leadership. This approach allowed all staff, particularly those working with consumers, to express views and ideas and contribute to the development of a shared action plan. Creating and promoting positive workplace experiences positively influences the care and coordination experienced by people with severe and complex mental illness.

Developing transformational leadership involves time and resources. However, when implemented the process was found to bridge any differences between staff perceptions and organisational values and led to better outcomes and experiences for people with mental illness.

Source: Beckett, Field [47]

## Recommendation 8. – Ensure workforces are equipped to deliver effective coordination

- 8.1 Ensure services and sectors are trained to provided culturally safe and effective coordination.
- 8.2 Ensure peer workers are treated as valued members of the workforce.
- 8.3 Build the capacity and confidence of consumers, carers and communities to engage in their own health and wellbeing journey.

#### Why this is a priority?

People with severe and complex mental illness have unique needs and require well-connected and experienced workers. This ensures there is continuity of care provided to the consumer, carer and family throughout their recovery journey.

Investment in adequate resourcing to ensure the workforce is adequately equipped and supported to provide effective coordination is crucial. A workforce that has opportunities to train and upskill will mean that staff are prepared to coordinate care in a culturally safe way that will meet the needs of each person with severe and complex mental illness.

The contribution of peer workers, carers and communities is invaluable in supporting coordination. When services harness these contributions within the workforce, the experiences of all persons directly and indirectly involved can significantly improve.

#### About the recommendation

#### **Recommendation 8.1**

All services must provide culturally safe and responsive care coordination to people with severe and complex mental illness. This requires access to adequate resources, supports and professional development. Adequate funding from governments is vital to support services in delivering effective coordination.

Regular training should be provided to all community, public and private health and social care services and sectors. Mechanisms to allow equal access to this training should be developed and practiced. Training sessions should cover relevant topics to support staff in effectively coordinating the various treatments and supports of consumers. This includes, but is not limited to:

- Understanding the discrimination and barriers consumers, carers and communities experience when accessing services, treatment and supports.
- Understanding of current services available within the local area and eligibility requirements.
- Providing and maintaining culturally safe coordination.
- How to access services including housing, psychosocial, community services and mental health, alcohol and other substance use services.
- Eligibility criteria of various services including housing, psychosocial, community services and mental health, alcohol and other substance use.

All services should have access to and provide training to staff on the following:

- The importance and value of the peer workforce in supporting and coordinating care for consumers, carers and communities.
- The importance and value of capacity building for consumers, carers and communities in achieving coordinated care.

All education and training must include evaluation, monitoring and feedback mechanisms that allow improvement of training. Measures to evaluate and monitor the consumer, carer and community satisfaction and experience of care coordination must be used.

#### **Recommendation 8.2**

All peer workers must be viewed as equal and valued members of the workforce. Services and sectors should strive to include peer workers that can connect with and support consumers, carers and communities in meaningful ways. Strong leadership will be fundamental to the smooth integration of peer workers within the workforce (see Recommendation 7).

Peer workers should have access to ongoing training and professional development to support them in providing effective coordination. Education and training sessions should be developed by, and where possible led by, peer workers. This ensures training is relevant to the unique challenges and experiences of peer workers.

Peer workers should have the opportunity to share their experiences and learnings with other members of the workforce. They must feel safe and supported to share and participate. Services should strive to reflect on these to improve care coordination.

#### **Recommendation 8.3**

Consumers, carers and communities are key stakeholders in the coordination of treatment and supports. Services and sectors need to work with consumers, carers and communities to build their capacity and confidence to be leaders in their own health and wellbeing journey.

Services and sectors should have access to funding and resources that support consumer, carer and community capacity building. For consumers receiving an NDIS package, funding should be allocated to support capacity building training and education. For consumers who are not eligible for the NDIS, or choose not to access the NDIS, capacity building training and education should be provided through other funding streams.

#### How could this look in practice?

#### Why Not a Peer Worker?

#### Australia

Flourish Australia have a strong peer workforce that complements and empowers teams to provide person-centred and recovery-oriented care.

Their approach to employing peer workers has changed the mindset of hiring managers when filing positions that work directly with people with mental health issues. The strategy challenged hiring managers to justify why a peer worker could not fulfil the requirements. This process supported an organisational cultural mindset shift and peer workers remain valuable assets to Flourish Australia.

Peer workers are required to meet certain expectations to fulfil their roles and responsibilities. Peer workers are also provided with adequate access to professional development and support to ensure job satisfaction and stability.

Source: Jackson and Fong [48]

## Recommendation 9. – Commit to improve and increase the use of data and technology in care coordination

- 9.1 Ensure electronic information sharing platforms are compatible across government and non-government services and sectors.
- 9.2 Collaborate with consumers, carers and communities in the development and implementation of electronic platforms.
- 9.3 Ensure consumers have the opportunity and choice to use digital technology (i.e. telehealth) to supplement face-to-face contact for remote monitoring and consultations.

#### Why this is a priority?

Enabling information sharing and multiagency care planning through a system-based commitment will improve the overall care, health outcomes and satisfaction of the consumers, carers and communities. A shared platform can truly harness collaborative working to maximise resources and improve outcomes for people.

Enabling appropriate and timely communication of data and information among professionals, consumers, carers and communities can support effective multiagency care planning and continuity of care. Services, sectors and professionals can identify who is involved in the persons care and understand how each service and professional will be involved in the person's care. This can minimise risk and facilitate seamless transitions between care episodes and settings.

Similarly, digital mental health platforms offer opportunities for facilitating care coordination. Phone and internet-based support services can be particularly effective for people in regional, rural and remote areas, particularly if shared platforms are used to help coordinate access. This means a person living in a regional, rural or remote area can seamlessly access a service located in a major city as the professional is able to access their records in a timely manner.

#### About the recommendation

#### **Recommendation 9.1**

Increase the interoperability of current information sharing platform or develop a new platform that enables effective information sharing. Any platform that is improved or developed should be consumer centred and led with the following objectives:

- To assist the workforce across government and non-government services and sectors to protect the
  confidentiality of consumers, only share data where necessary and in accordance with
  Commonwealth and state and territory information sharing and confidentiality legislation and
  guidelines.
- To enable people to have access to their own information and data to support self-care, appointment reminders and medication requirements.
- To enable multiagency care planning, providing a secure and efficient way for multiple services and sectors to input into, identifying as a minimum, the care coordinator and all services and professionals involved in the persons' care.
- To have regular workforce training to support safe information sharing.
- To promote and educate consumers, carers and communities on the privacy and security settings.
- To have evaluation and feedback mechanisms embedded for continuous improvement.

Governments have a responsibility to ensure that a regulative body ensures the safe use and sharing of consumer information on any electronic sharing platform.

#### **Recommendation 9.2**

To develop or improve on existing systems requires collaboration with consumers, carers and communities. This will assist in ensuring that the platform is safe and supported.

Time and dedicated resources by Commonwealth, states and territories are needed to develop, improve, implement, maintain and evaluate electronic tools. However, given the benefits of improved coordination within and across services, a strategic design of systems and understanding of the foundations required will ensure the best return on investment.

#### **Recommendation 9.3**

Consumers, carers and their communities have a right to choose how they would like to access the service or which professionals they engage with. Digital technology for communication and coordination such as telehealth and internet-based support services should therefore be available and offered to people and used when it is appropriate.

These services can be particularly effective for consumers, carers and communities in rural, regional and remote areas, especially if information sharing platforms are used to assist in coordinating access. Digital communication with consumers should not replace face-to-face but it can be used as an adjunct to increase access to services and support.

Co-designed with consumers, carers, clinicians, service providers and technical experts, the *National Safety and Quality Digital Mental Health Standards* address key safety and quality risks for digital mental health service users. Services, sectors and professionals are recommended to align with these best practices.

#### How could this look in practice?

#### **Child Link**

#### Victoria, Australia

The Child Information Sharing Scheme aimed for final implementation in 2021, will authorise a range of services and sectors to have access to information required to promote children's wellbeing and safety. The scheme is intended to promote collaboration and integration through identifying unmet needs and risks, promote early and effective intervention to improve overall outcomes for children and families.

The scheme will develop a web-based register, that will provide authorised professionals with critical information about the children in their care. The register will bring together data from existing systems and services to form a single and aggregated source of information about a child as well as their engagement in key childhood services such as school and child health services.

To ensure a holistic response the appropriate organisations and services that may have access to the scheme include health and support services, public hospitals, early childhood education care providers and schools.

Source: Engage Victoria [49]

#### **ILINKS**

#### **Liverpool and Sefton, United Kingdom**

Exploiting the benefits of existing and future technology, the aim of iLINKS is to provide the local health and social care workforce the relevant data and information to enable them to work collaboratively. The consumer remains at the centre of care, with the information sharing platform allowing for crossorganisational collaboration, improving the consumers experience and outcomes.

The system provides a structure for information sharing that facilitates a safe, legal and consistent approach to delivery. Depending on an individual's role (i.e. practitioner, carer or individual), only certain information will be provided by default based on the relevance in terms of delivery of care and risk.

Consent is the central component to the framework. Consumers are also able to benefit with reminders for appointments or tasks to complete at home.

Although, the system is yet to be evaluated, the opportunity to use technology to enable and improve access to real time, accurate information with and across service boundaries shows great benefits to improving coordination and collaboration.

Source: National Health Service [50]

### **OVERVIEW**

This section explores some key considerations when coordinating care for different groups. These include:

- Life stages and transitions
- Aboriginal and Torres Strait Islander people
- Culturally and linguistically diverse
- LGTBQIA+
- Persons living with a disability
- Regional, rural and remote communities

It is important to note that there may be other groups that have not been mentioned here that services will need to consider when coordinating care.









### Life stages and transitions

#### **Key considerations for services**

- Identify the person's life stage or transition point and recognise the impact that it can have on the ability to access services and sectors that support their mental health and wellbeing.
- Work in collaboration with other services and sectors to support the person, their carer and community to move between significant life stages and events.
- Regularly assess the physical health needs and supports a person may require when planning care.
- Acknowledge and provide assessments and coordination of treatment and supports with consideration of the social determinants influencing the person's environment and experiences.
- Empower and support carers, families and communities to be active participants in the coordination of care for the person.

Throughout a person's life there are major life stages that can have a significant impact on mental health and wellbeing, for example adolescent to adulthood and older age. It is critical that when working with a person moving through any major life stage, the whole person is considered to assist them in planning and engaging the relevant services and sectors that will support their recovery journey. This includes consideration and acknowledgment of the social determinants – housing, financial assistance, social support, education or employment – that influence the person's environment and experiences [51].

Equally important is a person's physical health. The co-occurrence of poor physical and mental health has been well documented. Mental illness often plays a role in increasing vulnerability to physical disability and poorer health outcomes [52]. People living with a mental illness have more than double the mortality rate compared to the general population [52]. The physical health needs of a person must therefore be regularly assessed and included in care planning. This highlights the importance for care planning and coordination to focus on the whole person and overall wellbeing and recovery.

A person's age will determine what services they have access to and the rights they have. The way a person interacts with and utilises services will also differ depending on the person's age and life stage. It is estimated that 75% of people with a psychiatric disorder experienced onset before 24 years of age [53]. Many young people present with mixed symptom patterns, often accompanied with substance misuse. These undifferentiated or un-diagnosable patterns can lead to challenges in accessing appropriate treatment and services, particularly when treatment approaches emphasise formal diagnoses. As a result, many young people are marginalised or excluded, ultimately leading to ongoing and greater mental health challenges [53]. The child-adult split in health care introduces discontinuities in care. This requires adequate attention and coordination to support the young person's life changes, recovery journey and to meet any developmental and engagement needs [54]. Various challenges in the transition from adolescence to adulthood include changes in consent, diagnosis, needs and goals as well as potential transitions in housing, education and employment.

Compared to the general population, older people are less likely to seek help, be referred by professionals and receive psychological treatments [55]. For some older people, access to appropriate treatment and support can be hindered by factors including finances, lack of transportation, fear of being a burden, and attitudes and beliefs toward mental health [56]. A review of barriers in the UK found that older people tend to fall through the gaps due to differing service criteria between adult and later life services [55]. For some older people there is stigma and generational factors influencing help-seeking.

Acknowledging the various barriers and working to understand and support older people with severe and complex mental illness feel safe to access the treatment and supports they require is vital for recovery and wellbeing [55]. Furthermore, consideration of the person's physical health, lifestyle behaviours and other age-related health conditions is necessary to ensure an integrated, whole of person approach [56]. Failure to do so, can contribute to increased risk of medical illnesses associated with higher mortality rates. For example, sedentary lifestyle, diet, smoking and alcohol and substance misuse [56]. Caring for older people primarily occurs in the community and involves significant input from informal carers such as spouses, family and friends [57]. Therefore, the person's carer and

community should also be appropriately recognised, supported and offered resources. It needs to be acknowledged that caring for someone with severe and complex mental illness can be demanding and may impact the carers health and wellbeing [57]. It is essential that carers also look after themselves and are offered support to ensure they can have fulfilled and contributing lives.

There may be some people who experience significant points of transition in their life, for instance prison release or entering motherhood. As with life stages, these events can have a significant impact on the persons mental health and wellbeing. In 2006, 80% of NSW prisoners had at least one mental health disorder compared to 31% within the general population [58]. Compared to their peers, prisoners recently released are more likely to be homeless, unemployed, have less family support, reside with other former prisoners or current drug users, or experience substance misuse [58]. During the immediate transition period from prison to the community, a person with severe and complex mental illness faces significant challenges including finding stable housing, employment and positive support networks [58, 59]. In addition, connecting with appropriate treatment and supports can be overwhelming for someone recently released from prison and may not be seen as a priority. Ensuring smooth coordination and transition for people re-entering the community is crucial in supporting recovery and minimising reoffending [58, 59].

## Aboriginal and Torres Strait Islander people

#### **Key considerations for services**

- Before engaging with Aboriginal and Torres Strait Islander communities or services, including consumers and carers, ensure that you and your service has participated in cultural safety and cultural competency training.
- Engage and partner with Aboriginal and Torres Strait Islander community-controlled services, Elders and communities when coordinating the individual's treatment and supports.
- Improve cultural awareness and sensitivity that involves the understanding of kinship and the
  various cultural nuances of Aboriginal and Torres Strait Islander consumers, carers and community
  across the different states and territories when coordinating treatment and supports.
- Acknowledge and provide the coordination of treatments and supports through compassion and
  respecting that the model of social and emotional wellbeing is the preferred model of service and
  works in collaboration with the Aboriginal community-controlled sector.
- Remember that no two Aboriginal and Torres Strait Islander communities have the same cultural
  history, and that kinship is defined differently for Aboriginal and Torres Strait Islander people
  compared to non-Indigenous people. Therefore, ensure all environments are appropriately
  resourced with language specific and culturally specific tools developed with Aboriginal and Torres
  Strait Islander consumers, carers and communities across all stages of care coordination.
- Include Aboriginal and Torres Strait Islander people in all decision-making 'nothing about us, without us.'

Colonisation has had traumatic and devastating effects on the physical and mental health of Aboriginal and Torres Strait Islander people [60, 61]. Cultural genocide, through dispossession, displacement and other forcible, often violent acts, has led to significant generational, and now intergenerational trauma [60, 61]. The impacts of colonisation and cultural genocide on Aboriginal and Torres Strait Islander populations are now widely acknowledged as the reason for many Aboriginal and Torres Strait Islander mental health issues [60].

Aboriginal and Torres Strait Islander people are the most disadvantaged group in Australia. Aboriginal and Torres Strait Islander people have a significantly reduced life-expectancy, poorer education and employment outcomes and higher justice system experiences compared to nonindigenous Australians [60, 61]. Data shows that the rate Aboriginal and Torres Strait Islander people report high and very high psychological distress is more than two and a half times the rate of other Australians [60, 61]. Suicide rates of Aboriginal and Torres Strait Islander people are twice the rate of other Australians and the rates of self-harm among Aboriginal and Torres Strait Islander populations have increased by 48% since 2004-2005 [60].

Racism, discrimination and social exclusion are long-standing experiences for Aboriginal and Torres Strait Islander people, sustained across generations  $[\underline{60},\underline{61}]$ . Many Aboriginal and Torres Strait Islander people still experience racism and discrimination today and report higher experiences of social exclusion compared to other Australians  $[\underline{60},\underline{61}]$ . The poor health outcomes of Aboriginal and Torres Strait Islander people need to be seen in the historic context of broader attitudes and policies  $[\underline{60}]$ .

At the foundation of Aboriginal and Torres Strait Islander mental and physical health is social and emotional wellbeing, encompassing the physical, emotional and cultural wellbeing of the individuals and their communities [26]. As illustrated in Figure 4, social and emotional wellbeing is multidimensional and intrinsically connected to all aspects of living, including family and kinship, culture and spirituality, connection, sense of belonging, reciprocity and the land [27].

The National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing is underpinned by nine guiding principles (Appendix A) which emphasise the holistic and whole-of-life definition of health held by Aboriginal and Torres Strait Islander people [26].

Culture and cultural identify are core to the social and emotional wellbeing of Aboriginal and Torres Strait Islander people [26]. Culture and cultural practices vary between Aboriginal and Torres Strait Islander tribes and communities across Australia. Parts of culture, cultural identity and cultural practices include dignity, self-determination and individual and community control over their physical environment. This can impact upon their social and emotional wellbeing and the decisions they make about their social and emotional wellbeing [25]. Therefore, it is vital that culture is considered and reflected in the delivery of health care for Aboriginal and Torres Strait Islander people.

Language and communication vary between Aboriginal and Torres Strait Islander populations and are key components to effectively coordinating treatment and supports for this population group with severe and complex mental illness. Proper consideration of social and emotional wellbeing in the development and coordination of treatment and supports is crucial to protect Aboriginal and Torres Strait Islander culture and way of life. Engaging and building trusting partnerships with Aboriginal and Torres Strait Islander services and professionals will facilitate connections with Aboriginal and Torres Strait Islander consumers and carers [26]. In practice, it is important that professionals try to understand the different perspectives in diagnosis and treatment, working with Aboriginal and Torres Strait Islander people to ensure there is understanding and acceptance [62].

Effective engagement through information sharing also needs to respond to any cultural and historical barriers related to the participation and understanding of Aboriginal and Torres Strait Islander people in decision-making and providing consent to the sharing of personal information.



Figure 4 Determinants of Aboriginal and Torres Strait Islander social and emotional wellbeing

Source: adapted from [63]

### Culturally and linguistically diverse

#### **Key considerations for services**

- Develop partnerships with local culturally and linguistically diverse-focused agencies and services when appropriate.
- Involve the consumer's family and community in care coordination and planning, with the consumer's permission.
- Create culturally safe environments for consumers, carers and their family, including language specific resources.
- Improve service provider awareness of culturally and linguistically diverse backgrounds, values and beliefs.

A significant proportion of Australia's population consists of people from culturally and linguistically diverse (CALD) backgrounds [64]. CALD groups and families refers to those born overseas or had at least one parent born overseas [31].

People from CALD backgrounds come from different walks of life and bring with them their unique and individual values, beliefs, customs and practices. It is important to acknowledge the diversity of CALD people and communities when coordinating care and consider the potential for people to overlap with other population groups including regional, rural and remote or gender and sexually diverse [65].

Evidence suggests that people from CALD backgrounds are simultaneously underrepresented in the group of people treated voluntarily for mental illness, and overrepresented in the group of people involuntarily treated or admitted for acute inpatient care for mental illness [65].

Barriers to accessing care for members of CALD communities are often cultural, structural and service-related barriers [31]. Factors such as language or cultural barriers, stigma and discrimination, feelings of shame and guilt, and limited awareness of supports available can create barriers to accessing care [31, 65].

This makes care coordination and providing culturally safe services within and across health and social care services and sectors particularly important.

Partnerships should be developed and fostered between services and sectors with CALD-focused services. This can enhance service accessibility and delivery for consumers. Coordinating with local services that can assist in meeting the unique needs of CALD consumers, carers and communities ensures the provision of holistic, trauma informed, person-centred care.

Translation and interpreter services should always be offered to consumers, their carer and communities and used if appropriate. This can improve experiences, satisfaction and overall health outcomes as it assists in appropriately identifying and understanding the needs, goals and desires of the person in a timely manner.

Family and social networks are also important for CALD communities in both preventing and recovering from mental health issues [65, 66]. This is a key consideration when coordinating care and working alongside a consumer. Care must be taken to ensure that information sharing and communication occurs only when consent has been provided, it is appropriate for the consumer and likely to result in improved outcomes.

### LGBTQIA+

#### **Key considerations for services**

- Promote trusting, safe and confidential relationships and environments throughout the person's care and recovery journey.
- Improve service and professional awareness and sensitivity of the cultures, needs and diversity of the LGBTQIA+ community.
- Partner with LGBTQIA+ services where appropriate.

LGBTQIA+ populations refers collectively to people who identify as lesbian, gay, bisexual, transgender, genderqueer, intersexed, Agender, Asexual, bodily diverse, queer, pansexual, sister-girls, brother-boys and other sexually diverse populations [67]. Recently, there has been increased awareness and recognition of the mental health and suicide outcomes in LGBTQIA+ populations [67]. The Fifth Plan recognises the increased risks of mental health and suicide outcomes among LGBTQIA+ populations, highlighting the need to reduce discrimination and stigma [2].

Identifying as LGBTQIA+ is an identified risk factor for many psychological symptoms [67]. However, poor mental health outcomes are not related to sexuality, gender identity or intersex characteristics in and of themselves. Rather, poor mental health outcomes arise due to experiences of discrimination, prejudice, abuse and exclusion in relation to their sexual and gender diverse identity, experience, and other trauma [67].

Discrimination and stigma remain barriers to accessing care [68, 69]. Many people from LGBTQIA+ populations will avoid certain situations due to fear of discrimination. This can lead to social exclusion or isolation, contributing to a higher prevalence of other risk factors associated with mental health including chronic health conditions, alcohol and other substance use, homelessness and poverty [70].

LGBTQIA+ services support people to connect with appropriate services. There remains a need to improve the delivery of culturally safe health care for LGBTQIA+ populations [69]. Gaps and deficiencies in LGBTQIA+ knowledge and skills among health care professionals impacts the consumer-professional relationship and the professional's ability to provide appropriately coordinated care [69, 71]. Open, honest communications and relationships are necessary to support LGBTQIA+ people. However, many do not disclose their sexual or gender status to general practitioners and other health and social care professionals [72].

Creating trusting, safe and confidential environments is crucial for the consumer-professional relationship and the delivery of culturally safe care. Providing LGBTQIA+ sensitive care also means recognising and understanding the diversity that exists within this population group and not assuming or treating all people identifying as LGBTQIA+ in the same way [69]. Development and implementation of services should involve LGBTQIA+ consumers and communities to create strong partnerships and welcoming environments. There is also opportunity to develop tailored online services to support mental health and wellbeing, providing additional culturally safe resources [69].

### Persons living with a disability

#### **Key considerations for services**

- Services and professionals should be prepared and be willing to adapt their approach, including accommodating any physical support needs.
- An interpreter should be offered, or the persons preferred communication system should be made available where appropriate.
- With consent, services and professionals should maximise involvement of the person's carer and/or community, such as their family, when coordinating care and planning.

People living with a disability, physical or intellectual, can experience higher rates of mental illness [73]. The increased risk of mental illness is often related to an interaction between a person's disability and other medical, social and psychological factors. This predisposition to mental illness is apparent across the lifespan, including in children and young people [74].

However, people living with a disability often experience barriers to accessing services and support. This prevents some people from receiving timely and appropriate treatment and supports. As a result of the co-occurrence of mental health and disability, people often require support from multiple services and sectors and therefore without good coordination, barriers to accessing and engaging with them may increase.

The potential barriers should therefore be considered when coordinating, planning and providing care for this specific population.

Potential barriers to care can arise from communication or physical disabilities. However, the barriers are often created by the services and therefore reduced by services themselves. Professionals and services should therefore have adequate training and awareness of such barriers and be willing to adapt their approach if needed. For example, the following considerations and adjustments could be made:

- Simplifying appointments, referral letters and discharge summaries by using easy to understand language.
- Arranging appointments that facilitate accessibility and the person's preferences such as time, location or any other health considerations.
- Offering an interpreter or alternative communication system if the person chooses to have one.
- Identifying and accommodating any physical support needs when meeting with the person or planning care.

To improve coordination and provide person-centred care, the involvement of family members, carers and communities should be included where possible and with the consent of the person. Carers and communities are likely to know the symptoms that indicate illness or deterioration and can assist in managing any anxiety, confusion or stress. They should therefore be considered partners and/or experts in the care of the individual. The person living with a disability and their preferences should be taken into account. Their preferences may be to attend the meetings or appointments on their own, and such requests should be respected and supported where possible.

### People living in regional, rural and remote communities

#### **Key considerations for services**

- Develop local partnerships with key health and social care services and sectors to form an integrated network of support.
- Promote and utilise e-health interventions where appropriate to supplement face-to-face.
- Consider offering additional support to carers and communities when coordinating consumers care, given the geographic barriers and subsequent increased burden.
- Develop trusting relationships at all levels to promote and maintain confidentiality.

Consumers, carers and communities living in regional, rural and remote locations face additional and unique challenges compared to those living in metropolitan areas. Regional, rural and remote communities in Australia are not homogenous and vary depending on their geographic location, size, proximity to other towns or regional centres, culture or population [75, 76]. Importantly, the proportion of Aboriginal and Torres Strait Islander people living in remote areas is also higher than metropolitan areas [76]. These communities experience a unique set of factors that contribute to their overall social and emotional wellbeing [77]. As a result, care coordination and multiagency care planning needs to take into account the needs of local populations, and variations between these communities.

Regional, rural and remote communities often simultaneously have lower health service levels and higher community connectedness [78]. Partnerships should therefore be developed and fostered between services and sectors available and the role of non-government or other community services should be increased.

Formal Memorandum of Understandings (MOUs) should be used to strengthen and build these strategic partnerships with key stakeholders. Developing partnerships could enable joint service planning, workforce innovation and support to improve care. For example, MOUs used between the Royal Flying Doctor Service and the South-West Hospital and Health Service and Southern Queensland Rural Health are important to build partnerships, increase workforce opportunities and improve health service delivery in regional, rural and remote communities [79].

Non-government and community stakeholders such as police and other social support services also play a valuable role given the integrated networks that exist in regional, rural and remote communities [66]. Developing relationships of trust between these services and health providers can lead to improved and more holistic support and care plans for people with severe and complex mental illness. For example, equipping police to better coordinate with health providers can result in the most appropriate support being provided if police are engaged in an incident relating to a person with a severe and complex mental illness.

Carers and communities often bear an increased burden of care where gaps currently exist in the support services available [66]. In regional, rural and remote communities with no access to crisis services, carers and communities, particularly family members, are often left to deal with significant incidents with minimal support and guidance. This means there is an increased need to ensure that structures are established to ease the burden on families and carers [66]. Proactively coordinating care with carers and communities, as well as providing support for them, is particularly valuable.

E-health services should be readily utilised and offered to partially remedy the gaps in support for consumers, carers and families. While e-health services are not a replacement for face-to-face support, they can be used in a supplementary manner.

For example, telehealth could be integrated alongside face-to-face to access specialist advice where geographic barriers exist and there is a lack of specialists available. Consumers needs, personal choice and ability to access telehealth and videoconfrencing should be considered and their preferences prioritised. Consideration and use of the National Safety and Quality Digital Mental Health Standards best practices would assist services when using digital technology to support consumers, carers and communities.

# Implementing, evaluating and maintaining the Guidelines

### Communication and education

The Guidelines will be available on the Department of Health's, Fifth National Mental Health and Suicide Prevention Plan webpage. The availability of the Guidelines will be communicated with all relevant stakeholders including policy makers, government and non-government organisations, clinical and nonclinical professionals, consumers and carers.

#### Review of these Guidelines

The Guidelines will be reviewed in 24 months from implementation unless data or evidence-based practices triggers the need for earlier review. At that time, the Department of Health will assess the extent of the review required, as outlined below. Any changes or amendments to the original Guidelines will be made in revised versions.

#### Full review and update

If a full review and update of the Guidelines is needed, either a new scope will be prepared or the original scope from the published guidelines will be used and relevant stakeholders will be informed.

#### Partial review and update

If a part of the Guidelines needs to be reviewed and updated, either a new scope will be prepared or the original scope from the published guidelines will be used and relevant stakeholders will be informed. The scope will clearly outline which section(s) of the Guidelines are to be reviewed and updated and which are not, including any section(s) that may be withdrawn.

## Gayaa Dhuwi (proud spirit) declaration

The Wharerātā Declaration, developed by the Indigenous mental health leaders in 2010, sets forth five important themes: 1) indigeneity; 2) best practice; 3) best evidence; 4) informed, credible, strategic, connected, sustainable leadership; and 5) influential and networked leadership [80, 81]. The Wharerātā Declaration strives to support Indigenous people access to cultural healers and culturally informed healing methods, achieving balance between Indigenous and mainstream approaches to mental health [80, 81].

The Wharerātā Declaration recognises the similarities and differences of Aboriginal and Torres Strait Islander experiences and is intended for adaptation by Indigenous people for their situations [81]. Since its development, this declaration has been endorsed by various key government mental health agencies across Australia, underpinning the formation of the National Aboriginal and Torres Strait Islander Leadership in Mental Health in 2013-2014.

Gayaa Dhuwi (Proud Spirit) Declaration is a companion declaration to the Wharerātā Declaration, for use by Aboriginal and Torres Strait Islander people. It makes the following declaration:

- 1. Aboriginal and Torres Strait Islander concepts of social and emotional wellbeing, mental health and healing should be recognised across all parts of the Australian mental health system, and in some circumstances, support specialised areas of practice.
- 2. Aboriginal and Torres Strait Islander concepts of social and emotional wellbeing, mental health and healing combined with clinical perspectives will make the greatest contribution to the achievement of the highest attainable standard of mental health and suicide prevention outcomes for Aboriginal and Torres Strait Islander people.
- 3. Aboriginal and Torres Strait Islander values-based social and emotional wellbeing and mental health outcome measures, in combination with clinical outcome measures, should guide the assessment of mental health and suicide prevention services and programs for Aboriginal and Torres Strait Islander people.
- 4. Aboriginal and Torres Strait Islander presence and leadership is required across all parts of the Australian mental health system for it to adapt to, and be accountable to, Aboriginal and Torres Strait Islander people for the achievement of the highest attainable standard of mental health and suicide prevention outcomes.
- 5. Aboriginal and Torres Strait Islander leaders should be supported and valued to be visible and influential across all parts of the Australian mental health system.

The Fifth Plan acknowledges and prioritises the improvement of Aboriginal and Torres Strait Islander people's mental health and suicide prevention. The National Strategic Framework for Aboriginal and Torres Strait Islander people's Mental Health and Social and Emotional Wellbeing 2017-2023 recognises the importance of Aboriginal and Torres Strait Islander leadership and supports the implementation of the Gayaa Dhuwi (Proud Spirit) Declaration. The National Guidelines understands the importance of Aboriginal and Torres Strait Islander leadership and contribution within the mental health system, supporting the implementation of the Gayaa Dhuwi (Proud Spirit) Declaration.

The Gayaa Dhuwi (Proud Spirit) Declaration can be found at: https://www.gayaadhuwi.org.au/

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# Appendix A: Principles underpinning Aboriginal and Torres Strait Islander holistic health

Principles underpinning the *National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2017-2023* [26].

#### Principle 1

Aboriginal and Torres Strait Islander health is viewed in a holistic context, that encompasses mental health and physical, cultural and spiritual health. Land is central to wellbeing. Crucially, it must be understood that when the harmony of these interrelations is disrupted, Aboriginal and Torres Strait Islander ill health will persist.

#### Principle 2

Self-determination is central to the provision of Aboriginal and Torres Strait Islander health services.

#### **Principle 3**

Culturally valid understandings must shape the provision of services and must guide assessment, care and management of Aboriginal and Torres Strait Islander people's health problems generally, and mental health problems, in particular.

#### Principle 4

It must be recognised that the experiences of trauma and loss, present since European invasion, are a direct outcome of the disruption to cultural wellbeing. Trauma and loss of this magnitude continues to have intergenerational effects.

#### **Principle 5**

The human rights of Aboriginal and Torres Strait Islander people must be recognised and respected. Failure to respect these human rights constitutes continuous disruption to mental health. Human rights relevant to mental illness must be specifically addressed.

#### **Principle 6**

Racism, stigma, environmental adversity and social disadvantage constitute ongoing stressors and have negative impacts on Aboriginal and Torres Strait Islander people's mental health and wellbeing.

#### Principle 7

The centrality of Aboriginal and Torres Strait Islander family and kinship must be recognised as well as the broader concepts of family and the bonds of reciprocal affection, responsibility and sharing.

#### **Principle 8**

There is no single Aboriginal and Torres Strait Islander culture or group, but numerous groupings, languages, kinships and tribes, as well as ways of living. Furthermore, Aboriginal and Torres Strait Islander people may currently live in urban, rural or remote settings, in traditional or other lifestyles, and frequently move between these ways of living.

#### **Principle 9**

It must be recognised that Aboriginal and Torres Strait Islander people have great strengths, creativity and endurance and a deep understanding of the relationship between human beings and their environment.