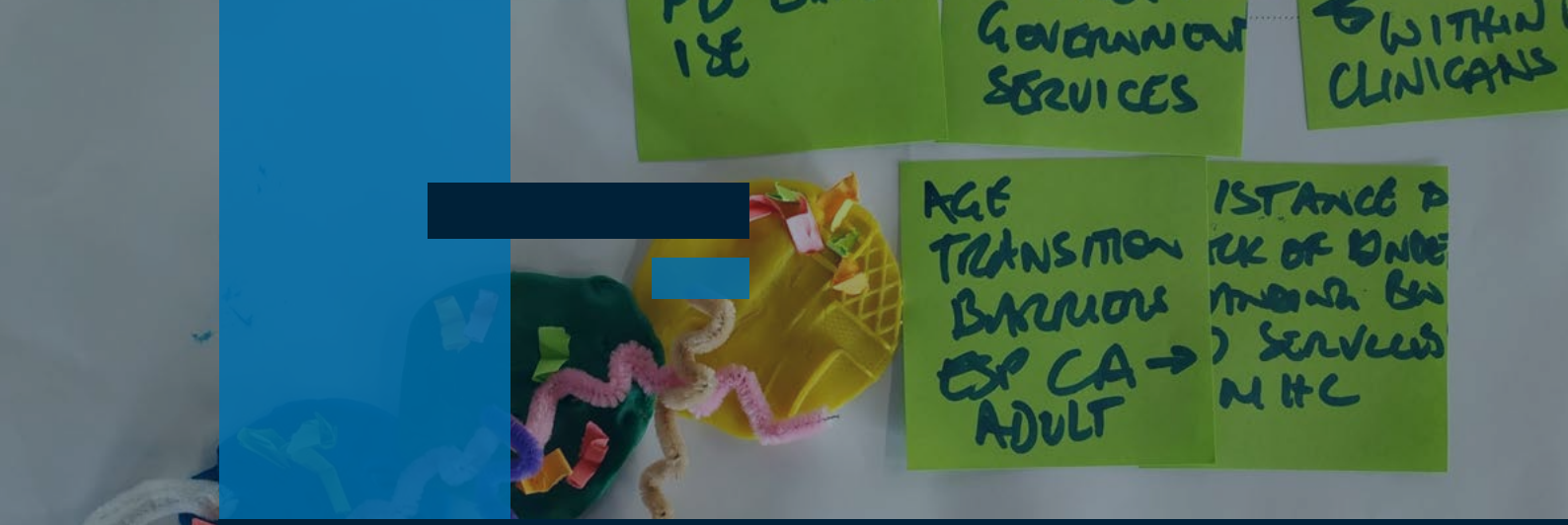
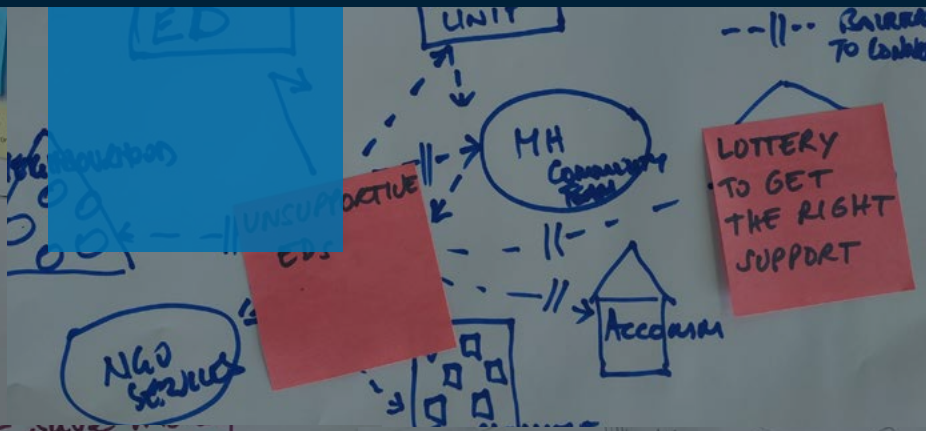
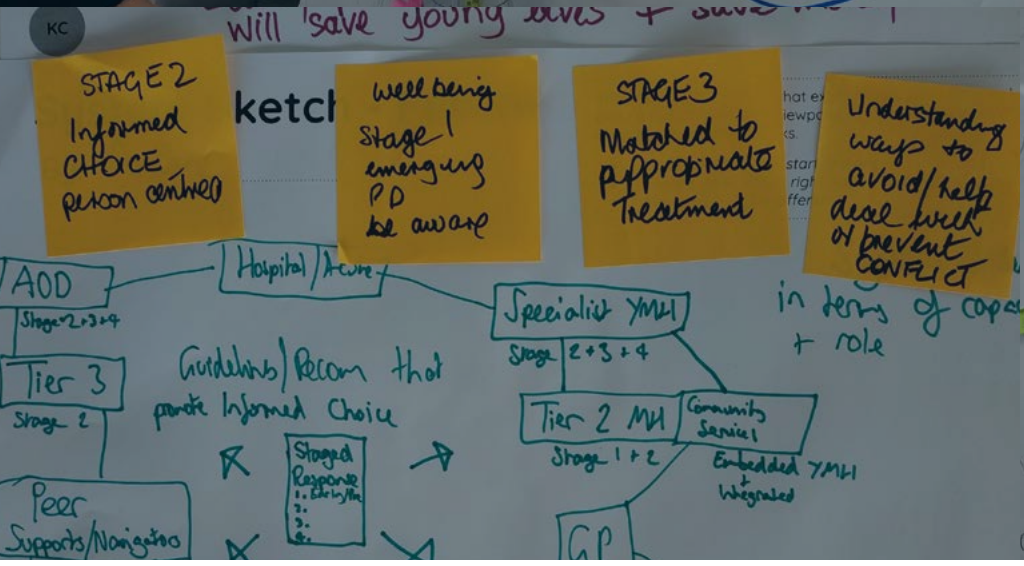
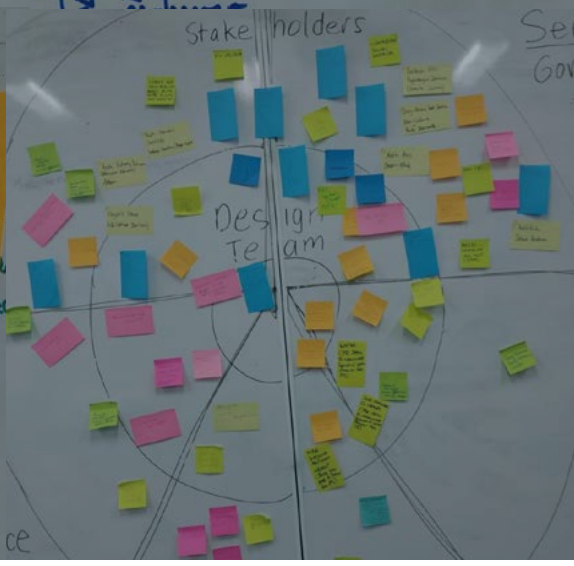


Statewide Model of Care for Personality Disorders

FINAL REPORT







WAAMH
Western Australian Association for Mental Health

Mental Health Network

FINAL REPORT

Statewide Model of Care for Personality Disorders

Prepared by

Western Australian Association for Mental Health (WAAMH)

in consultation with

Mental Health Network and Personality Disorders Mental Health Sub-Network

for

the Mental Health Commission of WA

NOVEMBER 2020

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FOREWORD

The Personality Disorders Subnetwork (PDSN) was established as part of the Mental Health Network in August 2016, in response to concerns raised by consumers, carers, clinicians and leaders across the mental health sector. Members of the PDSN aim to improve access to treatment and support for individuals with Personality Disorders (PD) and their families and carers, as well as ensuring access to training and support for clinicians. At the PDSN inaugural Open Meeting, held 30 August 2016 attendees identified these key themes:

- A need for training and education for the workforce, particularly in NGOs who are holding considerable responsibility in the community.
- Lack of adequate supervision for clinicians that equips them to deal with consumers with personality disorders; to prevent burnout and poor practice or re-traumatising of consumers.
- Lack of consistency in approach to inpatient treatment.
- Lack of a comprehensive, coordinated strategy through a peak body or Centre of Excellence for treatment of people with PD in WA.
- To establish evidence-based training, evaluation, coordinated service development and implementation and ongoing support for clinical services in maintaining services (to enable top-down and bottom-up service development).

After the Open Meeting, a Steering Committee was established comprising of consumer, family and carer representatives, as well as NGO, primary care, inpatient, community and private clinician representatives. Members were selected to cover a breadth of experience and expertise in personality disorders. A workplan based on the themes identified at the Open Meeting was developed. The members generously volunteered time to make progress on the themes identified at the Open Meeting Workplan. We began work on a Model of Care, however with limited resources and no funding, so progress was slow.

It was an auspicious day in April 2019 when Mental Health Network Co Lead Helen McGowan informed the Steering Committee that the Mental Health Commission was interested in funding a piece of work that would develop a Model of Care for individuals with a personality disorder living in WA. We thought our Christmases had all come at once! On the 9th of July 2019 the inaugural meeting between the PDSN steering committee, the Mental Health Network Co- Leads, the Mental Health Commission and WAAMH took place.

Now, four years after the inaugural meeting and a little over a year after the first project meeting the report you are reading is the result of tireless work of individuals passionate about improving the lives of individuals with Personality Disorders, and supporting the families, carers and clinicians who work with them.

Dr Sian Jeffery and Catherine Holland, Co-Chairs Personality Disorders Sub Network

ACKNOWLEDGMENTS

The project was undertaken with the financial and logistical support of the WA Mental Health Commission and WAAMH acknowledges the contribution of all Commission staff involved with the project from its inception.

WAAMH would specifically like to acknowledge the support, advice and guidance provided by Dr Helen McGowan and Rod Astbury, Co-Leads of the Mental Health Network and Catherine Holland and Dr Sian Jeffrey, Co-Chairs of the Personality Disorders Network, whose leadership and advocacy for the project over many years was critical.

The process was designed to ensure that the Model of Care is a comprehensive reflection of the voices, experiences, perspectives and needs of people with lived experience and those directly affected by personality disorders, including consumers, parents, family members, carers, support persons and friends. WAAMH would like to express thanks to all the individuals, agencies, and groups, who gave generously of their time, expertise, and commitment to contribute to development of the Model of Care.

In particular, we thank:

- Members of the Personality Disorders Model of Care Project Reference Group, all of whom are listed in Appendix 3 for their unwavering commitment and guidance.
- All those with lived experience of personality disorder, their carers, family members, and support persons who participated in the Project Reference Group, the Co Design process and the stakeholder engagement. They are listed in Appendix 4.
- Kelly Clark and Karen Wellington, the co-facilitators of the Co-design process for their leadership and guidance.
- Dr Peter Smith and Lisette Kaleveld who undertook the Literature Review and provided strategic advice at various points of the project.
- The many clinicians and service providers who participated in the Co-design process and the stakeholder engagement.
- The members of the Executive Advisory Group of the Mental Health Network, the various sub-networks, the various sub-networks of the Mental Health Network and other stakeholders who contributed their ideas and expertise.
- Associate Professor Michael Wright and Professor Helen Milroy for their guidance and strategic advice.
- Mark Pestell, South Metropolitan Mental Health Service for his support for lived experience participation in the project.

WAAMH wishes to acknowledge the custodians of this land, the Aboriginal people of the many traditional nations and language groups of Western Australia. We acknowledge the wisdom of Aboriginal Elders past, present and future and pay our respect to the Aboriginal communities of today.

EXECUTIVE SUMMARY

Personality Disorder (PD) is a condition which involves pervasive and persistent patterns of thoughts, emotions and behavior that result in impairment and distress. People living with PD are more likely to present frequently to health services, and the suicide rate for those with Borderline PD is up to 45 times the general population. Effective, evidence-based treatments exist but are not widely available. PD is a highly stigmatised condition and many people living with the condition report significant challenges in accessing care, support and treatment.

Some estimates are that around 6.5% of Australians are living with personality disorder and more conservative estimates are 1 to 4%. With a WA population estimated to be 2.615 million, there may be between 26,000-105,000 people in WA living with personality disorder.

Background

The development of the Statewide Model of Care (MOC) for Personality Disorders was funded by the WA Mental Health Commission (MHC) and undertaken by the WA Association for Mental Health (WAAMH), in partnership with the Mental Health Network and the Personality Disorders Sub-Network.

This project arose following feedback to the Mental Health Commission from family members of people with Personality Disorders reporting their unsatisfactory experiences when presenting in crisis at hospital Emergency Departments. The MHC requested that the Mental Health Network develop a Model of Care for the treatment and support of people with Personality Disorders in WA. Subsequently, people with Personality Disorder were identified as a population group requiring specific consideration in the WA State Priorities Mental Health Alcohol and Other Drugs 2020-24.

The project was overseen by a Project Reference Group made up of the Co-Leads of the Mental Health Network, the Co-Chairs and members of the Personality Disorders Sub Network which includes people with lived experience, clinicians, service providers and other stakeholders.

The process of developing the Model of Care was a highly collaborative process involving people with lived experience of personality disorders as consumer, carer and family member, mental health clinicians working in the public, not-for-profit and private sectors, psychiatrists and psychologists, service providers and policy makers.

Project Methods

The Model of Care (MoC) was developed in seven phases, which were revised to accommodate restrictions on face-to-face gatherings imposed during the coronavirus crisis in WA. The seven phases of the project were:
Phase 1: Establishment of the Project Reference Group & Planning (August 2019)
Phase 2: Scoping the work to be done and who was to do it (September 2019)
Phase 3: Literature Review (October-December 2019)
Phase 4: Mapping and Stakeholder Engagement (January-May 2020)
Phase 5: Co- Design Process (January-May 2020)
Phase 6: Analysis & synthesis of findings and design of the Model of Care (June-July 2020)
Phase 7: Reporting (August-October 2020).

Key Findings

Some of the key findings of the project are:

- People with PD continue to experience stigma, discrimination and exclusion; there is a need for system leadership and cultural change, support to consumers and families in self-care, advocacy, and peer support, and community awareness raising and education.
- People with PD can and do recover. There is a need for well understood and widely accepted philosophy, principles, and practices of care to guide how services and service providers will support the recovery of people with PD.

- Many care providers, lack the expertise and confidence to respond effectively to PD. Co-developing a system wide competency framework for PD, including the lived experience workforce, will address this issue and improve system integration.
- Though there are effective evidence-based treatments for people with PD and their families, they experience significant gaps in access to these, including to public, secondary community and inpatient treatment services in Perth and the regions, to primary community treatment for those with moderate needs (the missing middle) and to psycho-education and support for consumers and families. This requires investment in community treatment and family support services that can provide specialised care and response for people with PD and their supporters.
- Investment in technical assistance and expertise in responding to people with PD is required to support capacity building across WA in the general health, mental health and community sector as well as development of specialised workforce, care pathways, clinical guidelines, supervision skills, care standards, second opinions and advice on system navigation. This needs to be informed by multidisciplinary expertise and include lived experience.
- People with PD are particularly disadvantaged by poorly integrated and siloed system responses; there is a need for the co-design and development of a system wide PD mental health pathway to guide and inform practitioners consumers and families in navigating supports and services.
- Community support for social inclusion and participation including employment, education, housing is critical to recovery and approaches that integrate clinical and community support and address co-occurring needs are most effective.
- There is a need to develop specific responses to specific populations.

Model of Care

The Model of Care described in this Report was developed through a comprehensive participative co-design process led by people with lived experience, and also drew on findings of a review of literature and evidence, and comprehensive process of stakeholder engagement and service mapping. The final design of the Model of Care was shaped by the Project Reference Group and other stakeholders through a series of workshops.

The co-design process identified that system re-design is essential to meet the needs of people living with personality disorders and their families, carers and support persons.

The Model of Care represents a whole of system, whole of government and community approach to recovery- based, community- based care, support and treatment for people living with personality disorders, their families and carers.

The Model of Care comprises a detailed set of Principles (a systemic philosophy of care) and seven Elements, including:

- Prevention, Early Intervention and Self care
- Community Support
- Primary Care
- Community Treatment
- Specialist bed-based services
- Capacity Building
- Service Navigation and Integration.

The seven Elements of the Model of Care refer to locations or sites for intervention, ranging from whole population needs for promotion and prevention, through to treatment and specialised inpatient services for those with more severe, persistent, and chronic conditions. The Model of Care outlines the range of service responses needed by people living with PD as well as their families and carers and the wider community. The Model of Care aims to build on existing service systems and achieve greater equity of access, more appropriate care and more consistent access and service quality across the many variable and different models and systems of care, support and treatment that exist across the state.

Opportunities for Improvement

The Report outlines thirteen Opportunities for Improvement to achieve system reform, enhance existing services and address gaps requiring the establishment of new initiatives, programs or services. The Opportunities for Improvement are discussed in more detail in Section 6.7.

Recommendations

A staged approach to implementation is proposed that commences with the creation of awareness and understanding across the mental health system about the need for change and the proposed Model of Care, and that is built on collaborative partnerships and active commitment from key stakeholders in the mental health system, including people with lived experience, the Mental Health Commission, the Mental Health Network and its associated sub-networks, WA Primary Health Alliance, Health Service Providers (HSPs), non-government peak bodies and community mental health sector, public mental health services, the non-government sector and other key stakeholders.

The main Recommendations arising from the Project are:

1. Sector leaders approve Overarching Principles (considering those at pp 44-45 of the Report), as the underpinnings of a system wide culture of care for people with Personality Disorder. Domain specific principles (pp 45-49 of the report) are considered for endorsement for the parts of the sector where they apply.
2. A sector wide promotional program is undertaken to achieve a shared foundational knowledge and awareness of personality disorders and commitment to the principles of care.
3. A tiered PD competency framework and curriculum is developed to guide the capacity and skill development of those who work with, and provide care, support, and treatment for people with personality disorders across the life course and responsive to specific populations.
4. A commitment is made to ensuring HSP-wide access to evidence-based culturally secure community treatments for adolescents, youth, adults, and older adults with PD.
5. A commitment is made to ensuring HSP-wide access to evidence-based culturally secure inpatient treatments for adolescents, youth, adults, and older adults with PD.
6. An entity (Centre for Personality Disorders) is commissioned to provide capacity building, consultation, liaison and technical assistance for evidence-based community and inpatient treatments.
7. A state-wide person-centred treatment and support pathway is co-designed to serve as a facilitated navigational resource for primary and community care, community and inpatient treatment, care coordination and transition for people with personality disorder. This will also support access to care for those residing in rural regions and other catchment areas without specialised PD services.
8. The most immediate service gaps are agreed and addressed; the most pressing that have been identified in the course of the project are:
    - Consumer and family and carer (including young carers) education, peer support skills training, and support, including system wide access to the Family Connections program.
    - Integrated, evidence based and culturally secure community treatment and community support services for adolescents, youth, and adults with moderate needs. This would address a gap between primary care and public community treatment.
9. A workforce training and development program is designed and initiated aligned to the tiered competency framework.
10. A research/evaluation/information strategy is co-designed aligned to the Model of Care. It is proposed to include an assessment of the impact of such alternatives to Emergency Departments under development as the Safe Haven Cafes, Step-Up residential services, and the Mental Health Emergency Centre.
11. Long term service gaps are identified and addressed; those that have been identified in the course of the project are:
    - The development and expansion of locally responsive PD treatment and support services across regional and remote WA.
    - The co-design and development of Aboriginal-specific PD treatment and support services with Aboriginal com-

munity and service leaders.

- Developing, with the Education Department, a strategy that ensures schools can identify, support, and engage relevant services for children and teenagers at risk.
- A mental health promotion program that promotes positive attitudes and approaches to emotional regulation in communities and workplaces.

1. PROJECT OVERVIEW

1.1. Introduction

This report describes a state-wide Model of Care for the support, care and treatment of people living with personality disorders. The Mental Health Commission commissioned the WA Association for Mental Health (WAAMH) to develop a clinically sound, co-designed statewide Model of Care (MoC) for Personality Disorders. The Report was prepared by WAAMH in consultation with the Mental Health Network, the Personality Disorders Sub-Network and the Mental Health Commission (MHC).

1.2. Background to the Project

This project arose following feedback to the MHC from family members of people with Personality Disorders reporting their unsatisfactory experiences when presenting in crisis at hospital Emergency Departments. The MHC requested that the Mental Health Network develop a Model of Care for the treatment and support of people with Personality Disorders in WA. People with Personality Disorders have subsequently been identified as a population group requiring specific consideration in the WA State Priorities Mental Health Alcohol and Other Drugs 2020-24.

The Model of Care has been developed to be consistent with the directions set by the WA State Priorities Mental Health Alcohol and Other Drugs 2020-2024 and the Sustainable Health Review of comprehensive person-centred, recovery-oriented care with a balance of prevention, early intervention, treatment and support services. The policy context and drivers for the project are discussed in detail in Section 5.

1.3. Project Scope

The project deliverables are:

- Include a person- centred recovery-based approach to service delivery in the mental health sector
- Describe a treatment and support pathway for personality disorders encompassing self-care, informal community care, primary care, specialised community treatment and support and hospital services
- Articulate the key principles of care for people with personality disorders
- Identify key service elements of a Model of Care along treatment and support pathways that include service navigation, integration, referral and transition
- Outline a comprehensive state-wide Model of Care with metropolitan regional, rural and remote reach, informed by a thorough process of consultation with all relevant stakeholders
- Identify existing comprehensive services, opportunities to enhance existing services and gaps requiring the establishment of new services (as part of the mapping of the existing WA service system)
- Address needs across the age ranges of child and adolescent, youth, adult and older adult and for specific populations such as Aboriginal, ‘Culturally and linguistically diverse (CALD), lesbian, gay, bisexual, transgender, gender diverse, intersex, queer, asexual and questioning (LGBTIQA+) and those with co-occurring alcohol and other drug (AOD) issues
- Include mechanisms for capacity building such as information, education, training, development, and consultation liaison
- Be supported by evidence and jurisdictional examples from Western Australia, nationally and internationally (as part of the Literature Review canvassing WA, Australian and international research and programs)
- Include expectations and standards regarding:
    - Trauma-informed practice;
    - Physical health and assessment;

- Requirements to support people with co-occurring problems (e.g. mental health, alcohol and other drug use problems and disability;
- Family inclusive and child-centred and child-aware practice;
- Non-discriminatory and de-stigmatising service provision;
- Culturally and diversity secure and competent practice;
- Quality and safety; and
- Reporting and evaluation.

- The Model of Care will be informed by, and complement, the standards developed by the Office of the Chief Psychiatrist as part of the implementation of the *Mental Health Act 2014.*

1.4. What is a Model of Care?

The following definition of a Model of Care was adopted for the project:

> *An overarching design for the provision of a particular type of health service that is shaped by a theoretical basis, evidence-based practice and defined standards.*[1]

The Model of Care developed for this project outlines principles and elements that should apply to the provision of mental health care, support and services across a continuum of care to deliver the right care and support in the right place at the right time by the right team of people to respond to people with Personality Disorders.

The vision for the model of care described in the report represents a **whole of system, whole of government and whole of community approach to recovery oriented, person centred community-based care, support and treatment** for people living with personality disorders.

1.5. How the Project was conducted

The project was overseen by an Planning group comprising the Co-Leads of the Mental Health Network, the Co-Chairs of the Personality Disorders Sub-network, the WAAMH Projects Lead and a representative from the Mental Health Commission.

A Project Reference Group[2] was established to provide direction, advice, and guidance. The group was made up of members of the Personality Disorders Mental Health Sub-Network and included people with lived experience of personality disorder (as a service user, carer and family member), clinicians and service providers from the public mental health, non-government mental health and private sector, the Co-leads of the Mental Health Network, the Co-Chairs of the Personality Disorders Sub-network and representatives of WAAMH and the Mental Health Commission. The Project Reference Group met regularly throughout the project.

The methodology for the development of the Model of Care comprised seven phases undertaken over a 11-month period. Project activities were curtailed significantly for a 10-week period due to coronavirus restrictions and impacts, resulting in delays to phase 4 (the mapping and stakeholder engagement process) and phase 5 (the co-design process). The process and approach were revised to accommodate restrictions on face-face gatherings imposed during the coronavirus crisis in WA. The seven phases of the project were:

Phase 1: Establishment of the Project Reference Group, planning and relationship building (August 2019)
Phase 2: Scoping the work to be done and who was to do it (September 2019)
Phase 3: Literature Review (October-December 2019)

1 NSW Agency for Clinical Innovation, (2013), Understanding the process to develop a Model of Care. An ACI Framework, Sydney, 2013.

2 A full list of Reference Group members can be found in Appendix 3.

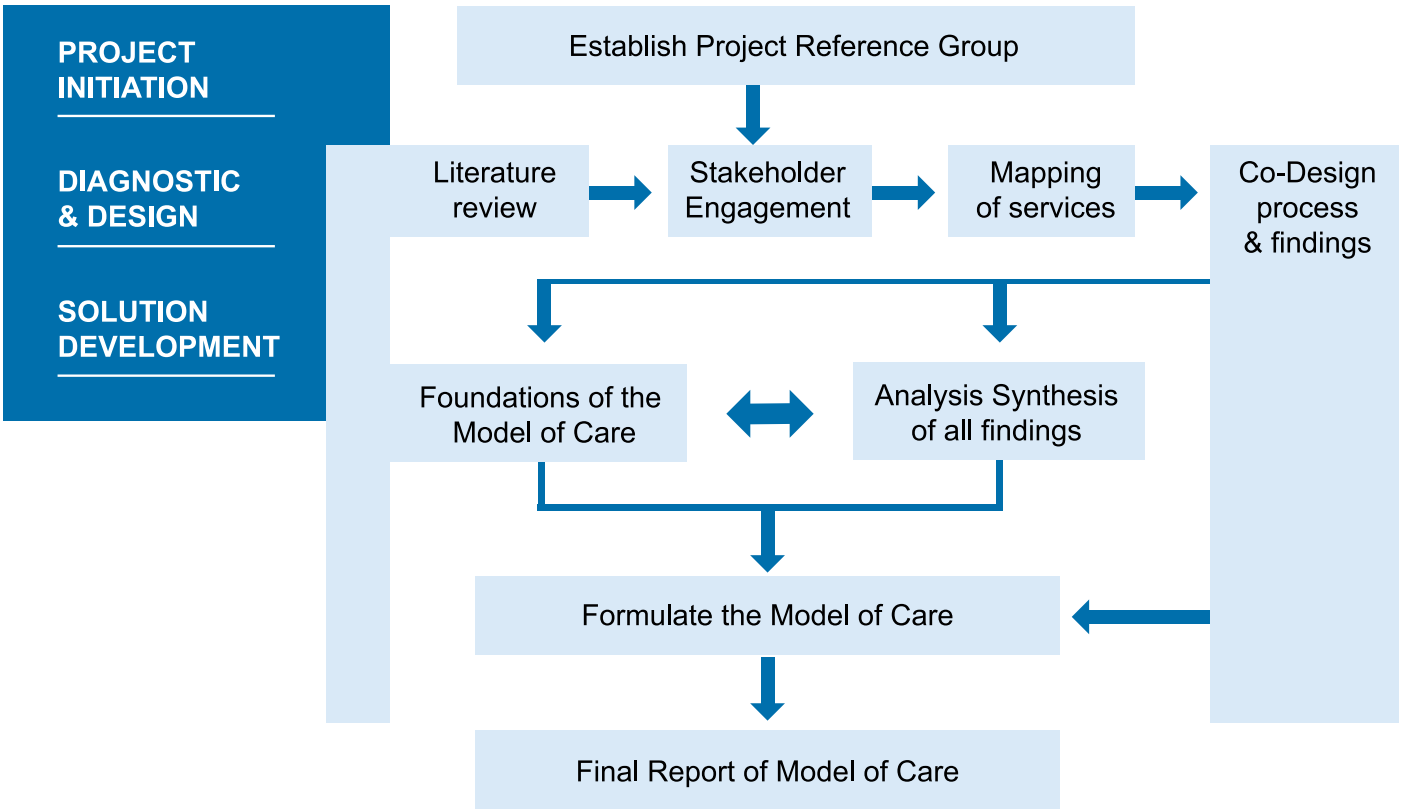
Phase 4: Mapping and Stakeholder Engagement (January-May 2020)
Phase 5: Co- Design Process (January-May 2020)
Phase 6: Analysis & synthesis of all findings and design of the model of care (June-July 2020)
Phase 7: Reporting (August-October 2020).

The key activities undertaken in each phase are discussed in detail in Appendix 2.

The Figure below shows how each stage of the project informed other stages and contributed to the development of the Model of Care and the final Report.

The MOC also draws on the best available evidence presented in the Literature Review, as well as the experience of mental health clinicians, service providers and policy makers.

Methodology



"They told me apparently I have a personality disorder. And they didn't really do no tests, no nothing, they talked to me a little bit and then they came out with a bunch of paperwork and said'. "Here, you have borderline personality disorder". I was like okay and they said. "You can go"
- Lived Experience Consumer and Co-Design Participant

1.6. A Word on Terminology and Language

The sensitive and contested nature of language and terminology to do with personality disorders is apparent throughout the project. Agreement on terminology is difficult to achieve. For this report certain terminology has been preferred for ease of understanding, although there are differences in opinion about the terminology.

The term personality disorder is often stigmatising, alienating and misleading and may be used to discriminate and label people. The label masks the nature of the problem and adds to the challenges people experience.[3] Often the term is used as a reason to reject individuals from receiving care, support and services.

There are conflicting views about the use of the term personality disorder. Some people believe that that the term personality disorder should be abandoned or changed. A risk of changing the terminology is that it may cause confusion and divert attention from the need to develop accessible, effective services.

There is no established consensus about the preferred designation of people who use mental health services. In this document the terms used are client, service user or person living with or diagnosed with personality disorder.

The term person with lived experience is used to include people with experience as a client or service user, carer and/or family member.

The term Aboriginal is used to refer to Aboriginal and Torres Strait Islander people, although this entcompasses many diverse communities.

We acknowledge that there may be differences in perspectives about the terms used in this document.

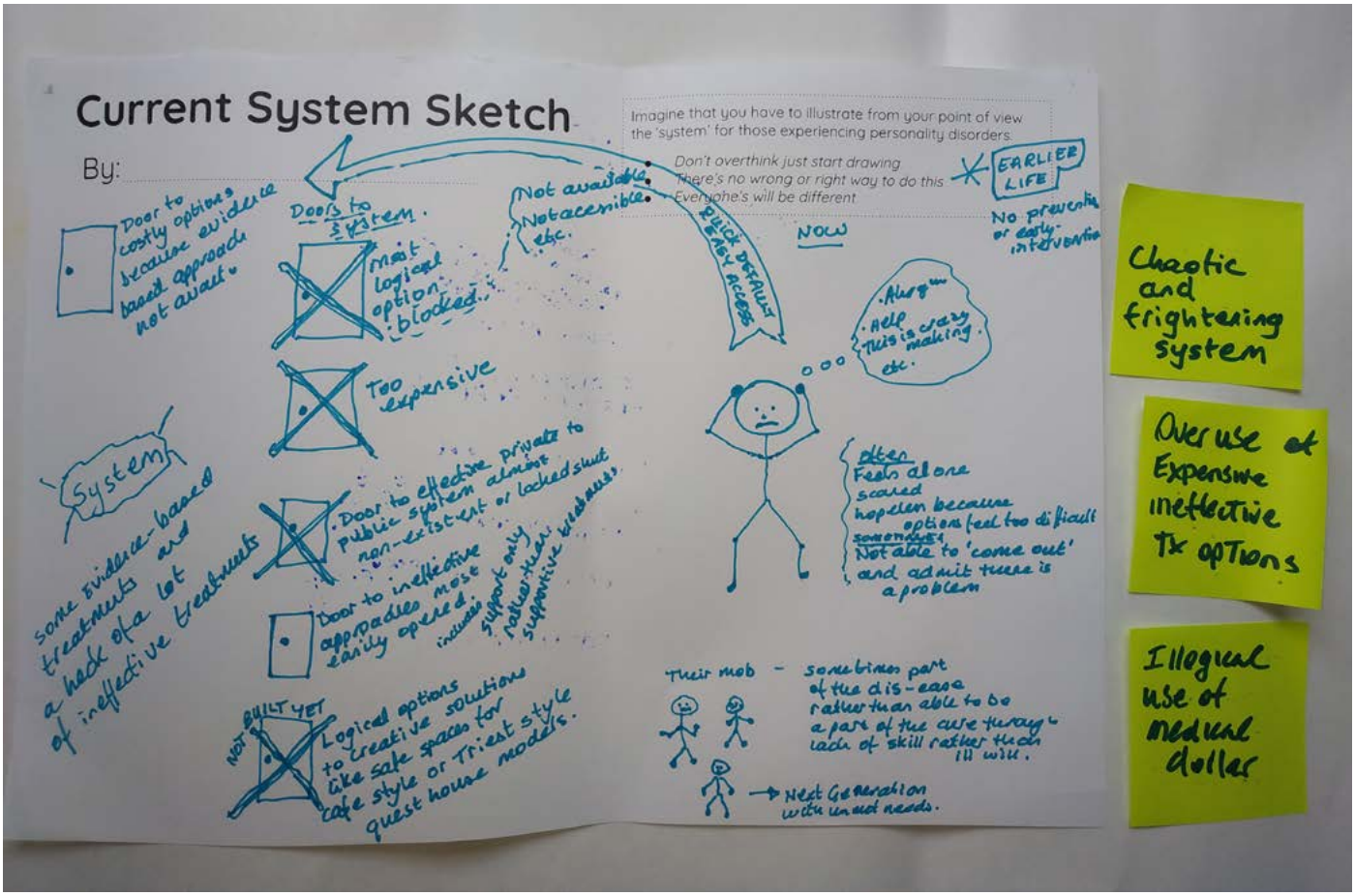
Definitions

In the context of this document the following definitions apply. These have largely been drawn from the *Mental Health Commission of WA Working Together: Mental Health and Alcohol and Other Drug Engagement Framework 2018 – 2025* and *Victorian Government Mental Health Lived Experience Engagement Framework 2019.*

Term	Definition
Consumer/service user	Consumers are people with a personal experience of mental health, alcohol and/or other drug issues, irrespective of whether they have a formal diagnosis or have accessed services and/or received treatment. **Note: we acknowledge that many people may prefer to use the words personal or lived experience, experts by experience, community members, clients, service users, patients, residents, customers, peers, or survivors.*
Carer	A person who provides ongoing care, support, and assistance to a person with disability, a chronic illness (which includes mental illness) or who is frail, without receiving a salary or wage for the care they provide. A carer may be a family member, friend or other person, including a person under the age of 18, who has a significant role in the life of the consumer

3 Centre for Mental Health, Mind, RCGP, NHS, Royal College of Nursing, BASW, British Psychological Society, Anna Freud National Centre for Children and Families, (2018), Shining lights in dark corners of people's lives. The Consensus Statement for people with complex mental health difficulties who are diagnosed with a personality disorder.

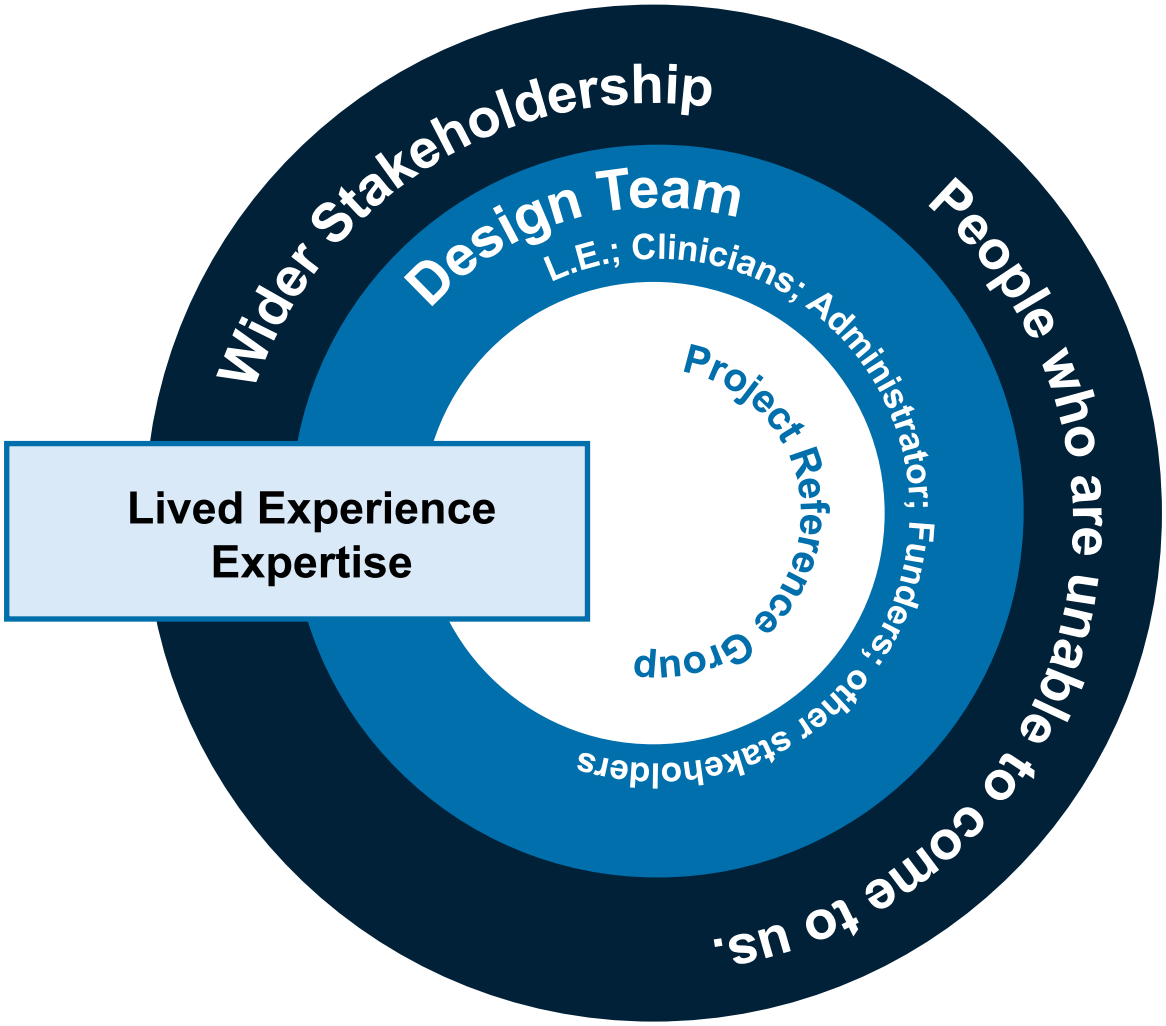
Term	Definition
Family	Includes the consumer and those with a significant personal relationship with the consumer. This includes biological and non-biological relatives, intimate partners, people in co-habitation, friends, those with kinship responsibilities and others who play a significant role in the consumer's life
Lived experience	Any person who identifies as having a current or past personal experience of psychological or emotional issues, distress, mental health and/or alcohol other drug issues, irrespective of whether they have a diagnosed mental illness and/or AOD issue and/or have received treatment. This definition also extends to family and friends who have personal experience of providing ongoing care and support to a person who has a lived or living experience as outlined above. *Note: we acknowledge that these terms may be uncomfortable, and some people prefer to use other terms to describe their experiences.
Lived experience perspective	An understanding of mental health based on having experienced mental health challenges or having cared for or supported someone with a mental health challenge. Such a perspective is acquired as a result of receiving, or being unable to receive, services, care or support in the mental health system. It is based on the belief that consumers and carers are 'experts by experience' about their own lives and carry the wisdom to best articulate their needs.
Lived experience workforce	The lived experience workforce includes peer, consumer and carer workers whose position description or role specifies that they have a lived experience. In the public and private mental health and community sectors, consumers and carers are increasingly being employed specifically to provide expertise based on their lived experience and associated skills. They are employed in positions with titles such as consumer advocate or carer advocate, consumer consultant or carer consultant, peer support worker or mentor.
Peer support	Peer support is provided between one or more people who have similar or shared experiences and who recognise each other as peers. In a mental health context, peer support can be understood as the help and support that people with lived experience of mental health issues can give to one another.
Recovery	Recovery is a term with different meanings in the mental health (and alcohol and other drug) sectors. Recovery is personal and social and means different things to different people. Personal recovery is defined within the National Framework for Recovery oriented Mental Health Services as 'being able to create and live a meaningful and contributing life in a community of choice with or without the presence of mental health issues'.
Trauma Informed approach to services/care	A program or organisation that is trauma informed realises the widespread impact of trauma and understands potential paths for recovery; recognises the signs and symptoms of trauma in clients, families, staff and others involved with the system and responds by fully integrating knowledge about trauma into policies, procedures and practices and seeks to actively resist retraumatisation.


Current System Sketch
By:
Imagine that you have to illustrate from your point of view the 'system' for those experiencing personality disorders.
Don't overthink just start drawing
There's no wrong or right way to do this
Everyone's will be different
EARLIER LIFE
No prevention or early intervention
Doors to system.
Door to costly options because evidence based approach not avail.
Not available
Not accessible
etc.
Quick default Ready access
NOW
most logical option blocked.
Too expensive
Door to effective private to Public system almost non-existent or locked shut
Door to ineffective approaches mose easily opened.
support only rather than supportive treatments
System
some evidence-based treatments and a heck of a lot of ineffective treatments
NOT BUILT YET
Logical options to creative solutions like safe spaces for cafe style or Triest style guest house models.
Allergic
Help
This is crazy making.
etc.
often
Feels alone
scared
hopeless because options feel too difficult
somewhere
Not able to 'come out' and admit there is a problem
Their mob - sometimes part of the dis-ease rather than able to be a part of the cure therapy
lack of skill rather than ill will.
Next Generation with unmet needs.
Chaotic and frightening system
Overuse of Expensive ineffective Tx options
Illogical use of medical dollar

2. THE VOICES AND PERSPECTIVE OF PEOPLE WITH LIVED EXPERIENCE

The voice of people with lived experience is all too often overlooked, particularly in the development and design of models of care and models of service, and the provision of services. This is to the detriment of individuals and families that services are set up to care for.

The figure below illustrates how the experience and perspective of people with lived experience of Personality Disorder (PD) was incorporated in every aspect of the project to ensure that the Model of Care is a comprehensive reflection of the voices, experiences and perspectives of people with lived experience and those directly affected by PD, including consumers, parents, family members, carers and friends.



From the commencement of the Project, the voices of people with lived experience, whether as service user, carer and/or family member shaped every stage of planning and development of the Model of Care (MOC). The MOC is a distillation of their experiences, aspirations and hopes. The project took several steps to achieve this, including

- Involving people with lived experience as consumer, carer and family member in the Project Reference Group. As the voice of people who have experienced living with a Personality Disorder (PD) or supporting someone with a PD it was critical that the Project Reference Group included a critical mass of people with lived experience.
- Actively involving people with lived experience in all project activities.
- Planning the Co-Design process so it was led by people with lived experience and actively involved a diversity of people with lived experience. The process enabled people with lived experience to work with a wide range of service providers, clinicians, service managers and policy makers to come together on the same level and work with the same purpose to design the MoC. Specific actions included:
    - Ensuring the Co-Design process was led and co-facilitated by a person with lived experience of PD
    - Forming a Lived Experience Design Group comprising people with lived experience to advice the facilitators of the Co-Design process. The group met regularly with the facilitators to ensure people with lived experience had shared understanding of the process and were able to participate actively and shape co-design events
    - Recruiting a diversity of people with lived experience to participate in the Co-Design process
    - Ensuring people with lived experience were reimbursed for their involvement.
    - Actively involving people with lived experience in the analysis and synthesis of data from all project activities and the formulation of the final Model of Care.

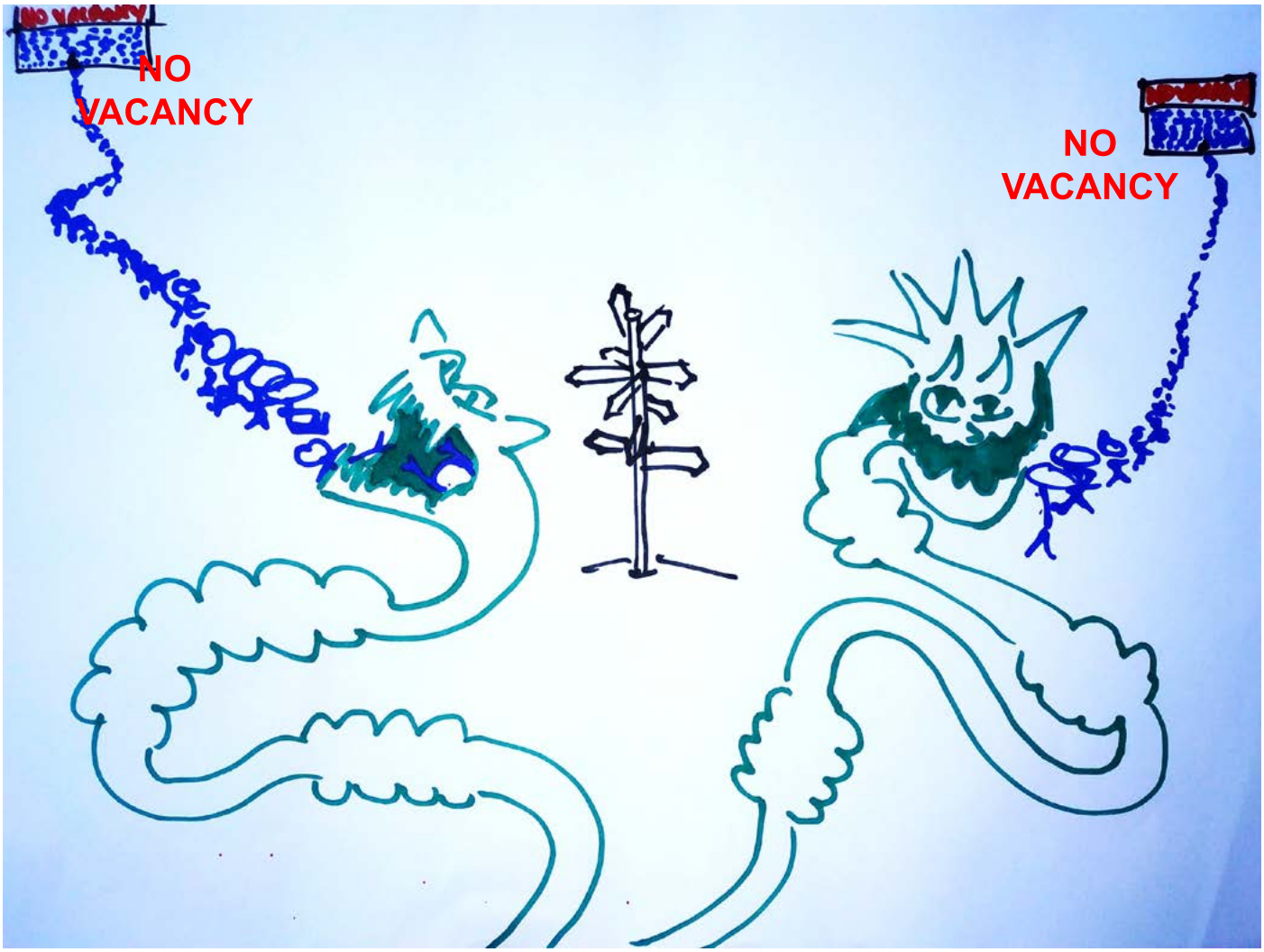
Two detailed reports were prepared to describe the process, structure, products, and outcomes of the Co-Design process.

As part of the process, people with lived experience (and service providers) provided visual and spoken testimonials about their experience with the existing mental health system and their vision for a system better able to respond to the needs of people with PD. A selection of illustrations and testimonials from the two reports is presented here.

Illustrations of the service system

Participants in the Co-Design process were asked to describe the “current system” as they experienced it and the “future system” as they envisioned it should be. Participants illustrated everything from their own emotions, inner-states, interpersonal relationships, to their experiences with services, impressions of the service system, and the relationship between services.


GO TO WORK
LAZY
TOO MUCH
NOT ENOUGH
GO TO WORK
GO TO WORK
GO TO WORK
GO TO WORK


NO VACANCY
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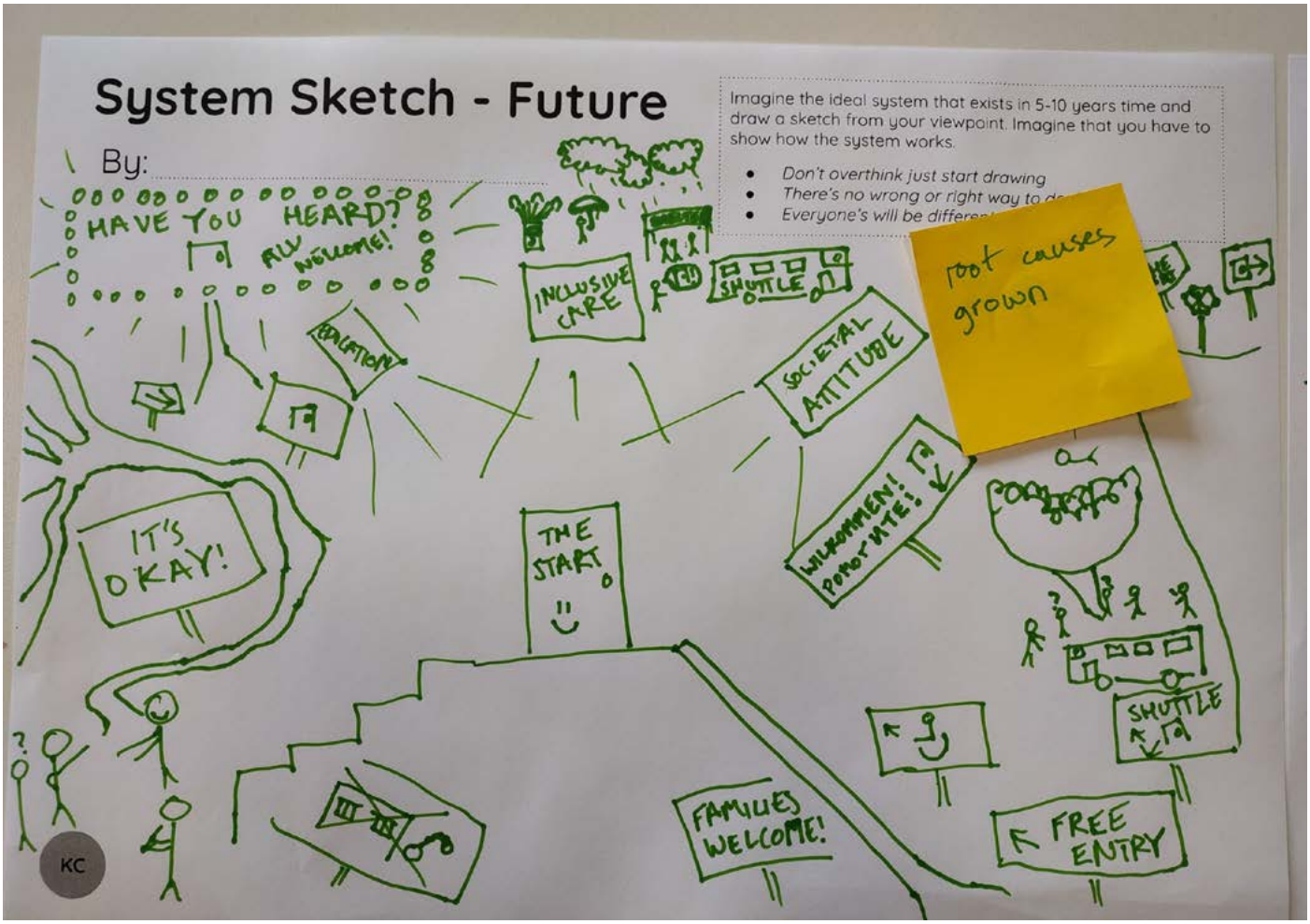
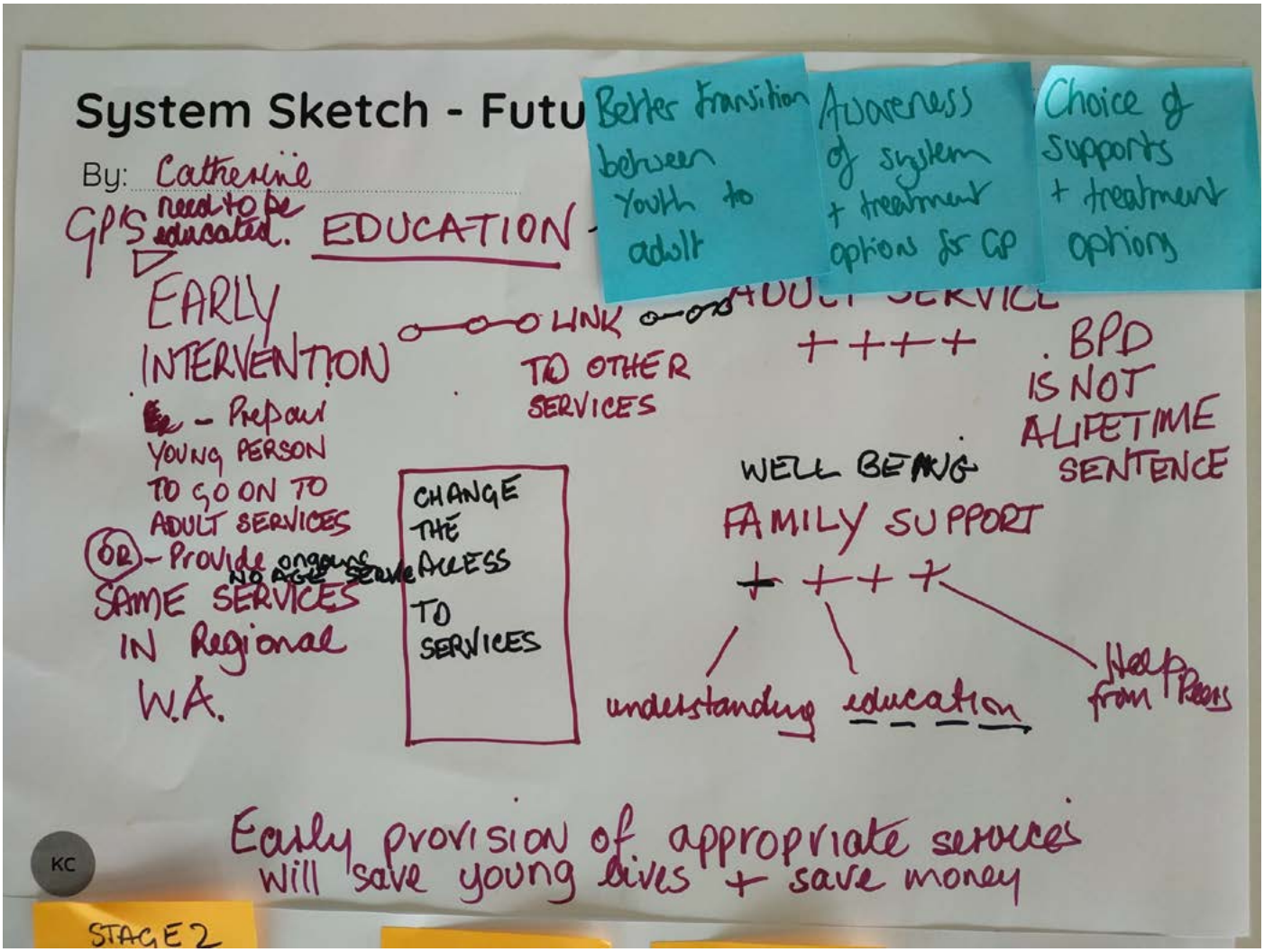

System Sketch - Future
By:
Imagine the ideal system that exists in 5-10 years time and draw a sketch from your viewpoint. Imagine that you have to show how the system works.
Don't overthink just start drawing
HAVE YOU HEARD?
ALL WELCOME!
INCLUSIVE CARE
SHUTTLE
SOCIETAL ATTITUDE
root causes grown
IT'S OKAY!
THE START
WILLKOMMEN! BIENVENUE!
SHUTTLE
FAMILIES WELCOME!
FREE ENTRY
KC


System Sketch - Futu
By: Catherine
Better transition between Youth to adult
Awareness of system + treatment option for GP
Choice of supports + treatment options
GPs need to be educated. EDUCATION
EARLY INTERVENTION
LINK TO OTHER SERVICES
+++++
BPD IS NOT A LIFETIME SENTENCE
- Prepare YOUNG PERSON TO GO ON TO ADULT SERVICES
OR - Provide ongoing SAME SERVICES IN Regional W.A.
CHANGE THE ACCESS TO SERVICES
WELL BEING
FAMILY SUPPORT
+ +++
understanding
education
Help from Peers
Early provision of appropriate services will save young lives + save money
KC
STAGE 2

During the co-design process people with lived experience of PD described how they were often treated with negativity and lack of understanding, and spoke about the stigma of being feared, viewed as troublesome and overly-dramatic, and undervalued to name a few. The voice and perspective of individuals brought together with similar experiences can provide solid suggestions and help address some of the issues, stigma and negativity towards people with PD and promote recovery.

"Each time our loved one was taken into emergency, in the public system, we were left waiting, given no information or included in discussions .Having to be triaged and wait in the full waiting room with a very distressed person who wants to run away is cruel for both carers and patient. When being discharged was no discharge plan and no advice on where to go after discharge."

"I have borderline personality disorder. I recently tried to end my life as I cannot access treatment and also cannot live like this anymore. I have had to move into a share house after leaving hospital four days ago. I am now out of the catchment area and go off the list for DBT again. I cannot recover without suitable treatment and it simply is not available unless you are 'stable' and have community support. Basically, this means that I am in a state of despair and only just surviving."

"Boxed in to treatment that does not work."

"Right at the top we need the statement- "people can and do recover from PD." If you said that right at the top, then from there everything flows."

"Anyone who lives in Perth should have access for comprehensive DBT rather than postcode lottery."

"More collaborative work happening, getting that philosophy out there. And it's got that positive hope- you can and do recover."

"When it comes to seeking treatment, the feeling of being a square peg not fitting into a round hole- not being the right shape. Not qualifying for treatment; needing to modify oneself in order to 'fit into the hole. Not always possible to do that."

"On one occasion we found our loved one in bed, unconscious and not responding we called an ambulance. When the ambulance guys arrived and examined our loved one, they were judgemental and negative. As they were taking our loved one to the ambulance, they were making negative comments. We were in a very distressed state and needed reassurance not negativity. Our loved one was in intensive care in an induced coma. After a couple of days, we asked where the our loved one's nightwear was. At that point we were told the ambos had to revive our loved one 3 times on the way to emergency which caused them to cut the nightwear off to carry out resuscitation. Nobody provided that information to us until I asked about the nightwear."

"Accessing the right supports feels like a lottery."

"They told me apparently I have a personality disorder. And they didn't really do no tests, no nothing, they talked to me a little bit and then they came out with a bunch of paperwork and said'. "Here, you have borderline personality disorder". I was like okay and they said. "You can go"

"Being in the gap of being too unwell to function well, but not unwell enough to 'qualify' for support (the system determining what support I can receive, rather than me being able to access the support I need.)"

"Lack of beds in the public system has led to our family in an emergency having to go private, costing our family $5000 + for a week."

"The normal clinical way of dealing with patients doesn't work with people suffering from emotional dysregulation. There's a reason why people describe it as walking on eggshells…a clinician who takes the power away by being in the 'expert' role will amplify the person's frustration and they will walk away. And once the bridges are burnt that's it, that window of opportunity for getting help is gone."

The Literature Review found that where researchers have consulted service users about their experience, people living with personality disorder are reported to describe feeling:

- Not an equal partner in treatment (Katsakou & Pistrang, 2018)
- A desire to be treated with dignity and respect (Borschmann et al., 2014)
- An inevitable sense of frustration with the system after making (yet again) lengthy circuitous journey's through various support services to get help (Carrotte & Blanchard, 2018)
- Patronised, discriminated against (overt not covert) and stigmatised in relation to their diagnosis (Dinos, Stevens, Serfaty, Weich, & King, 2004)
- That the diagnosis is about them not fitting and rejection (Horn, Johnstone, & Brooke, 2007)
- They are treated worse than before the diagnosis (Ramon, Castillo, & Morant, 2001)
- There are always waiting lists (Carrotte & Blanchard, 2018).

3. DESCRIPTION OF PERSONALITY DISORDER

This section draws heavily on academic and research literature presented in the Literature Review prepared for this project.

3.1 Description of Personality Disorder

There are many definitions of personality disorder. Most agree that personality disorders affect the way people think, act and feel about themselves and others. People with personality disorders tend to have ideas and feelings that negatively affect the way they relate to others, while also experiencing considerable negative feelings and thoughts about themselves. The features that define a personality disorder are the intensity, frequency and inflexibility of the powerful negative thoughts and feelings the person experiences.

The personality 'disorder' refers to a set of intense personality traits and behaviours that may have developed during childhood and adolescence that persist over time and continue to cause significant distress and barriers to a person's wellbeing and their ability to manage daily life. These also cause enormous stress for their family, friends and the wider community.

In the mental health system, PD refers to a type of complex mental health condition that can affect emotions, beliefs, attitudes and behaviour and cause significant distress and impairment across many aspects of life. The disorder is characterised by recurrent patterns of emotional distress, problems with thinking and behaviour and aspects of the self (identity, self-worth and self-direction) which have a detrimental impact on inter-personal relationships, difficulties with impulse control and daily functioning. These patterns persist over time and are long-term in nature. People with personality disorder find it hard to change their behaviour or adapt to different situations.

PD are often linked to previous traumatic events and persistent distress and are known to emerge in adolescence and continue through adulthood. Sometimes people develop a set of inflexible and extreme traits as a response to difficult early life experiences.

As a diagnostic label, personality disorder is considered to be stigmatising, controversial and pejorative for some, but remains in widespread use.

During periods of their life individuals with PD may be frequent users of mental health care services and at other times may need less support. People living with PD are more likely to present frequently to health services, and the suicide rate for those with Borderline PD is up to 45 times the general population. Effective, evidence-based treatments exist but are not widely available. PD is a highly stigmatised condition and many people living with the condition report significant challenges in accessing care, support and treatment.

"The normal clinical way of dealing with patients doesn't work with people suffering from emotional dysregulation. There's a reason why people describe it as walking on eggshells…a clinician who takes the power away by being in the 'expert' role will amplify the person's frustration and they will walk away. And once the bridges are burnt that's it, that window of opportunity for getting help is gone."
- Lived Experience Consumer and Co-design Participant

3.2. Definition

The term Personality Disorder (PD) was officially recognised in 1980, when the Third Edition of the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM) was published (DSM–III; APA, 1980).

The latest DSM-5[4] identifies 10 personality disorders, under an overarching definition of personality disorder as "an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment".[5] Each disorder is allocated one of three clusters based on shared features; Cluster A, comprising Paranoid, Schizoid and Schizotypal disorders; Cluster B comprising Border-line, Antisocial, Histrionic and Narcissistic disorders and Cluster C, comprising Avoidant, Dependent and Obsessive Compulsive Disorders.

There has been significant disquiet from the academic and research communities in relation to this categorical approach to diagnosis,[6] with the matter of whether mental states are conceptualised in categorical or dimensional terms long dividing the field. Consequently, the DSM-5 included a Section III Alternative Model for Personality Disorders. Similarly the 11th edition of the International Classification of Diseases (ICD-11) has adopted a dimensional approach to the classification of Personality Disorders that centres on global level of severity and five trait qualifiers.[7]

These changes signal the adoption of a dimensional system and indicates a greater acceptance that "disorder is an extreme expression of normal variation in the population... (and) disorder and normality differ only in degree but not kind"[8].

Currently clinical diagnosis of Personality Disorders commonly utilises a categorical approach with specific types of personality disorders defined by a particular cluster of symptoms. The literature review noted that there is concern regarding the limitations of this approach. The severity, chronicity and pattern of the symptoms guides treatment response. For those with less severe symptoms and/or in the early phases clinicians tend to avoid a formal diagnosis and instead utilise a multi-dimensional assessment process and a trans-diagnostic approach that focuses on providing support, addressing practical concerns and assisting with emotional regulation. However, those with more severe and persistent symptoms have been shown to benefit from more formal assessment, diagnosis and access to more specialised services.

The proposed Model of Care is pertinent for all PD types, although the literature review identified that most of the research and evidence-based treatments, focused on Cluster B Personality types (Antisocial, Histrionic, Narcissistic and Borderline), with particular emphasis on BordelinePD.

4 American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (DSM-5®). Washington: American Psychiatric Association.

5 American Psychiatric Association. (2013).

6 Clark, LA, (2007) Assessment and diagnosis of personality disorder; perennial issues and an emerging reconceptualization, Annual Review of Psychology, 58, 227-257: Wwidiger, TA and Trull, TJ, (2007), Plate tectonics in the classification of personality disorder: shifting to a dimensional model, American Psychologist, 62(2), 71.

7 Reed, GM,(2018), Progress in developing a classification of personality disorders for ICD-11, World Psychiatry, 17(2), 227-229.

8 Coghill, D & Sonuga-Barke, EJ, (2012), Annual research review: categories versus dimensions in the classification and conceptualization of child and adolescent mental disorders- implications of recent empirical study, Journal of Child Psychology and Psychiatry, 53(5), 469-489.

3.3. Prevalence

Some estimates are that around 6.5% of Australians are living with personality disorder[9] and more conservative estimates are 1 to 4% [10]. With a WA population estimated to be 2.615 million[11], there may be between 26,000-105,000 people in WA living with personality disorder. Prevalence rates are higher for women and recent prevalence data in a study population identified that approximately one in five Australian women were living with personality disorder.[12]

A number of large epidemiological studies (based on national registries) have documented an increase in reports of personality disorder, including Borderline Personality Disorder (BPD). Of the individual personality disorders, obsessive-compulsive (10.3%), avoidant (9.3%), paranoid (3.9%) and borderline (2.7%) were among the most prevalent.[13]

Personality disorder is highly prevalent in those with an offending history[14] and data collected from new prisoners entering the prison system in Western Australia highlights a prevalence of personality disorder in 38% of male and in 36% of female prisoners.[15]

The WA State Priorities Mental Health, Alcohol and Other Drugs 2020-2024 identifies priorities for the WA Government to reform and improve the mental health, alcohol, and other drug sector over the next 4 years. People with personality disorders are identified as a population requiring specific consideration. The State Priorities identify the need for the mental health sector to deliver contemporary models of person centred care in partnership with service users, families and carers, to ensure that various demographic groups are catered for and that adequate services are provided to people across all WA regions.

The Australian National Health and Medical Research Council (NHMRC) has established guidelines for working with people living with borderline personality disorder, as have specialised therapeutic services in Victoria (Spectrum, HYPE) and in New South Wales (Project Air). In addition, South Australia have released a state-wide BPD Collaborative (BPD Co).

3.4. Strategic Context: An emerging mental health priority

The profile of personality disorder has increased substantially over the last decade. It has been argued at a national[16] and international level[17] that a greater focus on personality disorder is needed, including prioritising treatment, coordinating more sensitive and less stigmatising responses and the need for more research.

9 Carrotte, E., & Blanchard, M. (2018). Understanding how best to respond to the needs of Australians living with personality disorder. Melbourne: SANE Australia.

10 NHMRC, (2013), Clinical Practice Guideline- Borderline Personality Disorder, Australian Government, 2013.

11 ABS. (2019). 3101.0 - Australian Demographic Statistics. Retrieved from https://www.abs.gov.au/ausstats/abs@.nsf /mf/3101.0

12 Quirk, SE, Berk, M, Pasco, JA, et.al, (2017), the prevalence, age distribution and comorbidity of personality disorders in Australian women, Australian and New Zealand Journal of Psychiatry, 51(2), 141-150.

13 Quirk, S. E., Berk, M., Pasco, J. A., Brennan-Olsen, S. L., Chanen, A. M., Koivumaa-Honkanen, H A Olsson, C. (2017). The prevalence, age distribution and comorbidity of personality disorders in Australian women. Australian & New Zealand Journal of Psychiatry, 51(2), 141-150.

14 Connell, C, Furtado, V, McKay, EA & Singh, SP, (2017), How effective are interventions to improve social outcomes among offenders with personality disorder: a systematic review, BMC Psychiatry, 17(1), 368.

15 Davison, S, Fleming, J, Butler, T, Morgan, V, Petch, Morgan F, Rock, D, Jones, J, Mitchell, M, Wright, M & Janca, A, (2015), Mental Health and substance use problems in Western Australian prisoners, University of WA Medical School.

16 Grenyer, B. F., Ng, F. Y., Townsend, M. L., & Rao, S. (2017). Personality disorder: A mental health priority area. Australian & New Zealand Journal of Psychiatry, 51(9), 872-875.

17 The Royal College of Psychiatrists. (2018). Personality disorder in Scotland: raising awareness, raising expectations, raising hope. CR214,. Retrieved from https:// www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr214.pdf?sfvrsn=ed59144_2

The Global Alliance for Prevention and Early Intervention for Borderline Personality Disorder calls for the reframing of personality disorder as a public health priority and highlights the need for early intervention.[18]

The WA State Priorities Mental Health, Alcohol and Other Drugs 2020-2024 identifies priorities for the WA Government to reform and improve the mental health, alcohol, and other drug sector over the next four years. People with personality disorders are identified as a population requiring specific consideration. The State Priorities identifies the need for the mental health sector to deliver contemporary models of person centred care in partnership with service users, families and carers, to ensure that various demographic groups are catered for and that adequate services are provided to people across all WA regions.

> "I had a patient who committed suicide and I felt so angry, sad and guilty-I couldn't access the care they needed and I don't want to do this work anymore."
>
> - Mental Health Clinician

The Australian National Health and Medical Research Council (NHMRC) has established guidelines for working with people living with borderline personality disorder,[19] as have specialised therapeutic services in Victoria (Spectrum, HYPE) and in New South Wales (Project Air). In addition, South Australia have released a state-wide BPD Collaborative (BPD Co). The work underway in other states demonstrates the growing recognition that there is a need for system leadership and cultural change and the establishment of unifying principles and practices.

3.5. Costs and resourcing

A recent report by the Western Australian Auditor General highlights that over the period 2013 to 2017 care was delivered to 212,000 people, and 10% of these people utilised 50% of emergency and community care and 90% of inpatient care.[20]

While these figures reflect the use of services by people with any mental health diagnosis, individuals living with personality disorder consistently demonstrate high patterns of service utilisation,[21] and are 2.3 times more likely than people living with other conditions to re-present to hospital within 28 days.[22] When people living with personality disorder are in crisis they may exhibit symptoms such as aggressiveness, impulsivity, self-harm and suicide attempts, which can be difficult for Emergency Department (ED) doctors to manage.[23] Much of the high service use cost in relation to BPD is due to the complexity of the condition but also to the inadequate and inefficient use of health resources.[24]

"Individuals with a PD cycle through the system. Revolving door"
- Mental Health Clinician

18 Chanen, A. M., Sharp, C., Hoffman, P., & Global Alliance for Prevention and Early Intervention for Borderline Personality Disorder. (2017). Prevention and early intervention for borderline personality disorder: a novel public health priority. World Psychiatry, 16(2), 215-216. doi:10.1002/wps.20429

19 NHMRC, (2013), Clinical Practice Guideline- Borderline Personality Disorder, Australian Government, 2013.

20 Office of the Auditor General. (2019). Access to State-Managed Adult Mental Health Services. Perth: Office of the Auditor General Retrieved from https://audit. wa.gov.au/wp-content/uploads/2019/08/Access-to-State-Managed-Adult-Mental-Health-Services.pdf

21 Meuldijk, D., McCarthy, A., Bourke, M. E., & Grenyer, B. F. (2017). The value of psychological treatment for borderline personality disorder: Systematic review and cost offset analysis of economic evaluations. PloS one, 12(3), e0171592

22 Lewis, K. L., Fanaian, M., Kotze, B., & Grenyer, B. F. (2019). Mental health presentations to acute psychiatric services: 3-year study of prevalence and readmission risk for personality disorders compared with psychotic, affective, substance or other disorders. BJPsych open, 5(1).

23 Shaikh, U., Qamar, I., Jafry, F., Hassan, M., Shagufta, S., Odhejo, Y. I., & Ahmed, S. (2017). Patients with borderline personality disorder in emergency departments. Frontiers in psychiatry, 8, 136.

24 Salvador-Carulla, L., Bendeck, M., Ferrer, M., Andión, O., Aragonès, E., & Casas, M. (2014). Cost of borderline personality disorder in Catalonia (Spain). European psychiatry, 29(8), 490-497

In Scotland, research indicated that investing in intensive, holistic approaches for personality disorder achieved substantial reductions in health care usage and expenditure in the short to medium term.[25] For example, Dialectical Behavioural Therapy (DBT) programs have been regarded as expensive, yet were found to result in overall cost savings.[26] [27]A significant body of research highlights that well evaluated psychotherapy is cost-effective and will reduce the use of health care resources.[28] [29] [30]There is a strong utilitarian and economic argument for implementing comprehensive treatment for people living with personality disorder.

3.6 Co-occurring conditions

For people living with personality disorder, co-occurring conditions are not the exception, but the norm.[31] Borderline personality disorder is somewhat linked with bipolar disorder and the presence of BPD in bipolar disorder[32] [33] [34] is associated with higher suicide risk, longer inpatient stay and higher cost during hospitalisation.

Personality disorder has been linked to substance use[35], reductions in quality of life[36], midlife cardiometabolic risk[37], and premature mortality.[38] Recent research identified that 5.9% of people living with borderline disorder died by suicide, with a suicide mortality rate of 1.4% for comparison subjects. Earlier studies reported suicide mortality rates for people living with borderline personality disorder to be almost 50 times higher than the general population.[39] [40]

To complicate these risks, front line clinicians, particularly in EDs, are more likely to see people living with personality disorder who attempt suicide or engage in self harm as attention-seeking, manipulative and as just 'acting out.' Ironically, people living with personality disorder are said to be "highly visible to clinicians, yet invisible to major epidemiological projects such as the Global Burden of Disease" [41]

25 Kane, E., Reeder, N., Keane, K., & Prince, S. (2016). A cost and economic evaluation of the Leeds personality disorder managed clinical network—A service and commissioning development initiative. Personality and mental health, 10(3), 169-180.

26 Amner, K. (2012). The effect of DBT provision in reducing the cost of adults displaying the symptoms of BPD. British Journal of Psychotherapy, 28(3), 336-352.

27 Wagner, T., Fydrich, T., Stiglmayr, C., Marschall, P., Salize, H. J., Renneberg, B., . . . Roepke, S. (2014). Societal cost-of-illness in patients with borderline personality disorder one year before, during and after dialectical behaviour therapy in routine outpatient care. Behav Res Ther, 61, 12-22. doi:10.1016/j.brat.2014.07.004

28 Amner, K. (2012). The effect of DBT provision in reducing the cost of adults displaying the symptoms of BPD. British Journal of Psychotherapy, 28(3), 336-352.

29 Meuldijk, D., McCarthy, A., Bourke, M. E., & Grenyer, B. F. (2017). The value of psychological treatment for borderline personality disorder: Systematic review and cost offset analysis of economic evaluations. PloS one, 12(3), e0171592

30 Hall, J., Caleo, S., Stevenson, J., & Meares, R. (2001). An Economic Analysis of Psychotherapy for Borderline Personality Disorder Patients. J Ment Health Policy Econ, 4(1), 3-8.

31 Newton-Howes, G., & Foulds, J. (2018). Personality disorder and treatment outcome in alcohol use disorder. Current opinion in psychiatry, 31(1), 50-56.

32 Bayes, A., Parker, G., & Fletcher, K. (2014). Clinical differentiation of bipolar II disorder from borderline personality disorder. Current Opinion in Psychiatry, 27(1), 14-

33 Paris, J., & Black, D. W. (2015). Borderline personality disorder and bipolar disorder: what is the difference and why does it matter? The Journal of nervous and mental disease, 203(1), 3-7.

34 Zimmerman, M., Martinez, J. H., Morgan, T. A., Young, D., Chelminski, I., & Dalrymple, K. (2013). Distinguishing bipolar II depression from major depressive disorder with comorbid borderline personality disorder: demographic, clinical, and family history differences. The Journal of clinical psychiatry, 74(9), 880-886.

35 Carrotte, E., & Blanchard, M. (2018). Understanding how best to respond to the needs of Australians living with personality disorder. Melbourne: SANE Australia.

36 Cramer, V., Torgersen, S., & Kringlen, E. (2006). Personality disorders and quality of life. A population study. Comprehensive Psychiatry, 47(3), 178-184.

37 Barber, T. A., Ringwald, W. R., Wright, A. G., & Manuck, S. B. (2019). Borderline personality disorder traits associate with midlife cardiometabolic risk. Personality Disorders: Theory, Research, and Treatment, 1-6. doi: 10.1037/per0000373

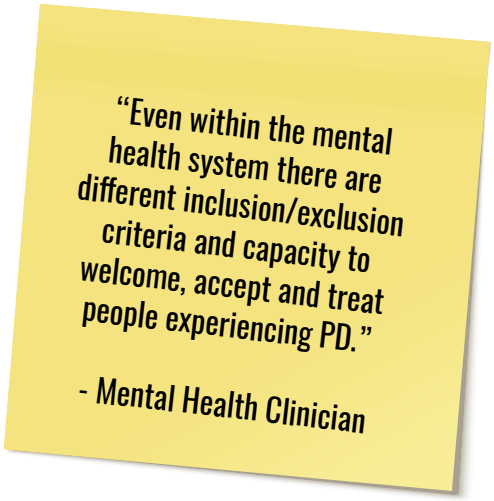
38 Fok, M. L.-Y., Stewart, R., Hayes, R. D., & Moran, P. (2014). Predictors of natural and unnatural mortality among patients with personality disorder: evidence from a large UK case register. PloS one, 9(7), e100979.

39 American Psychiatric Association. (2001). Practice guideline for the treatment of patients with borderline personality disorder. 158(suppl 10), 1-52.

40 Chesney, E., Goodwin, G. M., & Fazel, S. (2014). Risks of all-cause and suicide mortality in mental disorders: a meta-review. World Psychiatry, 13(2), 153-160.

41 Patel, R. S., Manikkara, G., & Chopra, A. (2019). Bipolar Disorder and Comorbid Borderline Personality Disorder: Patient Characteristics and Outcomes in US Hospitals. Medicina, 55(1), 13.

There is a cohort of people with complex co-occurring conditions, which might include anti-social personality disorder and severe offending, who will require access to specialist forensic mental health services as well as a range of public sector and community services, including health, mental health, disability services, drug and alcohol services, primary care, housing, legal services and community services. It is not anticipated that the Model of Care described in this report would meet all their needs, which would be better managed by a system and service response for people with complex and challenging needs. [42]



42 Consultation Draft- Targeted Review: People with Severe Mental Illness and Challenging Behaviour. Chief Psychiatrist Western Australia (2019)

4. EVIDENCE BASE

This chapter summarises findings from the Literature Review on the evidence base for various service models for personality disorders and describes examples from other jurisdictions and WA.

4.1. Service models for personality disorder: Australia and overseas

The Literature Review commissioned for this project explored various treatment and service models for personality disorder and provides more detail on the evidence base for the treatment and support for personality disorder. For example, in Australia some existing models and specialist practices include:

- Spectrum Personality Disorder Service, Statewide Centre of Clinical Excellence for Personality Disorders (Victoria)
- Helping Young People Early, Orygen, A prevention and early intervention program for young people (Victoria)
- Project Air Strategy for Personality Disorders (New South Wales)
- Statewide BPD Collaborative Model of Care (BDP Co) (South Australia)

Internationally

- National DBT Project to roll out DBT programs nationally (Ireland)
- Integrated Care Pathway (ICP) for people with PD (Scotland)
- NHS Highland Personality Disorder Service, specialist PD service and outpatient services (Scotland)
- Specialist Personality Disorder Service, with four tiers of specialisation (Wales)
- NHS South London and Maudsley day patient specialist service for people with personality disorder (South London and Maudsley)
- Borderline personality disorder pathway summary document, National Health Service Northwest Boroughs Healthcare (Northwest Boroughs)

While the Literature Review details each model in greater depth, some core elements that the models have in common, and that are endorsed through literature, are summarised below.

4.2. Core element: Psychotherapy

Direct clinical care and treatment for personality disorder includes psychological therapy, medication and family work. Specialist treatment is seen as essential for a small number of people where the personality disorder is severe or complex, or interacts in complex ways with specific cohort needs or circumstances (e.g. there are specific early years and new mothers programs, a young people's program, a criminal justice program and a program focused on the needs of Aboriginal people).

Structured individual and group therapy programs are delivered over several sessions over a period of time (with some being adapted programs), for example:

- *Dialectical Behaviour Therapy (DBT)*
- *Mentalisation Based Treatment (MBT)*
- *Psychoanalytic Clinic (PAC)*
- *Wise Choices Acceptance and Commitment Therapy (ACT)*
- *Complex Care Service (CCS)*
- *Brief Intensive Group Program*
- *Understanding and Managing Emotions 24-week program*
- *Anxiety management: Anxiety management uses a structured cognitive behavioural therapy (CBT)*
- *General psychiatric management (GPM)*
- *Cognitive analytic therapy (CAT)*

- *Schema therapy (ST)*
- *Systems Training for Emotional Predictability and Problem Solving (STEPPS)*
- *Coping and Succeeding (CAS) Day Service*
- *DBT STEPS-A: Schools-based DBT Intervention*

There are also new technologies (i.e. apps, mobile technology) that are changing the delivery of treatments and options. Although the evidence base is still developing, e-mental health interventions are starting to show promise (Fraser et al, 2016). Examples include:

- *Avatar-MBT*
- *Priovi electronic health program*
- *Mobile phone app DBT coach*
- *Moderated Online Social Therapy*

4.3. Core element: Training and capacity building initiatives

Sector development and upskilling mental health professionals to work more effectively with people living with personality disorder is seen as essential in both service models, as well as in the literature. This is important to extend to health staff and the wider community (including the non-government sector). Some examples include:

- Secondary consultations to other service providers to enable them to support people with personality disorders. Consultation modes may include recommendations on the general management and treatment of personality disorder, discussion of specific aspects of a clinical case, specific supervision for professionals engaged in delivering general or specific psycho-social treatments to patients with personality disorder, and full case consultation.
- Establishing a position or role for a clinician with specialist expertise in personality disorder within mental health or other health services to provide treatment, secondary consultation and training within their area mental health service.
- Employ lived experience workers and/or peer workers who bring their valuable perspective to the development and delivery of training, and foster groups for people living with personality disorder and their family. Training and supervision would be guided by their needs.
- Specific training for clinicians who routinely work with clients presenting with severe emotion dysregulation.
- Primary Clinicians that work directly with people living with personality disorder receive high-level supervision and coaching (sourced as necessary)
- Secondary Clinicians that provide support and deliver training (where appropriate), coaching and supervision.

4.4. Core element: System integration and referral pathways

There is a need to ensure that people living with personality disorder flow through the system seamlessly and with a sense of stability and predictability. Some ideas for how other jurisdictions have approached this include:

- Stepped care clinics within local health districts.
- Clear interfaces with a range of private practitioners and community-based services, including non-government organisations and Primary Health Network-funded services.
- Assessment and Brief Intervention Clinics (referral pathways during acute crisis experiences).

> "Limited professional development places, limited courses, limited experts."
>
> - Mental Health Clinician

- Crisis support and admission plans for patients with personality disorder developed and shared between relevant service providers.
- Referral and liaison with other community agencies (e.g. drug and alcohol, employment, or youth services).
- A Link Worker, who is a Personality Disorder Trained Practitioner. The Link Worker is to provide an extended socialisation phase for people who cannot engage in a program but for certain reasons cannot be safely discharged back to their General Practitioner (GP).

"Piecemeal-dependent on location. No overall system. No equity"
- Mental Health Clinician

4.5. Core element: Educating and advocating for families, carers and consumers

This could include:

- Face-to-face psychoeducation and support for people with personality disorders and their families and friends. There is also some capacity to support other services to offer such resources.
- Advocacy for the needs of people with personality disorder, their families and carers, and for improved resourcing of the mental health system that provides treatment and support.
- Education and awareness support for families, carers, and clinical and non-clinical service providers.
- Family Connections 12-week program.
- Family members or carers are involved in assessment, treatment planning, psychoeducation, and where indicated, Helping Young People Early (HYPE) program offers more formal family intervention sessions.
- CRISPS (Carers Require Information on Personality Symptoms) and TES (Training, Education and Support): Programs co-developed and co-delivered by a carer of a person living with personality disorder. The programs aim to improve well-being and confidence in carers to be able to look after the person they care for/live with more effectively.
- Carer programs: the pathway acknowledges the needs of carers and the value of programs co-delivered by a carer and a practitioner to help carers to develop skills, education, peer support.
- Family therapy.
- Lighthouse parenting program: a Mentalisation Based Treatment (MBT) for parents with personality disorders.

4.6. Core element: Prevention and promotion

The importance of services that include health promotion and advocacy (e.g. raising awareness of personality disorder and to reduce stigma) have been identified[43] as necessary. Specific processes identified[44] include the need to:

- Develop and implement public awareness campaigns about PD, and BPD in particular, similar to those organised by Beyond Blue in their awareness-raising campaigns on depression.
- Implement school-based programs to build awareness and resilience about Mental Health in general and PD more specifically.
- Fund and task consumer and carer organisations to undertake community awareness campaigns.
- As existing helplines find the complexities challenging, develop a 24/7 specialist telephone helpline and online

43 NHMRC, (2013), Clinical Practice Guideline- Borderline Personality Disorder, Australian Government, 2013.

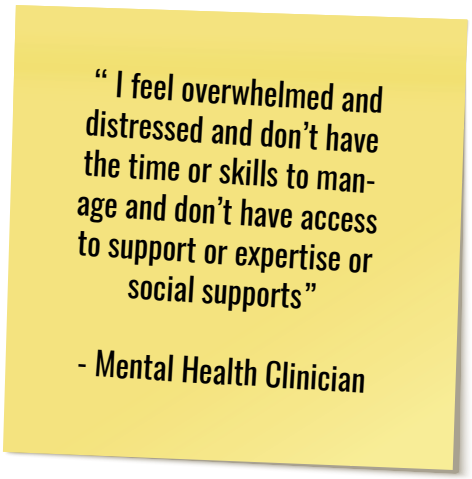
44 Spectrum. (2019). Submission to the Royal Commission into Victoria's Mental Health System. Retrieved from https://www.easternhealth.org.au/images/Spectrum_ Submission_to_the_Victorian_Royal_Commission_into_MH_July_2019.pdf

chat service for consumers, carers and clinicians that can offer specific assistance to suicidal PD populations, their families and carers, as well as the clinicians working with them.

4.7. Core element: Support for clinicians

This could include:

- Comprehensive assessment or a second opinion.
- Multidisciplinary team review.
- Input into the consumer's management and care plans.
- Lived Experience Project officers.
- Adequate training, supervision and opportunity for reflective practice should be provided for all staff working with people with personality disorder, as appropriate to their role.
- All staff should strive to demonstrate the principles of compassion, curiosity and empathy when working with people with personality disorder and challenge stigma by promoting good attitudes towards people with personality disorder.



4.8. Core element: Varying levels of intensity

Models of care intervention should match treatment to each person's needs and start with low-intensity interventions before moving on to interventions of increasing intensity.

Referrals to specialist services are indicated where there is:

- Complexity, including lack of engagement to treatments provided within other settings;
- Severity, as indicated by, for example, potentially lethal parasuicidal behaviour or emergency psychiatric hospital admission; and
- Lack of treatment progress after adequate trial of appropriate treatment, including identified need for a structured intensive intervention.

There is a cohort of people with complex co-occuring conditions, which might include anti-social personality disorder and severe offending, who will require access to specialist forensic mental health services as well as a range of public sector and community services, including health, mental health, disability services, drug and alcohol services, primary

care, housing, legal services and community services. It is not anticipated that the Model of Care described in this report would meet all their needs, which would be better managed by a system and service response for people with complex and challenging needs.

Another cohort that will require specific attention are people who present to emergency departments and mental health services with complex conditions that involve multiple disorders and multiple diagnoses. These clients present significant challenges for services and their workforce in terms of the skills and support required to respond to people so they are not prematurely pushed into a PD care pathway, or another care pathway, without their longitudinal needs being considered.

"Being in the gap of being too unwell to function well, but not unwell enough to 'qualify' for support (the system determining what support I can receive, rather than me being able to access the support I need.)"

- Lived Experience Consumer and Co-Design Participant

5. CURRENT POLICY AND SERVICE LANDSCAPE

5.1. Policy Context

Currently, there is no specific national or state policy framework or plan for people living with personality disorders. As such, there is no agreed set of priorities and few national or state policy initiatives which specifically address personality disorders.

However, the wider policy and service planning context is significant for the design and implementation of the Personality Disorders Model of Care. The Model of Care adheres to and aligns with principles and directions laid out in various policy frameworks, including:

Global

- United Nations, 2020 Report of the Special Rapporteur on the right to physical and mental health

National

- Fifth National Mental Health and Suicide Prevention Plan 2017
- Mental Health Statement of Rights and Responsibilities 2010
- National Standards for Mental Health Services 2012
- Productivity Commission Inquiry into Mental Health Draft Report 2019
- National Mental Health Commission Vision 2030: Blueprint for Mental Health and Suicide Prevention
- National Strategic Framework for Aboriginal and Torres Strait Islander People's Mental Health and Social and Emotional Wellbeing 2017-2023
- Gahaa Dhuwi Declaration
- Charter 2020: Principles for Mental Health Reform
- National Health and Medical Research Council- Clinical Practice Guideline for Management of Borderline Personality Disorder 2012

Western Australia

- Working Together: Mental Health and Alcohol and Other Drug Engagement Framework 2018-2025
- *Mental Health Act* 2014
- Sustainable Health Review 2018
- Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015-2025 and the Plan Update 2018
- Review of the Clinical Governance of Public Mental Health Services in Western Australia 2019
- Auditor General's Access to State Managed Adult Mental Health Services Report 2019
- WA State Priorities Mental Health, Alcohol and Other Drugs 2020-2024

The Model of Care is guided by, consistent with and supports global, national and state mental health reform agendas and policies, and provides a vehicle for achieving the reforms set out in the policy frameworks and documents. Some themes identified in those policy frameworks, that inform the Model of Care, are described below:

System re-design and reform and balancing the mental health system

The mental health system in Australia in its current form is not adequately meeting the needs of people living with mental health challenges, including personality disorder[45] and new ways of delivering mental health services are required.

45 Hartup, M., Vincent, B., Carrotte, E., & Blanchard, M. (2019). A Model of Care for Personality Disorder in Primary Health Networks (PHNs). Retrieved from SANE Australia: https://www.sane.org/images/adrc/SANE_PHN_PD_Study.pdf

The Productivity Commission's Draft Report[46], the National Mental Health Commission's Draft Vision 2030[47], the Sustainable Health Review[48] and the WA 10 Year Plan[49] all identify the need for comprehensive system re-design and reform of the mental health system to meet the needs of people living with personality disorders.

The Productivity Commission's Draft Report identified several priority systemic reforms, including:

- Prevention and early intervention for mental illness and suicide attempts.
- Addressing critical service gaps to ensure people have timely access to the services they require.
- Stronger role for and investment in services beyond health, such as housing and employment.
- Fundamental reforms to benefit clients and families to ensure seamless care pathways, care plans for people requiring care from multiple providers, care coordination for people with complex needs and online navigation systems.

The Sustainable Health Review (SHR) set directions for a more financially sustainable and patient centred health care system in WA.[50] The SHR found that the mental health system was funding centred rather than people centred, resulting in the needs of people being overlooked. In relation to mental health, the SHR calls for:

- Stronger partnerships between government and community organisations.
- A sharper focus on prevention, to reduce demand on the strained hospital system.
- Models of care in the community for groups of people with complex conditions.
- System wide approaches to identify and support people who are frequent users of health services, including extensive hospital-based services, to improve pathways of care and reduce presentations.

The WA Mental Health, Alcohol and Other Drug Services Plan 2015-2025[51] aims to re-balance and shift the mental health system from clinical services to a broader service spectrum that includes community based non-clinical services. The Plan outlines the need to balance the mental health system to reduce reliance on costly acute services.

The WA 10 Year Plan shows that community support is the service type least able to meet demand and states that the priority should be to boost investment in community-based support services. The Plan lays out a vision and strategies to re-balance the mental health system between hospital-based and community-based care so that more services are moved to the community, where appropriate. The Plan calls for a better balance in mental health services, with a greater focus on prevention, early intervention and community and psycho-social support.

People with personality disorders are a priority population group

The WA State Priorities Mental Health, Alcohol and Other Drugs 2020-2024 identifies priorities for the WA Government to reform and improve the mental health, alcohol, and other drug sector over the next four years.[52] Six priorities identified are prevention; community support; community accommodation; treatment services; sector development and system supports and processes.

People with personality disorders are identified as a population requiring specific consideration. The State Priorities identify the need for the mental health sector to deliver contemporary models of person centred care in partnership

46 Productivity Commission, (2019), Mental Health Draft Report, Volumes 1 & 2, Australian Government, Canberra, 2019.

47 National Mental Health Commission, (2020), Draft Vision 2030: Blueprint for Mental Health and Suicide Prevention, NMHC, Australian Government.

48 Sustainable Health Review, (2019), Sustainable Health Review: Final Report to the Western Australian Government. Department of Health, Perth, Western Australia, pp. 82. https://ww2.health.wa.gov.au/Improving-WA-Health/Sustainable-health-review/Final-report.

49 Mental Health Commission, (2019), Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015-2025 (Plan) Update 2018, Mental Health Commission, Government of Western Australia. Perth, 2019.

50 Sustainable Health Review, (2019), Sustainable Health Review: Final Report to the Western Australian Government. Department of Health, Perth, Western Australia, pp. 82. https://ww2.health.wa.gov.au/Improving-WA-Health/Sustainable-health-review/Final-report.

51 Mental Health Commission, (2019), Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015-2025 (Plan) Update 2018, Mental Health Commission, Government of Western Australia. Perth, 2019.

52 Mental Health Commission, (2020), WA State Priorities Mental Health, Alcohol and Other Drugs, Government of Western Australia, Perth, 2020.

with service users, families and carers, to ensure that various demographic groups are catered for and that adequate services are provided to people across all WA regions.

Embed recovery-oriented principles, practice and approaches in mental health policy, services and practice

Recovery approaches focus on gaining and retaining hope, understanding one's abilities and limitations, engaging in an active life that has value and meaning, a sense of personal autonomy and positive sense of self. Recovery occurs within a broader social context of individual, family and community relationships and is affected by the social determinants of mental health, including housing, gender, culture, privilege, developmental stage, income etc.[53]

Recovery oriented principles and practices are particularly applicable to personality disorder, highlighting the importance of care, support and treatment for personality disorder following recovery principles and practices.[54]

The Fifth National Mental Health and Suicide Prevention Plan, the National Mental Health Commission's Vision 2030[55], Charter 2020: Principles for Mental Health Reform[56], the National Framework for Recovery oriented mental health services and the WA Better Choices. Better Lives. Western Australian Mental Health (The 10 Year Plan) all endorse the recovery model for mental health services.

Features of the recovery model include holistic and person-centred service, responsiveness to those from diverse and marginalised backgrounds, responsiveness to carers, families and other support persons, promoting autonomy, focusing on strengths and personal responsibility, collaborative relationships, acknowledging and valuing lived experience, supporting social inclusion and challenging stigma.

Australia's National Standards for Mental Health Services, which apply to all Australian Government and State and Territory funded mental health services, require that services embed recovery principles and practice in service planning, culture, treatment support and service delivery.[57]

The recent Review of the Clinical Governance of Mental Health Services in WA describes variable implementation of recovery-oriented principles and practices in public mental health services in WA. [58]

Address the root causes of mental health issues

Charter 2020: Principles for Mental Health Reform[59] developed by Mental Health Australia and the community mental health sector across Australia calls for action to address the root causes of mental health issues, including eliminating stigma and discrimination and addressing the social and environmental determinants of poor mental health including housing instability, homelessness, unemployment and precarious employment, trauma, physical health, income support and environment. These root causes of poor mental health transcend the mental health and health sectors and require action by a range of non-mental health stakeholders.

53 Carrotte, E, Hartup, M, Blanchard, M, (2019), "It very hard for me to say anything positive": A qualitative investigation into borderline personality disorder treatment experiences in the Australian context, Australian Psychologist, 2019:54: 526-535.

54 Carrotte, E, Hartup, M, Blanchard, M, (2019), ibid.

55 National Mental Health Commission, (2020), Draft Vision 2030: Blueprint for Mental Health and Suicide Prevention, NMHC, Australian Government.

56 Mental Health Australia, (2019), Charter 2020: Principles for Mental Health Reform, 25 October 2019.

57 Department of Health, (2013), A National Framework for Recovery Oriented Mental Health Services, Australian Government, Canberra, Government of Australia, August 2013, Canberra.

58 Government of Western Australia, (2019), Review of the Clinical Governance of Public Mental Health Services in Western Australia, Final Report, October 2019.

59 Mental Health Australia, (2019), Charter 2020: Principles for Mental Health Reform, 25 October 2019.

Care, support and treatment to be provided in ways that respect the inherent dignity, clinical safety and human rights of people with mental health issues

The National Mental Health Commission[60] and the Fifth National Mental Health and Suicide Prevention Plan[61] aim to achieve a mental health system that ensures people living with mental health issues have their dignity respected and receive safe, quality, comprehensive care, support and treatment that is coordinated and relevant to their circumstances and needs, and enables them full and effective participation in society.

The report of the United Nations Special Rapporteur on the right to physical and mental health, *The Right of everyone to the enjoyment of the highest attainable standard of physical and mental health*[62], calls for greater investment in rights based mental health supports that address the psychosocial determinants of mental health and strengthen practices in the mental health sector that are peer-led, trauma-informed, community-led, healing, culturally secure, non-coercive and non-violent.

"On one occasion we found our loved one in bed, unconscious and not responding we called an ambulance. When the ambulance guys arrived and examined our loved one, they were judgemental and negative. As they were taking our loved one to the ambulance, they were making negative comments. We were in a very distressed state and needed reassurance not negativity. Our loved one was in intensive care in an induced coma. After a couple of days, we asked where the our loved one's nightwear was. At that point we were told the ambos had to revive our loved one 3 times on the way to emergency which caused them to cut the nightwear off to carry out resuscitation. Nobody provided that information to us until I asked about the nightwear."

Develop community-based mental health care approaches

The Charter 2020: Principles for Mental Health Reform and the *National Mental Health Commission's Vision 2030*[63] emphasises the need to create community-based approaches to mental health care to ensure people have access to care and support in their community in the least restrictive environment possible. A community-based approach places the person at the centre of the process and enables safe recovery while supporting a person's connection to family, culture, work, social supports, education and the community. Vision 2030 places community-based approaches at the centre of the mental health system. It promotes a whole of system approach to community-based care and support that is comprehensive and closely linked to, and integrated with primary and hospital care, and that comprises a continuum of care and support including early intervention and prevention.

The 2019 WA Mental Health Inpatient Snapshot survey[64] also identified an urgent need for additional community based mental health support and accommodation services. The Survey found that one hundred and seventy-eight (178) mental health consumers (or 27.1%) in inpatient units could be discharged if suitable community based accommodation and mental health support services were available. The survey identified that additional community-based accommodation and mental health support services in the community are urgently needed.

60 National Mental Health Commission, (2019), op.cit.

61 Australian Government, (2017), op.cit.

62 United Nations General Assembly, (2020), Right of everyone to the enjoyment of the highest attainable standard of physical and mental health. The Report of the Special Rapporteur on the right to physical and mental health, April 2020.

63 National Mental Health Commission, (2020), Draft Vision 2030: Blueprint for Mental Health and Suicide Prevention, NMHC, Australian Government.

64 Mental Health Commission, (2019), Mental Health Inpatient Snapshot Survey 2019 Western Australia Summary Report, Government of Western Australia

Improve access to evidence-based care and treatment and multidisciplinary services that place people with mental health issues at the centre of care

Evidence based care and treatment is an important support for people living with personality disorder. However, the recent report of the Office of the Chief Psychiatrist found the current approach to the provision of care, support and treatment in WA has become overly short term episodic and crisis driven and not suited to people who require ongoing coordinated support and treatment. The Report notes that much of the disability and distress experienced by people with severe enduring mental illness could be reduced if evidence-based care and treatment were more widely available and applied more systematically.[65]

Strengthen and invest in prevention and early intervention

Services and support that intervene early to prevent people from becoming mentally unwell and prevent emerging mental health issues from becoming more severe are vital.[66]

The adoption of prevention and early intervention programs and services across a variety of settings and targeting those most at risk is a key focus of mental health reform agendas, including the Productivity Commission's Draft Report, the Mental Health Statement of Rights and Responsibilities, the National Mental Health Commission's Vision 2030, the Better Choices. Better Lives. Western Australian Mental Health 10 Year Plan and the Fifth Mental Health Plan.

The WA State Priorities Mental Health, Alcohol and Other Drugs 2020-2024 identifies prevention as one of six priorities for the WA Government.[67]

Improve coordination, collaboration and integration of mental health services

Mental health services and supports are reported to be neither integrated nor co-ordinated for people living with serious mental illness and challenging behaviours in Western Australia and are complex and fragmented across Australia.[68]

A key focus of national and state mental health reform agendas is the development of stronger collaborative partnerships between public mental health agencies, non-government and private organisations and primary, specialist and multi-disciplinary professional service providers that place the client at the centre of all activities.

The WA State Priorities Mental Health, Alcohol and Other Drugs 2020-2024 indicates that system improvements required are[69]:

- Making access to services easier
- Achieving stronger collaboration between services to fill gaps in the continuum of care and enhance service access
- Developing models for navigating the mental health system that places the person at the centre and enable one point of entry for services
- Reducing red tape, streamlining documentation and working across systems and services to deliver better outcomes for clients.

65 Consultation Draft- Targeted Review: People with Severe Mental Illness and Challenging Behaviour. Chief Psychiatrist Western Australia (2019)

66 Mental Health Australia, (2019), Charter 2020: Principles for Mental Health Reform, 25 October 2019

67 Mental Health Commission, (2020), op.cit.

68 National Mental Health Commission, (2019), Monitoring Mental Health and Suicide Prevention Report, National Report 2019, NHMC, Sydney, 2019.

69 Mental Health Commission, (2020), op.cit

5.2. The current service landscape

The table below summarises key themes and issues about the current PD service landscape identified during the co-design and mapping process and the stakeholder engagement.

Theme	Issues identified
The experience of people living with personality disorders and their families and carers	• The current mental health system is not meeting the needs of people living with a personality disorder. • Many people living with personality disorder, as well as their families and carers and support persons, say there is a lack of specialist services and support, and those that exist are difficult to access and insufficient in scope. • Many services in their current form are not able to create the sorts of environments that are mentally healthy for people with personality disorder. The consequence of this is, understandably, anger, despair, and hopelessness. • In identifying what people living with personality disorder want from services and supports, it is understandable that they have high patterns of service utilisation, because their needs are not met. • Large-scale system reform and changes are needed, both informed by the evidence base, as well as integrated with the perspectives of service users and their carers and family members, and current understanding of how the various parts of the system are functioning.
Health Promotion and Prevention	• There is little PD prevention, promotion and early intervention in WA. • School programs and programs targeting children and young people do not adequately address emotional dysregulation and/or trauma informed responses.
Self-care	• There are a several online resources available, however these are not widely known or promoted.
Community Care and psychosocial support	• Non-government mental health services are attempting to develop specialist expertise to respond to people whose mental health issues labelled as personality disorders. • NGOs are providing community support to people with PD and report that they need better access to capacity building and skills development. • Rural and remote NGO mental health services have a pressing need to access high quality staff training on responding to and supporting people and developing skills to work with people with personality disorders. • Partly because of the pressure on public mental health services, and the limited access to specialist clinical services in rural and remote areas, many frontline non-government mental health services in rural and remote areas play a key role in responding to and supporting people whose mental health issues are often labelled as personality disorders.. • Psychosocial and community support provided by NGOs are critical in stabilizing people and must be recognized and incorporated into the model of care. • Non-mental health or ‘sideways services’ e.g. women’s health services, women’s centres, refuges, family services, day centres and housing services play a key role in identifying and supporting people. The model of care must recognise their role.

Theme	Issues identified
Primary Care	• While GPs can be a source of support and an entry point into seeking help, many lack knowledge and understanding and skills in assisting people living with personality disorders. • Primary care providers generally have limited understanding and under-developed skills in responding to and supporting highly distressed clients.
Community Treatment	• There is a lack of access to specialist evidence-based treatment and psychotherapy for personality disorder and it is described as a 'postcode lottery'. • Availability of evidence-based treatments and therapies are patchy. Some clinicians in the public system specialise in DBT and MBT, particularly in CAMHS, however the availability of DBT in the public system is limited and restricted. • Only a small number of practitioners have specialist skills in other approaches, such as Mentalization Based Therapy and Schema Focused therapy and these tend to be available in the private sector. • CAMHS (Child and Adolescent mental health) staff have trained in MBT and receive support and clinical supervision. Some services are heavily MBT based.
Specialised bed-based services (inpatient, alternative to inpatient)	• People living with personality disorder are often sent to EDs, where they are poorly managed (and symptoms often escalate), and often are discharged with a high level of unmet need. Other services use BPD/ EUPD diagnosis as exclusion criteria (even if not in overt ways). • Too dependent on individual clinicians, with the result that effective, successful and innovative models of service can change or be lost at the direction of new clinicians or managers.
Capacity Building, supervision, training & education	• One system challenge is that many clinicians lack the fundamental skills to diagnose personality disorder, unpack comorbidities and work directly with people living with personality disorder. • Even where providers have the skills and experience, there may not be recognition or understanding about the complex and emotional impact upon clinicians of working with personality disorders. In order to provide the type of environment and care that is suited to clients, clinicians require dedicated time for personal and group supervision which assists them to develop and maintain skills, remain empathic and hopeful and not burn out. This should be embedded in all services, and organisations must count this time as clinically relevant.
Service navigation & integration and the service system as a whole	• Services may purport to have a 'personality disorder pathway', but at times this may not be a true patient-centred therapeutic model of care – but rather a process designed to reduce time in, or prevent, inpatient care. • People with personality disorders often have to navigate services throughout their life at periods of symptoms exacerbation across child and adolescent, youth and older adult. For many people with personality disorders these transitions are particularly ineffective and not person-centred. • There are a range of public, not-for-profit and private sector programs and services available for people experiencing severe distress. However, these programs and services provide a fragmented, patchwork response that does not always deliver an effective and coordinated system of care. The result is that many individuals and families get lost in the system, fall out of the system and/or do not receive the care and support they need. • Large-scale changes are needed, both informed by the evidence base, as well as integrated with the perspectives of service users and their carers and family members, and their understanding of how the various parts of the system are functioning.

6. MODEL OF CARE

6.1. What is a Model of Care?

A Model of Care broadly defines the way services are organised and delivered. It outlines evidence-based, person-centred, best practice care and services for a person, condition, cohort group or population as they progress through the stages of a condition or event.[70]

For this project, the definition of a Model of Care is:

> *An overarching design for the provision of a particular type of health service that is shaped by a theoretical basis, evidence-based practice and defined standards.*[71]

6.2. Overview of the Model of Care

The vision for the Model of Care described in this Chapter represents **a whole of population, whole of system, whole of government and community approach to recovery- based, community- based care, support and treatment** for people living with personality disorders, their families and carers. The vision is consistent with the framework described by the National Mental Health Commission in its Vision 2030.[72]

The co-design process identified that system re-design is essential to meet the needs of people living with personality disorders and their families, carers and support persons.

The proposed Model of Care aims to:

- Expand and improve the capacity of the mental health system, mainstream health services and community service sectors to respond to the needs of people living with personality disorder, their families, and carers and support persons
- Strengthen the capacity of the system as a whole and mental health and other services to respond to people earlier in their experiences of their condition/distress/emotional dysregulation so they have better access to support and care when they need it and are less likely to experience acute crisis
- Expand in a staged way, specialist care, support and treatment options for people living with personality disorder, their families, and carers
- Develop and grow the capacity and skills of mainstream mental health services and the workforce, and service providers who work with, care for and support people living with personality disorder, their families and carers
- Expand the role and capacity of people living with personality disorder, and their families and carers to participate in and co-produce the planning, design, development, delivery, and evaluation of policies, care, support, services and treatment.

The Model of Care outlines the range of service responses identified during the project as needed by people living with personality disorders, as well as their families and carers and the wider community. The MOC focuses on the provision of mental health and other care, support and services across the continuum of services to deliver the right care and support in the right place at the right time by the right team of people.

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70 Based on WA Health Network, (2015), Model of Care: Overview and Guidelines Implementation of Models of Care and Frameworks-Progress Report, Department of Health, 2015.

71 NSW Agency for Clinical Innovation, (2013), Understanding the process to develop a Model of Care. An ACI Framework, Sydney, 2013.

72 National Mental Health Commission, (2020), Draft Vision 2030: Blueprint for Mental Health and Suicide Prevention, NMHC, Australian Government, pp. 18-20.

The Model of Care developed for this project comprises a detailed set of Principles and Practices (a systemic philosophy of care) and Elements.

6.3. Principles to Guide Prevention, Care, Service Development and Service Delivery for People with Personality Disorder

The guiding principles[68] were developed through the integration of feedback from the Co-Design process in combination with principles identified in the Literature Review undertaken for the project[73] and principles from specialist PD services in Australia (including Spectrum, Project Air, and BPD Co). It ensured that feedback captured from all 22 of the Narrative Cards developed in the Co-Design process was incorporated in the principles. This ensured wide reaching stakeholder input.

Previous work completed by the Mental Health Network (MHN), including the development of "Principles for Delivery and Development of Trans-regional Services"[74] were also reviewed and relevant principles incorporated. The principles were then reviewed by the PD Model of Care Project Reference Group. Feedback was incorporated and prioritised to form a succinct yet comprehensive set of Overarching Principles, as well as more specialised principles for domains of care.

The Table below describes the Overarching Principles that underpin a positive culture of care and more Specialised Principles of Care for specific domains.

Overarching Principles that underpin Positive Culture of Care
• Hope-filled; Individuals with Personality Disorder (PD) can and do recover and engage in meaningful lives and are worthy of kindness, support and quality care • Compassionate, flexible, empathetic, open, non-judgemental, consistent, reliable, validating, encouraging and seeking to understand the origins of behaviours. • Recovery focused; care is empowering, person-centred, tailored to the individual's strengths, goals and values and optimises self-determination and self-management of mental health and wellbeing. • Trauma informed care and services; recognises the prevalence of trauma history in people with PD and its impact on the emotional, psychological, and social wellbeing of people and communities. Avoids unnecessary retelling of trauma, especially to untrained staff. • Least restrictive; care should reinforce positive behaviours, rather than punish negative behaviours. • Culturally safe; staff are trained and competent to provide care which is respectful of Aboriginal and other cultures and communities. • Staged Care; personalised and based on multidimensional assessment with access to early intervention which is least intrusive and intensive and dependent on readiness to engage • Collaborative; Care is provided in partnership with consumers and their supporters (with consent), and integrated with others clinicians, peer-workers, care providers and services as required and appropriate, especially as co-occurring needs are common. • Safe transfer of care; includes liaison, shared planning, co-ordination and empowering consumers to participate in handover/transition planning. Sensitivity and awareness that fears of rejection and abandonment may be triggered at handover of care.

73 Smith, P & Kaleveld, L, (2019), Personality Disorder A Literature Review, prepared on behalf of the Western Australian Association for Mental Health for the Personality Disorder Project Reference Group.

74 Mental Health Network, (2017), principles for Delivery and Development of Trans-regional services, December 2017, Perth, Western Australia.

Overarching Principles that underpin Positive Culture of Care
• Responsive to Crisis: Timely access to a range of appropriate options, for support and assessment of people in crisis by trained care providers, informed by risk assessment and collaboration with consumer and their support persons. • Community-based responses are prioritised and alternatives to ED and inpatient admission are considered. A focus on reduction over time of inpatient admissions is considered. • Competent; Care providers engage in regular supervision and training ensuring they are competent to provide best-practice, culturally safe and evidence-based care. A trans-diagnostic approach is utilised during early stages of engagement and early intervention, focusing on practical support, validation and provision of safety. Formal diagnosis is made by trained clinicians and guides care and treatment in specialised services. • Training and Supervision; Should ensure staff are provided relevant training, supervision and support including in trauma, crisis intervention, de-escalation and coregulation competence. • Continuous Improvement; Emphasis on dissemination of expertise and capacity building. Open feedback is encouraged from all members at all levels of the system and must include those with lived experience. A no-fail, no-blame approach is taken to ensure continuous improvement of the system. Adverse outcomes should inform system change and not blame the consumer.

The overarching principles detailed above apply to all care providers that interact with individuals with PD. Listed below are principles that are domain specific which were developed using the same process as for the overarching principles. The following principles are intended to supplement the overarching principles and are more applicable to specific circumstances, cohorts, and settings.

Domain	PRINCIPLES
Personalised Care-Specific Populations and Stage of Life	• Cultural background, stage of life and phase of care must be considered when providing support, assessing needs, and considering diagnosis and formulation. • The care of Aboriginal people is informed by respect for Aboriginal culture, understanding of history of trauma and engagement with Elders and Aboriginal workforce. Services should be delivered in an environment that is welcoming and culturally safe for Aboriginal people. Care must be in partnership with consumers and their community as well as other care providers, and wrap around the individual and their community to address multiple issues. • The particular needs of individuals from Multicultural and diverse communities must be considered and appropriate advice and expertise should be engaged. • The particular needs of new mothers and their babies, youth and elderly must be considered and appropriate advice and expertise should be engaged.
Prevention & Self-Care	• Promotion of self-care, for people with PD or at risk of PD, occurs via general media campaigns, as well as throughout the education system, community services and health systems. • Providers of Care to pregnant women and young families should be skilled in identifying babies and children at risk and supporting their families. They should be aware of pathways to access more specialised care where needed. • The Education system should prioritise staff training regarding emotional development of children and teenagers, identification and support for those at risk; and information regarding pathways to access more specialised care where needed.

Domain	PRINCIPLES
Community Support	• Should adhere to overarching principles. • Should ensure training and support for staff regarding early identification of those at risk of PD and be aware of pathways to access more specialised care where needed. • Should ensure staff are provided relevant training, supervision and support including in trauma, crisis intervention, de-escalation and coregulation competence. • Staff working with people with PD or at risk of PD should follow a trans-diagnostic approach with access to specialist assessment and advice as necessary. Collaborate with other care providers when needed, provide active care-coordination responsive to co-occurring needs. • Should provide psycho-social support, within scope of practice, expertise, that is strengths based and empowering of the individual and their family/carer/supporters. Should maximise the consistency of caring relationship and support especially during transitions between service providers. There should be clear guidelines for consumers and their supporters regarding scope and limits of support available. • Will develop formal arrangements with other care providers where necessary to ensure collaborative care and seamless pathways to other care and support where needed. • Should be commissioned by government with sustainable funding, which can sustain collaborative care, workforce development and sustained access to care for consumers.
Whole of Government response, community response	• Support for a whole of government approach that supports those with PD or at risk of PD. This should include Mental Health, Health, Drug and Alcohol Services, Housing, Employment, Police, Child Protection, Courts, Local Councils, and Education. • Employers are provided with training to enable them to provide support to individuals with personality disorders within their workplaces.
Primary Care	• Primary Health Care providers are the usual first point of contact when there are significant concerns for people with PD or at risk of PD. • Engagement and support for the individual and family/supporters is critical. • They should be appropriately trained and supported by specialised mental health services, where necessary. • The care and treatment approach for those without specialist mental health training should utilise a trans-diagnostic approach, that focuses on care needs, problem solving, support, building relationship, empowerment and referral to more specialised services where appropriate. • They should collaborate with other key specialist and non-specialist mental health care providers from across the sector where necessary.

Domain	PRINCIPLES
Mental Health and Drug and Alcohol Clinicians	• Clinicians should be trained and supported to work with people with PD or at risk of developing PD. • Clinicians should work collaboratively with consumers regarding treatment choices and be compassionate, empathetic, open, non-judgmental, consistent, clear, reliable, predictable, validating, encouraging and offer choice, foster trust, and convey hope. • Clinicians should work collaboratively with family and supporters with the consent of the consumer. • Clinicians should develop skills and capacity to respond positively to the spectrum of interpersonal challenges that can present in the therapeutic relationship (such as hypersensitivity, ambivalence, verbal aggression). • Clinicians must work within an evidence- based framework, with clear and ethical boundaries of responsibility and care, that reflect training, expertise, supervision, reflective practice and risk management • Clinicians working with people with PD require dedicated time for reflection and supervision and support to avoid and manage vicarious trauma • Clinicians should work collaboratively with other service providers and ensure “warm” handovers and clarity of roles and responsibilities.
Assessment	• A trauma-informed approach to assessment should be utilised for young people and those who are first presenting to primary care and non-specialised mental health services. This should be collaborative, practical, solution-focused and not reliant on formal diagnosis. • Referral for formal assessment by mental health specialists with expertise in assessment of PD should be reserved for those where a trans-diagnostic approach to assessment and treatment has not been successful. • Treatment, care and support should be guided by formulation rather than diagnosis alone. Formal diagnosis of PD should be made with caution, by those with training and expertise as misdiagnosis can be unhelpful, discriminatory and result in inappropriate treatment. Early diagnosis should also be avoided as can be used to discriminate and exclude people from care, or channel individuals into inappropriately intensive care. • Consumers should be able to ask for removal of their diagnosis when they no longer meet diagnostic criteria.
Treatment and Response to Risk and Crisis, including Emergency Departments	• Crisis and risk are responded to with a trauma-informed and evidence-based perspective. Clinicians adopt an open stance, are clear about the current problem, communicate empathically with the consumer, and develop a collaborative management and safety plan, which balances short and long term risk. • Consumers have access to a range of evidence-based pathways to manage crisis including, brief admissions, drop-in centres, crisis cafes, phone support, mobile outreach mental health teams, mental health observation units, and emergency departments.

Domain	PRINCIPLES
Hospital Settings	• Hospital admissions should be recovery-oriented and informed by a collaborative approach with consumers and their supporters. • Hospital admissions, for people whose presentation is consistent with diagnosis of PD, should be delivered in the context of an integrated model of service which includes skilled assessment and patient controlled, brief, voluntary admissions, supported by timely hospital outreach. In many cases, it is preferable to engage a person in community-based care rather than admitting to hospital.
Medication	• Pharmacotherapy is not recommended as a primary treatment for PD and should generally only be used to target specific symptoms or comorbid conditions.
Working with families and carers	• Families and supporters should have access to services which validate their stress, avoid blame, provide psycho-education and information about crisis interventions and services, as well as build skills in de-escalation, co-regulation and self- care. • With consent from the individual, clinicians should offer to meet with supporters and provide education about the person's diagnosis, prognosis and treatment. • Family and systems therapy should always be considered, especially for children and young people.
Ongoing community treatment	• People with persistent symptoms consistent with a diagnosis of PD should have access to a consistent clinician in the community. This clinician is the individual with the primary psychotherapeutic relationship and they should have appropriate training, psychotherapeutic expertise and support. This primary clinician should provide guidance to the other clinicians and service providers providing crisis interventions, additional treatment care and support. • All treatments offered are evidence-based and connected by a unifying philosophy and principles of care. • An additional and appropriately trained care coordinator may be required to ensure coordination of care and access to care providers. • Peer workforce is valued. There is commitment to training and inclusion of peer workers in all mental health service teams.

"I have borderline personality disorder. I recently tried to end my life as I cannot access treatment and also cannot live like this anymore. I have had to move into a share house after leaving hospital four days ago. I am now out of the catchment area and go off the list for DBT again. I cannot recover without suitable treatment and it simply is not available unless you are 'stable' and have community support. Basically, this means that I am in a state of despair and only just surviving."

- Co-Design Participant with Lived Experience as a Consumer

Domain	PRINCIPLES
Planning, Implementation and Management, of all Specialist Clinical Services for People with PD	• All services involved with individuals with a PD must show evidence of the above Principles. • An integrated and sustainable system is planned and implemented that supports and treats those with PD and those at risk. • At least one service with sufficient resources and multidisciplinary expertise, including lived experience, is commissioned to provide leadership for the sector. This should primarily focus on capacity building for the health, mental health and community services sector with respect to care and support for those with PD or at risk. This should include consultation, liaison, training, second opinions, development of clinical guidelines and standards, advice on system navigation, and service development. This service considers feedback from consumers, carers and clinicians regarding services and leadership. • A state-wide plan should be developed for managing mental health crises, which includes those with PD. This should include a comprehensive set of services that are integrated and appropriately resourced. • Health Service Providers collaborate and develop integrated governance structures to ensure equity of access, quality assurance and comprehensive coverage of the state's population for those diagnosed with PD or at serious risk of PD. • Health Service Providers should have training, supervision, policy and protocols in place which are trauma-informed, recovery focused and evidence based, to assist staff and clinicians to sustainably respond to those with PD or at risk. • Health Service Providers have planned pathways to care and are appropriately resourced to respond to crises for those with PD. • All care providers have a demonstrated commitment to actively ensuring safe, supported and effective transition between providers/ streams, including child to adult, youth to adult services, WACHS to metropolitan, Health Services provider to NGO and/or GP.

"There is service angst in regards to treating individuals with personalty disorders"

- Mental Health Clinician

6.4. Elements of the Model of Care

The table below describes the elements of the Model of Care in the form of a staged pathway for escalating, care, support and treatment depending on a person's needs, levels of distress and level of vulnerability.

The seven elements of the Model of Care are:

- Prevention, Early Intervention and Self care
- Community Support
- Primary Care
- Community Treatment
- Specialist bed based-services
- Capacity Building
- Service Navigation and Integration

The table describes the seven elements of the model of care based on locations or sites for intervention, ranging from whole population needs for promotion and prevention, through to treatment and specialised inpatient services for those with more severe, persistent, and chronic conditions.

The elements are not mutually exclusive. In practical terms, a person living with personality disorder may require and/or benefit from care, support and treatment from multiple elements (locations) at the same time and/or may access that from different elements depending on the level of severity and distress they experience at a different times.

The model has been designed to build on existing service systems and achieve greater equity of access, more appropriate care and more consistent access and service quality across the many variable and different models and systems of care, support and treatment that exist across the state.

"My hope for the future. People with PD and their family/significant others would have access to a centralised point of triage to help them find an empathic, evidence-based service that meets their needs at the time- whether that be brief psychosocial support, longer term therapy or whatever suits them best."

- Mental Health Clinician

Elements (the What)	Means (the How)
Prevention, Early intervention and Self Care • PD informed, culturally responsive, community education, awareness, acceptance, and promotion (in schools, workplaces, communities) • Developmentally appropriate PD informed education curricula, policies & procedures, trauma awareness/competence training & early intervention (parental, perinatal & infant, children & adolescent, youth, adult, older adult) • Consumer PD education, support, and self-care (online, peer, individual, group) • Family PD education, support, and self-care (online, peer, individual, group in generalist and specialist settings) • Early intervention programs for at risk groups (e.g. HYPE Lit Review)	• By health promotion provider (PD-specific expertise engaged) • By health, education, and social care providers (PD-specific expertise core or engaged) • By self-care providers (PD-specific expertise core or engaged) • By self-care providers (PD-specific expertise core or engaged)
Community Support • PD informed co-designed philosophy, model, and principles of care • Trauma, crisis intervention, de-escalation and coregulation competence • PD competent psychosocial intervention and support • PD peer education, support & advocacy programs • Co-occurring AOD responsiveness and competence • Family PD education, advocacy, and support (e.g. Family Connections). • Care co-ordination with continuity of support • Culturally safe and competent PD intervention and support (e.g. aboriginal elder led, transculturally designed • Prioritised and integrated with treatment responses.	• By education and training provider with community support and content expertise, along with structured organisational support • By training provider with community support and PD peer and co-occurring expertise (core or engaged) along with structured organisational support • By family education advocacy and support provider. MHC to commission. • Through the provision of mental health supported accommodation and mental health psychosocial supports, including housing support, mental health literacy, family and individual psychoeducation, supportive counselling, employment support, education & training and family interventions. • Through access to alcohol and other drug support, access to health services, access to affordable housing, physical health programs, disability support, self-help, problem solving, life skills, family and domestic violence, sexual abuse and assault counselling, legal and justice support financial counselling and support, cultural and artistic supports, creative activities, physical activity and recreation. • To be developed further via Aboriginal and multi-cultural mental health co design consultation processes.

Elements (the What)	Means (the How)
Primary Care • PD informed co-designed philosophy and principles of care • Trauma, crisis intervention, de-escalation and coregulation competence • PD responsive primary medical care (physical health, co-morbid conditions) • PD specific primary care assessment, collaboration, consultation, and referral • Primary PD specific treatment (GP, psychologist, and other allied health) • Culturally safe and competent primary PD care	• Designed by PD MOC Project, WAPHA to be consulted, CMC to approve • By educational institutions and training providers with Primary Care and content expertise (core or engaged) • By a training provider with Primary Care and PD expertise (core or engaged), WAPHA to mandate • By a training provider with Primary Care and PD expertise (core or engaged), &/or by consultation/liaison • By a Primary Care training provider with PD expertise (core or engaged), or a PD training provider • To be developed further via aboriginal & multi-cultural mental health co design consultation processes
Community Treatment • PD informed co-designed philosophy and principles of care • Dimensional diagnostic assessment • Comprehensive empirically sound, PD specific (e.g. DBT, TFP, MBT, GLOW) and non-PD specific (e.g. systemic, family), individual and group treatment, support and follow up • Co-occurring AOD responsiveness and competence • Integrated, personalised, structured care co-ordination with continuity of access • Intensive, warm, transition, transfer, and referral support • Family PD education, skills development (e.g. CRISPS, TES), and support • PD peer programs • Culturally safe and competent PD treatment and support (e.g. Aboriginal elder led, transculturally designed)	• By training provider with PD & co-occurring expertise (core or engaged), &/or by consultation/liaison • To be developed further via aboriginal & multi-cultural mental health co design consultation processes

Elements (the What)	Means (the How)
Specialised bed-based services (inpatient, alternative to inpatient) • PD informed co-designed philosophy and principles of care • Empirically sound goal oriented short-term inpatient treatment (Enhance, MADE4life) • PD competent crisis assessment, triage, and referral • Non-restrictive de-escalation and behavioural support • Intensive, warm transition, transfer, and referral support • Culturally safe and competent PD treatment and support	
Capacity Building • Unified, system wide model, philosophy, and principles of service, support, treatment and care • Leadership driven multi-level PD informed service awareness raising & cultural change • A comprehensive PD competency framework • PD specific professional development and education; specialist services (tiered, specific population responsive, online and in person) • PD specific professional development and education; generalist (health, education, other) services • PD specific professional development and education; psycho-social support services • PD specific professional development and education; peer workers • Cultural awareness and safety design, training, and capacity building • PD specialised consultation & liaison • PD peer workforce development – job roles, core competencies • Reflective practice supervision & consultation • Fidelity and quality assurance • Comprehensive system wide data gathering and reporting (Precedents in other Models of Care) • Evaluation and Research	• By professional development and education provider with community treatment and PD expertise • By professional development and education provider with generalist and PD expertise • By professional development and education provider with psycho-social and PD expertise • By professional development and education provider with peer and PD expertise • To be developed further via aboriginal & multi-cultural mental health co design consultation processes • By PD specialists • By a workforce specialist with peer and PD expertise • By PD informed supervisors and PD specialist consultants • By external quality assurance provider with PD expertise (core or engaged)

Elements (the What)	Means (the How)
Service navigation & integration • Integrated, shared service plans (Precedents in other Models of Care). • Integrated treatment and support for co-occurring conditions (e.g. AOD, physical health, dual disability, WACHS Forensics consults). • PD specific clinical care /service pathways (Precedents in other Models of Care). • Navigation and connection specialist roles (including peer models)	• By system pathways mapping • By provision of key information to support referrals and navigation of the service system

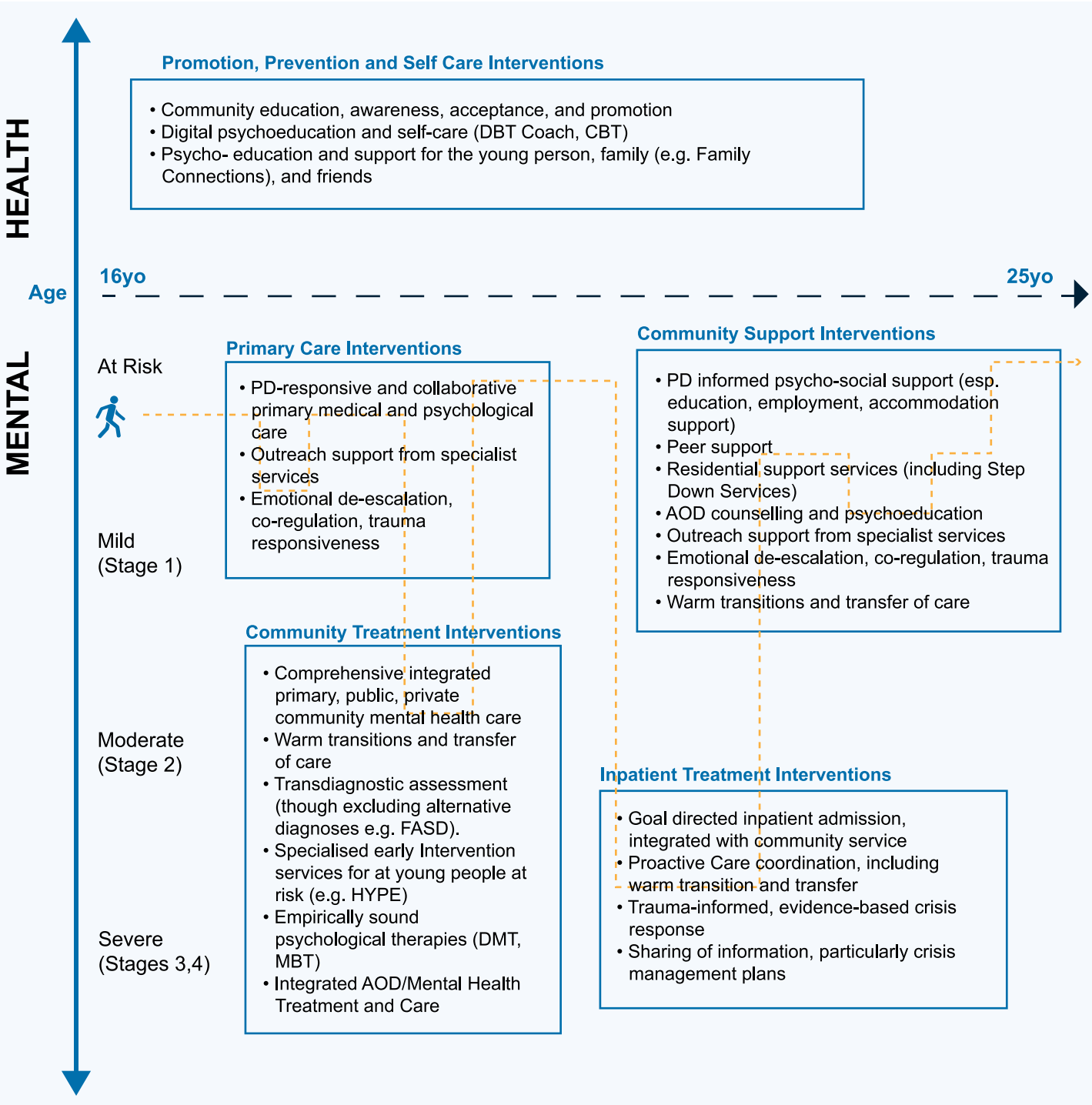
"When it comes to seeking treatment, the feeling of being a square peg not fitting into a round hole- not being the right shape. Not qualifying for treatment; needing to modify oneself in order to 'fit into the hole. Not always possible to do that."
- Lived Experience Consumer and Co-Design participant

6.5. Overview of the Model of Care: A Staged Pathway

Figure 3 provides an example of how the model of care could be applied to the youth cohort, and includes the hypothetical pathway of a young person who is at risk at 16 year old and who experiences periods of remission and recovery and staged interventions over time. It is an adaptation from Rohleder in Hickie et al (2019,p.S33). As a staged care model, it seeks to move beyond using a "fail-first" approach, where the initial level of care is of low intensity and is only increased if the individual does not respond, to ensure that interventions are offered in a timely way and that people receive the "right care, first time". A staged approach requires collaborative, personalised, multi-dimensional assessment and integrated, timely interventions targeting individualised personal and social outcomes.

The staged model is a useful framework for the development of a statewide treatment and support pathway which would serve as a navigational resource for primary and community care, community and inpatient treatment, care coordination and transition for people with personality disorder across the life course and inclusive of specific populations.

Staged Trajectory Pathway Personality Disorders - Youth



6.6. Priorities for improvement: Opportunities to enhance existing services and gaps requiring the establishment of new services

This section sets out a range of potential opportunities to achieve system reform, enhance existing services and establish new initiatives, programs or services. Suggested actions are in line with the system re-balancing reform directions earlier outlined in the State Mental Health Priorities document and the Sustainable Health Review. Opportunities and Actions are described under two headings: Care Pathway and Capacity Building.

Care Pathway

Opportunity 1: Develop and deliver PD-specific health promotion and prevention and early intervention programs.

Stigma and discrimination and negative attitudes from health workers and the general community remain significant factors impacting the experiences of people with PD, their families, carers and friends. There is limited understanding about personality disorders in the general community and little positive representation of people living with these conditions. There is a need to improve awareness and understanding of PD within the community. Any such initiatives should involve individuals with PD, their families and carers. A particular target group should be first line services and workplaces (mainstream health workers, teachers etc) as highlighted during stakeholder engagement, including awareness raising, attitudinal change and specific populations.

Other strategies could include:

- Multifaceted and targeted strategies to address stigma and discrimination incorporated into campaigns such as Think Mental Health.
- Improve awareness of PD within the general community groups.
- Raise awareness and capacity among key groups such as teachers and others working in schools, childcare providers, social welfare providers and assist these workers to identify at risk children and families or children/families of concern and develop referral pathways and appropriate support.
- Promoting care options and pathways.

Schools can play a role in equipping and supporting young people to seek and access support for emotional dysregulation. Schools play an important role in equipping and linking children with the skills to help regulate emotions, particularly among children and young people considered to be 'at risk', and raise awareness that there are a range of strategies, such as mindfulness, that can contribute to supporting young people with emotional dysregulation challenges.

Some early intervention programs have demonstrated their efficacy, particularly for young people. Work is needed to develop, implement, and/or scale up existing early intervention programs such as HYPE, adolescent and teen DBT and expand these to more settings, including rural and regional areas and specific cohorts.

" My hope for the future. Early intervention and education to assist those with personality disorders, their families and the wider community as a whole."
- Mental Health Clinician

Opportunity 2: Grow the capability of people with lived experience of PD, both consumers, carers and families through self-care, psychoeducation, peer support, leadership and advocacy.

People with lived experience of personality disorders, and their families and carers hold unique insights into how the mental health system and services can respond better to the needs of people with personality disorder. They have understanding and expertise based on their personal experience or experience of supporting a person(s) with mental health issues.

Strategies worth pursuing include, increasing the active participation of people with lived experience in treatment, care and policy making; increasing the participation, influence and leadership of people with a lived experience of personality disorders; growth and expansion of peer work and lived experience roles; expansion of peer support and development of peer controlled and peer led organisations.[75]

Treatment guidelines for PD acknowledge that families, partners and carers play an important role and need to be actively included in all stages of the individual's care, treatment and recovery, and provided access to supports and other services. Working with families and carers of people with personality disorder is a neglected but much needed priority.

In broad terms, peer support is support provided between one or more people who have similar or shared experiences, and who recognise each other as peers. In a mental health context, peer support can be understood as the help and support that people with lived experience of mental health issues can give to one another. Peer support can be provided through a professional or lived experience work role, or informally through friendships and support groups.

There is a strong evidence base for the effectiveness of peer support and lived experience programs for people experiencing mental distress.[76] Peer support has demonstrated unique benefits in supporting engagement, promoting hope, activating self-management, combating stigma and facilitating wellbeing. Indeed, peer support has a better evidence base than many other interventions. [77]

Peer support programs for people with personality disorder and their family members and carers have been developed by Project Air and Spectrum in other states, and several support groups are available for people with borderline personality disorder in WA.

Lack of specialist support for families and carers is a problem, particularly in rural areas. More needs to be done to support families and ensure family and carer involvement is adequate, with greater provision of psychoeducation support, carer and family support that is sufficient in scope and accessible to those who need it. Group and individual psychoeducation are needed to support and equip families and carers to respond in ways that are supportive of the person with PD, as well as their own wellbeing and enhance their capacity to maintain the relationship.

Specific actions include:

- Re-orient the way care, support, services and treatment are provided to emphasise the active inclusion of consumers, carers, family members and support persons.
- Achieve a sustained commitment to a sector wide approach to develop a peer and carer workforce to provide care support and services to people living with personality disorders.
- Develop peer workforce pathways for people with living with personality disorder. Programs such as the ASPIRE project, run as a partnership between CoMHWA, 360 Health and 360 Community Health and employers in the mental health and disability sectors could provide specific opportunities for people with personality disorders.
- Develop and support peer led and governed organisations and programs that could provide opportunities for people with personality disorder.
- Develop and secure funding for paid roles for people with lived experience of PD, including but not limited to peer worker or peer support roles in ED, inpatient care, community treatment programs, primary care roles, community mental health services, prevention and early intervention.
- Expand and increase peer support services and programs for people with personality disorders. Projects such as CoMHWA's Co Designing Futures Project and Peer4Wellbeing Project aim to develop and expand mental health support groups and these may provide opportunities to expand peer support programs for people with personality disorder.

75 Gray, F & O'Hagan, M, (2015), The effectiveness of services led or run by consumers in mental health; rapid review of evidence for recovery oriented outcomes. An evidence check rapid review by the Sax Institute for the Mental Health Commission of NSW, Sydney, August, 2015

76 Gray, F & O'Hagan, M, (2015) op cit.

77 O'Hagan, M, (2019) Witness statement to the Royal Commission into Victoria's Mental Health System.

- Embed human rights driven co-design and co-production into the development and delivery of services, care, support and treatment programs so that these initiatives draw on the PD collective knowledge and experience of service users, their family members, carers and support persons.

The proposed Centre for Personality Disorders (described in more detail in Opportunity 11) could play a key role in amplifying the lived experience voice, expanding the lived experience workforce, and fostering family and peer support programs for people living with and affected by personality disorders and their families and carers. The Centre could play a role in educating mental health workers and clinicians about the important role that family members and carers can play. This could involve partnerships with consumer, carer and family groups such as Consumers of Mental Health WA, Helping Minds and Mental Health Matters 2, as well as the Personality Disorders Sub-network and other consumer, family and carer groups.

Opportunity 3: Further build community support responses; especially care coordination, psycho-social support, family support and accommodation support and address social determinants.

The adverse personal, social and economic consequences of PD are severe. They can include persistent functional disability, high family and carer burden, incomplete education with fewer qualifications and disproportionately high unemployment, physical ill health, greater burden of mental disorders, recurrent self-harm, and an increased suicide rate.

One consequence is that people with personality disorders, as well as their families and carers, experience significant socio-economic disadvantage as a result. The combination of increased exposure to stressors, the costs associated with accessing appropriate support and treatment, the demands of caring which make it difficult to undertake paid work, the financial impact of living with or supporting someone with a personality disorder and reduced access to supports provide a context for understanding how socio-economic disadvantage is often the experience of people affected by personality disorders.

Community support responses and psychosocial support services provided by NGOs and community organisations play a significant role in prevention and early intervention in the course of the development of personality disorders, particularly for young people, and in recovery support. Rather than being subsidiary to treatment, these services should be accorded equal significance.[78]

These responses have the potential to moderate risk factors, improve developmental outcomes and avert significant disruption to 'normal' development caused by mental health challenges.[79]

Potential service responses and interventions include, substance use reduction, access to health services, housing support, mental health literacy, family and individual psychoeducation, physical health programs, supportive counselling, employment support, education & training, family interventions, disability support, self-help, problem solving, life skills, family and domestic violence, sexual abuse and assist counselling, legal and justice support financial counselling and support, cultural and artistic supports, creative activities, physical activity and recreation.

Increasing the availability of these services and developing the capacity of NGO providers of these services to work more effectively with people with personality disorders has the potential to deliver significant benefits.

Recovery oriented principles and practices are particularly applicable to personality disorder, highlighting the importance of access to care, support and treatment; a sense of personal autonomy, positive sense of self and hope and optimism; relational support; social support and family and carer support. However, the challenges around embedding recovery based responses into the mental health system severely disadvantages people living with and affected by personality disorders.

78 Ng, F, Townsend, ML, Jewell, M, Marceau, E & Grenyer, BFS, (2020), Priorities for service improvement in personality disorder in Australia: Perspectives of consumers. Carers and clinicians, Personality and Mental Health, DOI:10.1002/pmh.1485, 2020

79 Chanen, AM, Berk, M & Thompson, K, (2016), Integrating Early Intervention for Borderline personality Disorders and Modd Disorders, Harvard Review of Psychiatry, 24:5, September/October 2016: 330-341

Issues of housing, employment, income, education and training, relationships, financial wellbeing, recreational and creative activities, and other social supports make a major contribution to recovery, however these are often considered as secondary or subsidiary to mental health treatments. Relational support, involving friends, family, acquaintances, support persons and others who are close to the person living with personality disorders, is often the forgotten component of recovery.

Opportunity 4: Respond to the needs of specific populations; Aboriginal, CALD, LGBTIQ, Forensic, Rural and Remote.

This is discussed in more detail in Section 6.8.

Opportunity 5: Strengthen the role of primary health care for people with PD.

The demand for support and care for personality disorders falls heavily on the primary care sector, however many practitioners lack the knowledge, skills, capacity, and confidence to respond to the needs of people with mental health difficulties characterised as personality disorder. This problem is compounded by the lack of referral pathways.

There is often a lack of consistency in primary care services due to limited mental health clinical experience and limited understanding and capabilities to work with people whose mental health difficulties can be characterised as personality disorders.

The provision of role specific, enhanced education, training and consultation to upskill and increase the mental health confidence and capabilities of primary care practitioners can yield significant benefits. GPs and primary care practitioners require training and education opportunities to develop their skills in responding to PD, including:

- Developing understanding and empathy towards people with personality disorders
- Responding in ways that do not perpetuate stigma and discrimination
- Timely detection and referral pathways to specialist services
- Earlier recognition of mental health problems and suicide risks
- Identification of those at risk who may benefit from screening, treatment
- Knowledge and skills for the provision of personalised support for people living with personality disorders, their families and carers.

Additional roles that might benefit from such training and education include primary health staff, child health, maternal health and family services staff, Aboriginal health workers and community service providers.

GPs are the first point of contact for many people seeking help with personality disorders and they provide a variety of mental health services and often refer people to specialist mental health services. However, the Literature Review found that General Practitioners are often unaware of treatment options for people living with personality disorder and face a range of challenges in treating people living with personality disorder, particularly when there are comorbid issues and clinical complexity, when they were confronted with challenging behaviours, and in navigating the service and support system.

General Practitioners would benefit from developing the skills necessary to provide effective care for people living with personality disorder A feature of PD models in other states is the provision of training for GPs focusing on good clinical care and core competencies, guidance on negotiating pathways through the mental health system, and where requested, more specialised personality disorder therapy training. Such training for GPs should be developed in collaboration with the specialist providers of GP training and the public health system.

Opportunity 6: Improve access and increased availability of evidence-based community treatment.

A range of effective and evidence-based interventions exist and there is strong evidence for treatment and therapeutic interventions and psychosocial treatment models for mental health difficulties characterised as personality disorders[80].

80 Smith, P & Kaleveld, L, (2019) ibid.

Despite the increasing number of evidence-based treatments and clear evidence about the benefits of treatment[81] , people living with personality disorders have difficulty accessing evidence-based treatments and supports that have proven to result in remission and recovery for many people. In particular, people have difficulty accessing treatment early in the development of mental health issues, and early in any crisis or worsening of their mental health.

The Office of the Chief Psychiatrist of WA found that the current approach to the provision of mental health treatment, care and support has become overly short term, episodic and crisis driven and not suited to people who require ongoing coordinated support and treatment[82].

Treatment services for people with personality disorder are predominantly provided within the public mental health system and as part of universal healthcare, for example through the Better Access to Mental Health Services program, although the cost of those services can be prohibitive and are insufficient to meet needs.

Availability of specialist treatment services in the public mental system is patchy and insufficient to meet the needs of people with personality disorder. There are often wait lists and access is difficult and limited in many areas, particularly regional areas.

Some non-government mental health services currently provide evidence-based treatment services, such as DBT informed initiatives, and there may be an increased role for NGO's in providing treatment services.

Ensuring the active involvement of people with lived experience is important as it aligns with the recognition of a person-centred approach to mental health care. Maximising self-determination and self-management of mental health and wellbeing are vital to a recovery approach.

Specific actions could include:

- Develop a Personality Disorder Clinical Specialist initiative to enhance the capacity of public mental health services to service and address the treatment and support needs of people with personality disorders[83].
- Increase the availability of specialist evidence-based treatment programs (such as DBT, MBT, Schema Therapy).
- Put mechanism and processes in place to support mental health services and programs to adhere to evidence-based guidelines.
- Ensure that all public mental health services provide a consistent level of evidence-based treatment services commensurate with need across the metropolitan area and in regional areas. Access to these services would need to be transparent in terms of therapeutic interventions available, inclusion/exclusion criteria and wait list times.
- Ensure that treatment approaches incorporate recovery-oriented practice, therapy and psychosocial support in partnership with consumer and peer organisations.
- Develop brief interventions to enhance the capacity of mental health services in the public sector, NGOs and private sector providers to increase access to evidence-based treatment and care for a larger number of people with PD, particularly for people with mild to moderate severity.
- Coupled with this is the need to ensure that clinicians and service providers have access to initial and ongoing training and regular supervision, consistent with the provision of high quality, adherent treatment programs.
- Support the expansion of specialised treatment programs provided by NGOs, such as 360 Health and Lifeline and through the private sector.

81 Ng, F, Townsend, ML, Jewell, Marceau, EM & Grenyer, B, (2020), Priorities for service improvement in personality disorder in Australia: perspectives of consumers, carers and clinicians, Personality and Mental Health, 2020, DOI.1002/pmh.1485

82 Consultation Draft- Targeted Review: People with Severe Mental Illness and Challenging Behaviour. Chief Psychiatrist Western Australia (2019)

83 The Victorian Government recently announced a Personality Disorder Clinical Specialist Initiative that will enhance the capacity of six Victorian mental health services to meet the treatment and support needs of people with PD. Additional funding is being provided to ensure the entire mental health sector is better trained and supported to address the treatment needs of people with personality disorder.

The proposed Centre for Personality Disorder (see Opportunity 11) should play a role in providing education and training, supervision, and consultation to support the establishment, delivery, enhancement, and expansion of specialist treatment programs.

> *"For young people, services are virtually non-existent. they rarely get diagnosed, given their youth, so treatment isn't an option. Even in ongoing crisis and multiple ED presentations, they are told its behavioural, not mental health and turned away."*
> ***- School Psychologist***

Opportunity 7: Increase the availability of evidence based, recovery-oriented Inpatient services.

Inpatient facilities

Inpatient units play a critical role in helping people access accurate diagnostic assessments, de-escalate from a crisis situation and access unique and appropriate supports

Mental health inpatient service should have a comprehensive evidence based, recovery focused approach to responding to people presenting with personality disorders and emotional dysregulation. Features of such an approach include:

- Adopting the principles of the MOC
- Adopting evidence-based models such as ENHANCE (an RPH developed Clinical Pathway for the Acute Inpatient Care of Patients with Emotionally Unstable Personality Disorder) and Patient Controlled Crisis Admission Plans (Fiona Stanley Hospital)[84]
- Client/patient-controlled admissions
- Dedicated beds for people with personality disorders
- Multi-disciplinary team that has a consistent and continuous relationship with clients
- Availability of longer controlled admission if needed
- Availability of peer workers and lived experience workers and development of a career pathway for peer and lived experience workers
- Strategies to recognise, listen, support and involve carers, family members and support persons.
- Availability of evidence based therapeutic interventions and recovery-oriented options
- Strategies to reduce stigma and discrimination
- Clearly documented policy and procedures and clinical guidelines for responding to people with personality disorder
- Specific fit-for-purpose program to develop and regularly update the skills, understanding and capacity of the workforce to support people with PD
- Discharge planning, which includes family members carers and support people
- Inreach by community mental health services and connection to the outpatient team
- Supported outpatient transition and warm referral and handover which can involve Clinical Psychology, Occupational Therapy and/or Social Work clinicians from the inpatient unit providing short term transitional support
- Clear pathway of support, treatment and referral options.
- Specific staff role, such as a handover nurse or transition worker to aid the client's transition to GP, specialist providers, outpatient and community services

84 Some feedback provided by stakeholders suggest that developing an ENHANCE like inpatient model at some hospitals may need adaptation of the hospital funding model for it to be financially viable.

Step Up Step Down Services

Step-Up Step-Down Service providers report that people with personality disorders represent a substantial proportion of their clients. Step-up Step-Down Services play a significant role as alternatives to inpatient services for people with personality disorders and as step down services following inpatient discharge. Staff of Step-up Step-Down Services would benefit from ongoing PD specific training, development and consultation support.

Opportunity 8: Improve crisis and emergency responses to people with PD.

Emergency Departments

Recent estimates indicate that around 26% of people presenting to ED for mental health crisis have mental health challenges that can be characterised as personality disorders. [85]

People with personality disorder are often turned away when they seek help, including from Emergency Departments. Emergency Departments can also be a counterproductive environment for people with personality disorders and can exacerbate maladaptive behaviours. To complicate these risks, some front line clinicians, particularly in EDs, may see people living with personality disorder, including those who attempt suicide, as attention-seeking, manipulative and as just 'acting out'[86] .

To respond more effectively ED staff, front line practitioners and first responders, such as paramedics and police require:

- Upskilling to understand, identify and appropriately respond to people with personality disorder
- Access to education, training, supervision and consultation support to build understanding and empathy and to improve attitudes and behaviours towards people with personality disorder
- Clear pathways for support, treatment and referral options for people attending in serious distress
- Access to non-clinical alternatives to ED for people with personality disorders seeking support outside normal service operating hours.
- Advice, guidance and support from peer workers and lived experience workers.

"Each time our loved one was taken into emergency, in the public system, we were left waiting, given no information or included in discussions. Having to be triaged and wait in the full waiting room with a very distressed person who wants to run away is cruel for both carers and patient. When being discharged was no discharge plan and no advice on where to go after discharge."
- Family Carer

"We need an alternative to inpatient units"
- Mental Health Clinician

The work done by Consumers of Mental Health WA (CoMHWA) on Alternatives to Emergency Departments describes a number of possible models[87].

An important enhancement to existing services will be to establish more alternatives to ED including for example, the Safe Haven Cafe approach which operates effectively for people with PD in the UK and is being piloted in WA and the proposed One Stop Shop proposal currently in development by the WA Mental Health Commission.

85 Beatson, J, Broadbear, J, Sivakumaran, J, Moss, F, Kotter, E & Rao, S, (2016), Missed Diagnosis: The emerging crisis with BPD, Australian and New Zealand Journal of Psychiatry, December, 2016:50 (12):1139-1145.

86 NHMRC, (2013), Clinical practice guideline for management of borderline personality disorder, https:www.nhmrc.gov.au/about-us/publications/clinical-practice-guideline-borderline-personality: NHMRC, Centre for Research Excellence in Suicide Prevention, (2015), Care after a suicide attempt.

87 Consumers of Mental Health WA, (2019), Alternatives to Emergency Departments, Project Report, CoHMWA, Perth, 2019.

It will be important to monitor whether people with personality disorders access the Safe Haven Cafes currently operating at Royal Perth Hospital and Kununurra Hospital. These initiatives provide people with mental health issues a safe place after hours for those who may otherwise attend ED and are also designed to assist people learn about their own response to crisis and develop self-management skills. If these initiatives prove successful, they should be extended to include people with personality disorders and to community sites and locations outside of hospitals.

Another opportunity for enhancement is the provision of peer support work in EDs, including how peer support could be available to people who attend ED for emotional distress resulting from a mental health condition, including personality disorder. The recent report *Examining the role of mental peer support in emergency departments* provides an evidence base and strategies for the establishment of mental health peer support programs in ED[88].

Opportunity 9: Improve care coordination, transitions and service integration.

The delivery of integrated and coordinated care and care pathways has been a priority for the mental health system for many years, however people living with personality disorders experience substantial difficulties accessing the services they require, navigating waiting lists and telling their stories multiple times. Care for people with personality disorders is uncoordinated and there are no clearly articulated care pathways.

People with personality disorder require a well-articulated coordinated care pathway that ensures:

- Person centred care that accommodates their needs
- Access to service when they need them
- Access to a clear and seamless referral pathway
- Continuity of care based on information flow
- Single care plans for people requiring care and support from multiple providers
- Care coordination through a care co-ordinator who can work with the person, their family and carers and clinicians and service providers to establish the type of services needed and provide assistance in accessing and co-ordinating these
- Online navigation pathways for PD referral pathways that extend beyond the health sector
- The option of specialist support coordination.

"More collaborative work happening, getting that philosophy out there. And it's got that positive hope- you can and do recover."
- Lived Experience Consumer and Co-Design Participant

Capacity Building

Opportunity 10: Adopt and embed a universal system wide philosophy and principles of care of people with PD

The Principles described in 6.3 provide a systemic philosophy of care and best practice principles that underpin the whole of system approach to community-based care, support and treatment.

Opportunity 11: Establish a Centre for Personality Disorders.

The establishment of a Centre for Personality Disorders is seen as a priority to drive and support the systemic change required to implement the Model of Care and to improve the capacity of mainstream mental health services to respond more effectively to people with personality disorder, their families and carers. The WA Eating Disorders Outreach and Consultation Service (WAEDOCS) is a model that provides similar services.

88 Minshall, C, Roennfeldt, H, Hamilton, B, et.al, (2020), Examining the role of mental health peer support in emergency departments, Melbourne Social Equity Institute, University of Melbourne, 2020.

The primary role of the centre would be to support and build capacity across the mental health system and the sector to assist with the design and establishment of evidence based, recovery-oriented services for people with PD and provide training and education, modelling of best practice and development of practice frameworks and guidelines The Centre would advocate for the systemic change needed to implement the Model of Care.

Possible roles for the Centre could include:

- Act as central resource centre for PD and create awareness and disseminate information about PD
- Develop lived experience capacity and peer and lived experience support
- Provide education, training and development
- Provide consultancy advice, liaison and support
- Support service development across all settings
- Model and disseminate best practice, including development of a PD competency Framework and development of clinical and practice guidelines
- Support rural practitioners
- Establish partnerships
- Supporting research and data collection

The Centre would need to bridge the public mental health system, the community mental health non-government sector and the private sector and provide services to all sectors. As such, it should be established as a partnership between the public mental health system and the community mental health (NGO) sector, and the Mental Health Network and the Personality Disorders Sub-Network.

Opportunity 12: Develop the workforce.

The capability of the workforce is possibly the most critical element of the model of care. Building the capacity and capabilities of the workforce to work effectively with individuals with personality disorder should be a major priority.

Develop tiered PD competency framework and curriculum for personality disorders

Cross-disciplinary personality disorder competency frameworks and multi-disciplinary training curriculums are increaingly being developed[89]. Personality disorder specific competency frameworks have been developed in the UK and USA[90].

The UK Personality Disorder Knowledge and Understanding Framework aims to develop the capabilities, skills and knowledge of multi-agency workforces in mental health, health, social care and criminal justice, and features several tiers; raising awareness, developing understanding and effectiveness, train the trainer, gender specific training and expanding expertise and enhancing practice[91].

In Australia, the BPD Foundation is partnering with Project Spectrum to roll out a national multi-disciplinary training strategy and curriculum for mental health clinicians. The curriculum is guided by the NHMRC Guidelines and has distinct delivery strategies: webinars, E- learning tool, intensive 2-day workshops, including a Train the Trainer component and register of endorsed trainers, and post training mentoring and supervision.

The need to develop the capacity and skills of those who work with, support and provide care, support and treatment for people with personality disorders, and their families and carers emerged as a major issue during the co-design process, the literature review and stakeholder engagement.

89 A competency framework is a way of describing the skills, attributes and capabilities required by people who work with and support a cohort of people, such as people living with PD, their family, carers and support persons. An evidence- based tiered competency framework provides a blueprint for quality person centred recovery practice by different practitioners.

90 Roth, AD & Pilling, S, (date unknown), A competence framework for psychological interventions with people with personality disorder, Research Department of Clinical, Educational and Health Psychology, University of California.

91 Institute of Mental Health, (2020), Personality Disorder Knowledge and Understanding Framework https://www.institutemh.org.uk/education/knowledge-and-understanding-framework/143-overview

The development of a tiered[92], role specific PD competency framework, as well as a curriculum development/training and supervision plan for practitioners working with people with personality disorders, their family members and carers, including peer and lived experience workers, is a major priority requiring attention. The competency framework should be responsive to and co-designed with Aboriginal, CALD and LGBTIQ groups and stakeholders and relevant to those working with people across the life course. The framework would also focus on workers in regional, rural and remote areas.

This could include knowledge of PD and empirically sound competencies in de-escalation, co-regulation, cultural competence and trauma responsiveness and should enable the personal and professional development of participants to ensure they have the maturity and emotional depth and capacity to work with people experiencing emotional distress and dysregulation.

In developing the tiered competency framework for PD, it will be necessary to identify the level and types of competencies required to provide evidence based, recovery- focused support, care and treatment to people with personality disorders and identify the training and supervision requirements for each stage of development.

The critical aspect of a tiered competency framework is that operates as a tool to guide personal and professional development and improve relationships and practice, rather than a 'tick box' compliance and process driven tool. It should also give equivalence to emotional development and emotional depth, as well as intellectual skills, clinical capacities, and professional development.

The framework would specify tiered competencies for various roles, including peer and lived experience worker, GP, community mental health worker, clinicians, specialist treatment provider, first responder, ED staff, inpatient unit staff, forensic practitioners, primary care provider and community worker to name just a few.

The proposed Centre for Personality Disorder should play a lead role, in partnership with the Personality Disorders Sub-Network, and other partners, in developing the Personality Disorder Competency Framework. The Framework could provide the strategic direction for the development of a PD training curriculum and strategy for WA. It will be important to align the tiered competency framework with the work being done internationally and nationally by the BP Foundation, Project Air and Spectrum and the work being done to develop competency-based frameworks in related areas, such as the Competency Development Progression Pathway for MBT Clinicians.

Opportunity 13: Develop a research and evaluation and data gathering capacity

There are multiple opportunities to incorporate a strong research and evaluation component into the model of care and the proposed Centre for Personality Disorders and establish partnerships with academics and tertiary institutions. This should include but not be limited to clinical and treatment research, but also include research into social determinants, the needs and experiences of people living with personality disorders and various stakeholders, and the need for and effectiveness of a range of interventions.

People living with personality disorder, as well as their family members and carers need to be active participants in any research processes, not just as service users, but as active research participants and experts by experience.

92 The tiered nature of the framework refers to different levels and types of competencies required by those who deliver more complex tiered support and services.

6.7. Needs across the life course

A deliverable of the project is to identify needs across the life course for identified age ranges, shown in the Table below. Some examples of the type of services that can address these needs are included.

The information presented in the table below is drawn from many sources, including the literature review, the service mapping, stakeholder engagement and the personal and professional experience of members of the Project Reference Group and the Personality Disorders Sub-Network.

Life course stage	Element	Examples of some services
Perinatal and Infant	• Family support to at risk pregnant women and young families • Identification of infants at risk • Knowledge of pathways to specialised support	GPs Child Care Services Midwives Community Nurses Specialised Perinatal ad Postnatal Mental Health Care Providers (e.g. Mother Baby Units)
Child and Adolescent	• Developmentally appropriate PD informed education curricula, policies & procedures • Education staff trained in emotional development and trauma awareness/competence • Identification and support of students at risk • Knowledge of pathways to specialised support • Family psychoeducation and support • Family and systems therapy	School Psychologists Child and Adolescent Mental Health Services Primary care service providers E.g. Better Access Sessional Psychological Therapy, GPs Lifeline's DBTeen NGO services
Youth	• Community education, awareness, acceptance, and promotion (esp. education settings, workplaces) • Digital psycho-education and self-care (DBT Coach, CBT) • PD-responsive and collaborative primary medical and psychological care • PD informed psycho-social support (esp. education, employment, accommodation support) • Residential support services (including Step Down Services) • Peer support	GPs Headspace Better Access Sessional Psychological Therapy Community Managed Psychosocial Support Services Community Managed Family Support Services Youth Axis Youth Link Youth Reach South Public Youth Inpatient Service (EMYu; FSYu)

Life course stage	Element	Examples of some services
Youth	• Family psycho-education and support • Transdiagnostic assessment (tho excluding alternative diagnoses e.g. FASD) • Specialised Early Intervention services for at young people at risk (e.g. HYPE) • Empirically sound psychological therapies (DBT, MBT) • Integrated AOD/Mental Health Treatment and Care • Goal directed inpatient admission integrated with community service • Proactive Care coordination, including warm transition and transfer • Trauma-informed, evidence based crisis response	Residential Services e.g Ngatti, ARYA house NGOs: Youth Focus
Adult	• Community education, awareness, acceptance, and promotion • Psycho-education and self care • Family psycho-education and support • PD-responsive and collaborative primary medical and psychological care • PD informed psycho-social support • Peer support • Dimensional diagnostic assessment • Empirically sound psychological therapies (DBT, MBT) • Integrated AOD/Mental Health Treatment and Care • Goal directed inpatient admission integrated with community treatment and support • Proactive Care coordination, including warm transition and transfer • Trauma-informed, evidence-based crisis response	BGPs Better Access Psychological Therapy Community Managed Psychosocial Support Services Community Managed Family Support Services Public Community Mental Health Services Public Inpatient Services Private Inpatient Services Private Outpatient Services

Life course stage	Element	Examples of some services
Older Adult	• Community education, awareness, and promotion • PD expertise in primary care, aged care and general mental health services • Family and consumer psycho-education and support • Specialist PD outreach, liaison, mentoring and training • Flexible and proactive care coordination, particularly at transition points (e.g. on entering out of home care) • Access to specialised PD services	GPs General Health Services Aged Care Services Public Community Mental Health Services Older Adult Mental Health Inpatient Unit

6.8 Addressing the needs of specific populations

Aboriginal people

Community prevalence surveys indicate that 4–16% of Aboriginal and Torres Strait Islander people meet diagnostic criteria for personality disorder[93], however, there is little information relating to the prevalence, diagnosis or response to personality disorders in Aboriginal communities[94]. Aboriginal stakeholders said the concept of personality disorders is unfamiliar to many Aboriginal communities and several spoke about the high incidence of 'PD like' distress among Aboriginal people.

Making a diagnosis of personality disorder in Aboriginal culture is complicated by social, cultural and historical contexts where a more accurate interpretation of symptoms may be explained by lack of cultural security and cultural misunderstandings,[95] high incidence of distress as a result of intergenerational, historical and everyday trauma and cultural dislocation caused by colonisation, disrupted kinship systems, the intergenerational impact of social and cultural marginalisation and actions by state agencies[96].

Aboriginal people are often given diagnoses of mental illness because they appear to fit the criteria. However, practitioners, Aboriginal clinicians and service providers, Aboriginal community members and researchers consulted during this project believe that factors exacerbating individual's presentation for a diagnosis of personality disorder are better explained by cultural and social factors and pervasive and complex historical and inter-generational trauma[97].

In a personal communication Professor Helen Milroy wrote:

> *"For Aboriginal people living with the transgenerational trauma and current levels of racism and disadvantage, the assessment and treatment of personality disorder is contentious within a cross cultural context. Also, with the high rates of imprisonment, there is a bias towards antisocial personality labels. In children, aggressive behaviour from Aboriginal boys is often met with a label of conduct disorder when some of these boys have PTSD and are responding to adverse environments. While we continue to apply personality disorder labels and ignore trauma, we are missing the obvious. This is particularly so with BPD and ASP types. As well, how do we giving meaning to life experiences if we ignore the historical legacy and current levels of racism in the Australian context.*

The Lowitja's Institute's report Journeys to Healing and Strong Wellbeing found that Australia's mental health system is inadequate to deliver good mental health for Aboriginal people as it is insufficient and under-resourced and poorly designed from a cultural point of view for Aboriginal people. Issues such as lack of cultural safety, workforce issues and systemic racism further compromise the ability of the mental health system to meet Aboriginal people's needs[98].

In addition, differences in understanding between western and Aboriginal concepts of mental health and mental illness contribute to deficiencies in the mainstream mental health system's policies and service response. Many Aboriginal people do not conceptualise a medical or clinical model of mental illness but have a much more holistic concept of mental health which encompasses connections between physical, social, cultural, environmental, spiritual, emotional, family and community wellbeing, not just of individuals, but of families, cultures and the wider community. The term 'social and emotional wellbeing' encapsulates this[99].

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93 Parker, R & Milroy, H, (2014), Aboriginal and Torres Strait Islander Mental Health, in Dudgeon, P, Milroy, H & Walker, R, (2014), Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice, Telethon Institute for Child Health/Kulunga Research Network & Commonwealth of Australia, Perth, 2014.

94 Nasir, BF, Toombs, MR, Kondalsamy-Chennakesavan, S et.al, (2018), op.cit.

95 Fromene, R, Guerin, B & Krieg, A, (2014), Australian Indigenous Clients with Borderline Personality Disorders Diagnosis: A contextual review of Literature, The Psychological Record, 2014: 64, pp. 559-567.

96 Fromene, R, Guerin, B & Krieg, A, (2014), ibid.

97 Fromene, R, Guerin, B & Krieg, A, (2014), ibid.

98 Lowitja Institute, (2018), Journeys to Healing and Strong Wellbeing. A project conducted by the Lowitja Institute for the National Mental Health Commission, The Lowitja Institute, Melbourne, June 2018.

99 Commonwealth of Australia, (2017), National Strategic Framework for Aboriginal and Torres Strait Islander People's Mental Health and Social and Emotional Wellbeing 2017-2023, Department of Prime Minister and Cabinet, Canberra, 2017.

The Gayaa Dhuwi (Proud Spirit) Declaration[100] and the Lowitja Institute[101] call for a "best of both worlds approach" which supports Aboriginal people's connection to culture and cultural healing and access to culturally safe and competent clinical mental health services. In practical terms this should include:

- Engaging with Aboriginal elders
- Collaboration with Aboriginal controlled organisations
- Entrust ownership of the design and delivery of mental health and PD services to Aboriginal services and organisations and Aboriginal people
- Utilise, support and upskill the existing skills, capacity and potential of Aboriginal organisations and the Aboriginal workforce with experience and expertise in mental health and social and emotional wellbeing[102].
- Design programs and services that are culturally safe, trauma-informed and lived experience based that respond to the mental health and wellbeing needs and diversity of Aboriginal people.
- Expand and improve mental health and social and emotional wellbeing services in Aboriginal community-controlled health organisations (ACCHOs) to incorporate a stronger focus on personality disorders.
- Address historical and cultural determinants of mental health resulting from colonization, racism, discrimination and intergenerational trauma from Stolen Generation practices, family dislocation and assimilationist policies and frequent re-traumatisation and situational trauma.
- Acknowledge and provide support to families, elders and community leaders as they are often left to respond to critical mental health challenges in the absence of adequate support, both in terms of counselling treatment and support that is both culturally and clinically relevant[103].

While some key Aboriginal stakeholders were consulted during the project, it was beyond the scope of this project to develop an Aboriginal specific response to PD. More work needs to be done to develop an Aboriginal specific response to PD, and this should be led by Aboriginal stakeholders. Key stakeholders could include: Wungan Kartup Specialist Aboriginal Mental Health Service; other public mental health services that work with Aboriginal people; NGO mental health services that provide services and support to Aboriginal people; Aboriginal Medical services; Aboriginal controlled organisations working in the family, domestic violence, counselling, housing, homelessness, justice and AOD areas; Aboriginal elders; Aboriginal clinicians and academics and other key Aboriginal groups, as well as the Mental Health Network, Personality Disorders Sub-Network and the WA Primary Health Alliance.

Culturally and Linguistically Diverse (CALD) people

Western Australia is the most culturally diverse state in the most culturally diverse country in the world. The MOC acknowledges the importance of culture and the migration experience of CALD people living with personality disorders, their families and carers and support persons.

The mainstreaming of mental health systems and approaches does not work for culturally diverse people and communities and understanding cultural norms and sociocultural history and consideration of the dynamic interactions between personality traits, developmental histories of adversity and current social context is critical[104].

Intergenerational trauma is an essential consideration in working with people of culturally and linguistically diverse backgrounds. Many immigrant and refugee communities struggle with unresolved trauma, grief and loss and challenges of adjusting to Australian culture, language and ways of life and different cultural and social expectations. Mental and

100 National Aboriginal and Torres Strait Islander Leadership in Mental Health, (2015) Gayaa Dhuwi (Proud Spirit) Declaration, NATSILMH.

101 Lowitja Institute, (2018), Journeys to Healing and Strong Wellbeing. A project conducted by the Lowitja Institute for the National Mental Health Commission, The Lowitja Institute, Melbourne, June 2018.

102 Dudgeon, P , Derry, KL & & Wright, M, (2020), A National COVI-19 Pandemic Issues Paper on Mental Health and Wellbeing for Aboriginal and Torres Strait Islander People, Transforming Indigenous Mental Health and Wellbeing Grant, The University of Western Australia, Poche Centre for Indigenous Health.

103 Westerman, T, (2020), Whole of community suicide prevention forums for Aboriginal Australians, Australian Psychology, 2020, 55:363-374.

104 Ronningstam, E. F., Keng, S.-L., Ridolfi, M. E., Arbabi, M., & Grenyer, B. F. (2018). Cultural aspects in symptomatology, assessment, and treatment of personality disorders. Current psychiatry reports, 20(4), 22; Ryder, A. G., Sunohara, M., & Kirmayer, L. J. (2015). Culture and personality disorder: from a fragmented literature to a contextually grounded alternative. Current opinion in psychiatry, 28 (1), 40-45.

emotional distress are experienced within cultural, social and historical contexts. A transcultural approach reflects and seeks to explore a person-centred perspective within the individual's social and cultural context.

For many people of CALD background, experiences of racism, stigma related to mental health issues, lack of cultural competence and responsiveness, lack of understanding about mental health, distrust of services and negative experiences with mental health services act as key barriers to accessing mental health services[105].

The influence of culture specifically in relation to PD has not been considered sufficiently. Expressions of PD are reported to be extremely varied particularly in relation to culture. The need for practitioners to be culturally competent, particularly in relation to diagnosis, is therefore crucial.

Some service responses include.

- Establish and, maintain strong connections with CALD and migrant and refugee communities
- Employ workers from CALD and migrant and refugee communities
- Upskill the mainstream mental health workforce to be more culturally responsive and capable of culturally competent practice
- Operate in locations where people of CALD and migrant and refugee background live
- Utilise accredited interpreters and understanding how to work with interpreters
- Understand, recognise and acknowledge the impact of cultural factors and respond accordingly
- Seek advice and support from people with understanding and experience in culturally responsive care and treatment.

Rural and remote

There are major challenges involved in delivering mental health services in regional and remote areas. These include the paucity of clinical services, the large distances involved in delivering services, the sigma of seeking help, the lack of specialist clinicians in areas such as personality disorders and the lack of appropriate care[106]. Feedback from people with lived experience in regional areas confirms the lack of PD services, resources and support available in rural and remote areas[107].

Overall, there are few specialist services for people with personality disorders in rural and regional areas. Some local DBT programs have been established. Whilst some DBT programs continue to be provided, such as a DBT program offered in the South West through public mental health services, others that were established have ceased operating due to a lack of funding, changes in priorities or service requirements, the tyranny of distance and/or unavailability of qualified and trained staff. Efforts are underway to develop DBT programs in other regions and these initiatives should be supported.

Due to the challenge of developing specialist PD services in rural and regional settings there is a need to develop evidence-based brief and early interventions and psychosocial support interventions. The WA Primary Health Alliance, Mental Health Network, Personality Disorders Sub-Network and key NGO peak bodies such as WA Association of Mental Health (WAAMH), WA Network of Alcohol and Other Drug Agencies (WANADA, and Consumers of Mental Health WA (CoMHWA) could be consulted about a possible role in supporting the development of brief interventions and psychosocial interventions for rural and remote areas.

Several brief interventions have demonstrated their effectiveness. Project Air has developed a Brief Intervention Manual and four session program that provides practical therapeutic techniques as the first step in treatment as well as an Ad-

105 Orygen, (2019), Designing mental health services for young people from Migrant and Refugee Backgrounds: Good Practice Framework, Centre for Multicultural Youth and Orygen, Melbourne, 2019.

106 Commonwealth of Australia, (2018) Accessibility and quality of mental health services in rural and remote Australia, Senate of Australia, Community Affairs Reference Committee, December 2018.

107 Carrotte, C & Blanchard, M, (2018), Understanding how best to respond to the needs of Australians living with personality disorder, Report prepared for SANE Australia, June 2018, Melbourne.

olescent Brief Intervention model for for responding to emerging personality disorder[108]. An evaluation of the Project Air Brief intervention found it to be an effective first step within a whole-of-service model of care and able to contribute to a significant reduction in distress, as well as self-harming suicidal ideation[109].

A brief 13-week DBT skills program has also demonstrated its effectiveness in terms of ease of implementation and increased clinical improvements[110].

Some NGOs in regional areas are responding to the need for PD community support and psychosocial services by expanding their capacity and service offerings. This includes providing training and education of staff to respond to people with personality disorders, offering programs such as Family Connections for parents and families, sponsoring training on DBT and developing DBT informed service responses, and strengthening their capacity to respond to PD as part of their mental health services. The WA Primary Health Alliance could be consulted about a possible role in expanding the capacity of the NGO sector in rural and regional areas to respond to PD issues and to fill gaps in services and support.

In SA, BPD Co appointed PD clinicians to build capacity of country services directly, and travel to country locations and utilise 'virtuSAal (virtual) clinics' in the context of limited availability of local clinicians skilled in working with people living with personality disorder. Digital and online services may be another way to expand service delivery and reach people in rural and regional locations.

The proposed Centre for Personality Disorders should play a role in providing capacity building support, including training, education and consultation to services, clinicians and practitioners and people with lived experience in regional areas to build their capacity to respond to and support people with personality disorder.

Lesbian, gay, bisexual, transgender/transsexual, intersex and queer/questioning and gender diverse (LGBTIQ)

Lesbian, gay, bisexual, transgender/transsexual, intersex and queer/questioning and gender diverse (LGBTIQ) Australians are more than twice as likely to have high or very high level of psychological distress compared to heterosexual people (23-28% compared to 11%)[111].

The LGBTIQ population is at higher risk of being victims of aggression and physical and sexual abuse[112]. LGBTIQ people have significantly poorer mental health and higher rates of suicide than other Australians. Same sex attracted LGBTIQ young people are six times as likely to have attempted suicide compared to their heterosexual peers[113]. Beyond demonstrating an overrepresentation of BPD in sexual minorities, research has not further explored explanations for the association or articulated services and supports for people living with personality disorder[114].

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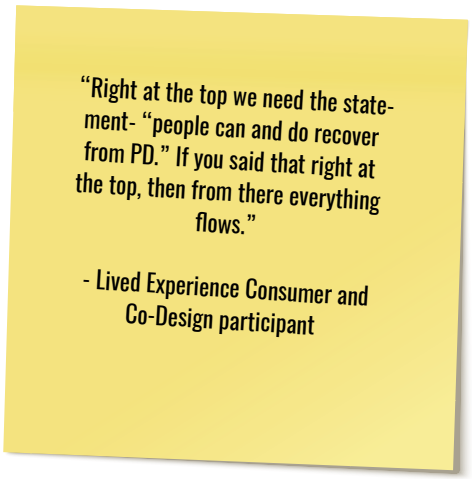
Forensic

Personality disorder is highly prevalent in those with an offending history with people in correctional settings having higher rates of personality disorder than those in the general community[115]. In Australia, 43.1% of adult prisoners met the criteria for a personality disorder relative to 9.2% in a community sample.[116] Data collected from new prisoners entering the prison system in Western Australia highlight a prevalence of personality disorder in 38% of male and in 36% of female prisoners.[117]

Some key issues identified include:

- The Specialist Mental Health Court is very effective in diverting people with PD from further offending and custodial outcomes.
- Community support targeted at addressing accommodation, vocational and financial management needs is critical
- Family and consumer peer support is very effective. The Mental Health Court Diversion and Support Program (START) Court has a family peer program which is very successful.
- The Specialist Forensic Services focus on to the severe (generally high risk) population
- There is a need for access to more empirically sound community treatment for the Forensic PD group
- There is a need for PD specialised consultation & liaison & practice supervision



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7. IMPLEMENTING A STATEWIDE MODEL OF CARE FOR PERSONALITY DISORDERS

7.1. A Collaborative Staged Approach to Implementation

The scope of the Model of Care described in this report is a whole system community wide program of innovation and reform that will need to be implemented over several years. It involves multiple systems, organisations and practitioners, service providers and people with lived experience across all health service regions and the mental health system as well as the wider public, NGO and private sectors.

It needs to build on and strengthen the capacity of existing services in the public mental health sector, the non-government sector, the health and community services sector and the private sector to respond better to people living with personality disorders and to develop and implement a number of new initiatives and service responses to fill existing gaps.

The process of developing the model of care has involved an innovative collaborative partnership between the Mental Health Network, the Personality Disorders Sub-Network, including a critical mass of people with lived experience, WAAMH (in its role as the peak body for the community mental health sector) and the Mental Health Commission. Using a similar collaborative partnership approach, coupled with a significant commitment to co-production and co-design with people with lived experience and those directly affected will be the best way to implement the Model of Care.

7.2. Recommendations

A staged approach to implementation is proposed that commences with the creation of awareness and understanding across the mental health system about the need for change and the proposed Model of Care, and that is built on collaborative partnerships and active commitment from key stakeholders in the mental health system, including people with lived experience, the Mental Health Commission, the Mental Health Network and its associated sub-networks, WA Primary Health Alliance, the Health Service Providers (HSP)[118], non-government peak bodies and community mental health sector, public mental health services, the non-government sector and other key stakeholders:

1. Sector leaders approve Overarching Principles (considering those at pp 44-45 of the Report), as the underpinnings of a system wide culture of care for people with Personality Disorder. Domain specific principles (pp 45-49 of the report) are considered for endorsement for the parts of the sector where they apply.
2. A sector wide promotional program is undertaken to achieve a shared foundational knowledge and awareness of personality disorders and commitment to the principles of care.
3. A tiered PD competency framework and curriculum is developed to guide the capacity and skill development of those who work with, and provide care, support, and treatment for people with personality disorders across the life course and responsive to specific populations.
4. A commitment is made to ensuring HSP-wide access to evidence-based culturally secure community treatments for adolescents, youth, adults, and older adults with PD.
5. A commitment is made to ensuring HSP-wide access to evidence-based culturally secure inpatient treatments for adolescents, youth, adults, and older adults with PD.
6. An entity (Centre for Personality Disorders) is commissioned to provide capacity building, consultation, liaison and technical assistance for evidence-based community and inpatient treatments.
7. A state-wide person-centred treatment and support pathway is co-designed to serve as a facilitated navigational resource for primary and community care, community and inpatient treatment, care coordination and transition for people with personality disorder. This will also support access to care for those residing in rural regions and other

118 Health Service Providers are responsible for delivery of health services to defined catchment areas in WA.

catchment areas without specialised PD services.

8. The most immediate service gaps are agreed and addressed; the most pressing that have been identified in the course of the project are:
   • Consumer and family and carer (including young carers) education, peer support skills training, and support, including system wide access to the Family Connections program.
   • Integrated, evidence based and culturally secure community treatment and community support services for adolescents, youth, and adults with moderate needs. This would address a gap between primary care and public community treatment.
9. A workforce training and development program is designed and initiated aligned to the tiered competency framework.
10. A research/evaluation/information strategy is co-designed aligned to the Model of Care. It is proposed to include an assessment of the impact of such alternatives to Emergency Departments under development as the Safe Haven Cafes, Step-Up residential services, and the Mental Health Emergency Centre.
11. Long term service gaps are identified and addressed; those that have been identified in the course of the project are:
    • The development and expansion of locally responsive PD treatment and support services across regional and remote WA.
    • The co-design and development of Aboriginal-specific PD treatment and support services with Aboriginal community and service leaders.
    • Developing, with the Education Department, a strategy that ensures schools can identify, support, and engage relevant services for children and teenagers at risk.
    • A mental health promotion program that promotes positive attitudes and approaches to emotional regulation in communities and workplaces.

8. CONCLUSION

The profile of Personality Disorder (PD) has increased substantially over the last decade. It is widely recognised that a greater focus on PD is needed in the mental health system, including prioritising support, care and treatment, coordinating more sensitive and less stigmatising responses and the need for more research.

In WA, the WA State Priorities Mental Health, Alcohol and Other Drugs 2020-2024 identifies priorities for the WA Government to reform and improve the mental health, alcohol, and other drug sector over the next four years. People with personality disorders are identified as a population requiring specific consideration.

The State Priorities identifies the need for the mental health sector to deliver contemporary models of person centred care in partnership with service users, families and carers, to ensure that various demographic groups are catered for and that adequate services are provided to people across all WA regions.

This report and the proposed Model of Care for Personality Disorder provides a mechanism to deliver on those priorities.

The Model of Care proposed in this report is the culmination of four years leadership by the people with lived experience, clinicians and service providers involved in the Personality Disorders Sub-Network, with support from the Mental Health Network.

Development of the Model of Care care has involved an innovative collaborative partnership between the Mental Health Network, the Personality Disorders Sub-Network, including a critical mass of people with lived experience, WAAMH and the Mental Health Commission.

Using a similar collaborative partnership approach, coupled with a significant commitment to co-production and co-design with people with lived experience and those directly affected will be the best way to implement the Recommendations of this Report and the Model of Care.

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APPENDICES

Appendix 1: List of Acronyms and Abbreviations

ABiC	Assessment and Brief Intervention Clinic
ABS	Australian Bureau of Statistics
ACT	Acceptance and Commitment Therapy
ADHD	Attention-deficit/hyperactivity disorder
AIHW	Australian Institute of Health and Welfare
AOD	Administrative Order on Consent
APA	American Psychiatric Association
APD	Avoidant (or anxious) personality disorder
ASPD	Antisocial personality disorder
AVH	Auditory visual hallucinations
AVPD	Avoidant personality disorder
BEST	Brief Education Supported Treatment
BPD	Borderline personality disorder
CALD	Culturally and linguistically diverse
CAMHS	Child and adolescent mental health services
CARC	Community Affairs References Committee
CAS	Coping and Succeeding
CAT	Cognitive analytic therapy
CBT	Cognitive behavioural therapy
CCS	Complex Care Service
CMHT	Community Mental Health Team
CONSORT	Consolidated Standards of Reporting Trials
CRISPS	Carers Require Information on Personality Symptoms
DBT	Dialectical behavioural therapy
DBT STEPS-A	Dialectical behavioural therapy Skills Training and Emotional Problem Solving for Adolescents
DBT-A	Dialectical behavioural therapy – Adolescents
DBT-I	Dialectical Behaviour Therapy – Individual therapy
DBT-PE	Dialectical Behaviour Therapy Program Elements
DBT-S	Dialectical Behaviour Therapy skills training group
DBT-ST	DBT skills training
DPD	Dependent personality disorder
DSM-5	DSM-5 Diagnostic and Statistical Manual of Mental Disorders, 5th edition
DSM–III	Diagnostic and Statistical Manual of Mental Disorders, 3rd edition
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4th edition
EC	Extended care
ED	Emergency Department
EUPD	Emotionally Unstable Personality Disorder
FC	Family Connections

GLOW	Goals for Life: Opting for Wellness
GPM	General psychiatric management
GPs	General Practitioners
HPD	Histrionic personality disorder
HYPE	Helping Young People Early
ICD-10/11	International Classification of Diseases, 10th or 11th edition
ICP	Integrated Care Pathway
IPT	Interpersonal Therapy
LGBTIQ	Lesbian, gay, bisexual, transgender/transsexual, intersex and queer/questioning and gender diverse
LHN	Local health network
MBT	Mentalisation Based Treatment
MBT-DH	Day hospital mentalization-based treatment
MBT-FACTS	Mentalisation-based Families and Carers Training and Support
MHC	Mental Health Commission
MHEC	Mental Health Emergency Centre
MS-BPD	Making Sense of Borderline Personality Disorder
NAMI	National Association for Mental Illness
NGOs	Non-government organizations
NHMRC	National Health and Medical Research Council
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIMHE	National Institute for Mental Health in England
NMHC	National Mental Health Commission
NPD	Narcissistic personality disorder
NSMHWB	National Survey of Mental Health and Wellbeing
NSSF	National Social Security Fund
NSW	New South Wales
OCD	Obsessive-compulsive disorder
OCDP	Obsessive compulsive personality disorder
OCP	Office of the Chief Psychiatrist (Western Australia)
OTAU	Optimised treatment-as-usual
PAC	Psychoanalytic Clinic
PC	Productivity Commission
PD	Personality Disorder
PDS	Personality Disorder Service
PDT	Photodynamic therapy
PHNs	Primary Health Networks
PPD	Paranoid personality disorder
PTSD	Post-traumatic stress disorder
RCTs	Randomised Control Trials
SA MOC	South Australia Model of Care

SAPOL	South Australia Police
SGT	Standard group therapy
SHB	Self-harming behaviours
SPD	Schizotypal personality disorder
ST	Schema therapy
S-TAU	Specialist treatment as usual
STEPPS	Systems Training for Emotional Predictability and Problem Solving
SZPD	Schizoid Personality Disorder
TAU	Treatment as usual
TAU CBT	Treatment as Usual Cognitive Behaviour Therapy
TES	Training, Education and Support
UK	United Kingdom
USD	United States Dollars
WA	Western Australia

Appendix 2: Methodology and Approach

The methodology for the development of the model of care consisted of seven phases and progressed over a 12-month period. Project activities were curtained significantly for a 12-week period due to COVID-19 restrictions and impacts, resulting in delays to phase 4 (the mapping and stakeholder engagement process) and phase 5 (the co-design process).

More detail about each phase is shown in the table below

Phase	Activities
Phase 1: Establish the Project Reference Group, undertake planning and relationship building (August 2019)	• Meet with the Co-Chairs of the Mental Health Network and co-chairs of the Personality Disorders Sub Committee. • Meet with the Steering Committee of the Personality Disorders Sub Network. • Establish the Steering Committee of the Personality Disorders Sub Network as the Project Reference Group (PRG) and review gaps in membership. • Recruit new members of the Project Reference Group (more lived experience members, AOD specialist, primary care, NGO) • Hold regular monthly meetings of the newly formed Project Reference Group throughout the life of the Project.
Phase 2: Scope the work to be done and who is to do it (September 2019)	• Develop a project plan with the Project Reference Group and identify who will do the work. • Due to the relatively small budget, decide to contract external people with expertise to undertake the Literature review and the Model of Care Co-design process. • Develop Expressions of Interest for consultants to undertake the Literature Review & the Model Co-Design process.
Phase 3: Literature Review (October-December 2019)	• Prepare & distribute EOI. • Establish a small group of the Project Reference Group to review applications and select the best consultant. • Assess 5 applications and appoint successful applicant. • Project Reference Group meets with and briefs the consultants. • Consultants provide a draft Literature Review and feedback is sought from the Project Reference Group, the Mental Health Commission and the Executive Group of the Mental Health Network.
Phase 3: Literature Review (October-December 2019)	• Detailed feedback is provided to the consultants and revisions made to the Literature Review • Final Literature Review is provided.

Phase	Activities
Phase 4: Mapping and Stakeholder Engagement (January-July 2020)	• Establish a small group of PRG members to oversee and undertake the engagement process. • Develop a mapping template & information to be collected. • Gather information from stakeholders including. o Associate Professor Michael Wright, Curtin University of Technology o Professor Helen Milroy, University of Western Australia & Commissioner National Mental Health Commission o Mental Health Network Multicultural Sub-Network Steering Committee o Mental Health Network Forensic Mental Health Sub- Network Steering Committee o Mental Health Network Older Adult Mental Health Sub-Network o WA Country Health Services (WACHS) stakeholders o Aboriginal service providers and stakeholders o Rural and remote non-government mental health organisations o Mental Health Network Youth Mental Health Sub-Network
Phase 5: Co- Design Process (January- May 2020	• Prepare & distribute an EOI to undertake the process • Establish a small group of the Project Reference Group to review applications and select the best consultants • Assess 5 applications and appoint facilitators • Facilitators prepare a plan for the co design process • Establish a lived Experience Design Advisory Group which meets regularly to advise the Facilitators • Undertake Co-design process which includes face to face and remote (zoom) sessions. • Final Report of Co- Design is provided
Phase 6: Analysis & synthesis of all findings and design of the model of care (June-July 2020)	• Develop and prepare summaries of all findings to assist the Project Reference Group • Conduct two workshops with the Project Reference Group and invited guests. • Prepare working draft of the Principles and Elements of the model of care
Phase 7: Reporting.	

Appendix 3: Personality Disorders Project Reference Group

The Project Reference Group met regularly between August 2019 and July 2020, and provided considerable advice and guidance and comprised the following representatives

Emma Hayes	Lived Experience Consumer
Trish Owen	Lived Experience Consultant and Consumer
Marie Manfredini	Lived Experience Carer
Carolyn Harders	Lived Experience, Carer
Catherine Holland	Co-Chair, Carer Peer Support Worker
Kelly Clark	Lived Experience Consultant and Consumer
Dr Sian Jeffrey	Co-Chair, DBT Coordinator Senior Clinical Psychologist, Alma St Centre
Dr Helen McGowan	Co-Lead Mental Health Network
Sandra McMillan	Senior Clinical Psychologist, Youth Unit, Fiona Stanley Hospital
Dr Giulia Pace	Child and Adolescent Psychiatrist, Head of Service, Touchstone CAMHS
Judith Packington	Senior Social Worker, Rockingham Kwinana Mental Health Service
Dr Matt Ruggiero	Clinical Psychologist, Private Practice and Lecturer Curtin University
Dr Elizabeth Webb	DBT Coordinator, Senior Clinical Psychologist
Alicia Wilson	Senior Project Officer, Acute CAMHS
Rod Astbury	Co-Lead Mental Health Network
James McCloy	WACHS representative, Bunbury Mental Health Service
Colin Penter	Projects Lead WAAMH
Ashleigh Owen	Principal Policy Officer, Mental Health Commission
Linley Ford	North METRO DBT program
Pauline Cole	Psychiatrist, DBTeen project, private psychiatric hospital (Marian Centre)
Adam Frawley	Clinical Nurse Specialist Mental Health Emergency Centre, Royal Perth Hospital
James Healey	Acting Mental Health Team Leader/Psychologist 360 Health
Liana Marrone	Senior Policy Officer, Mental Health Commission
Emma Timms	Principal Policy Officer, Mental Health Commission

Appendix 4: List of individuals and agencies who contributed information and ideas to the project

Individuals who contributed to the Literature Review

Brin Grenyer	Professor of Psychology, University of Wollongong, and Director of the Project Air Strategy for Personality Disorders
Brooke Packham	Advanced Clinical Lead Psychology, Rural and Remote Mental Health Service, South Australia
Catherine Holland	Lived Experience - carer and carer peer support, Co-Chair Personality Disorders Sub-Network & Member of the Personality Disorders Project Reference Group
Catheryn Pilcher	Clinical Manager, Spectrum Statewide Personality Disorder Service, Eastern Health, Victoria
Daniel Flynn	Clinical Lead of the National DBT Ireland project, Mental Health Services Cork Kerry Community Healthcare, Ireland
Elizabeth Webb	Private practitioner, Member of the Personality Disorders Project Reference Group
Judy O'Sullivan	Principal Project Manager, Borderline Personality Disorder Collaborative, South Australia
Lars Mehlum	University of Oslo, National Centre for Suicide Research and Prevention (NSSF)
Louise McCutcheon	Senior Program Manager at Orygen and Helping Young People Early (HYPE)
Maria Marfredini	Carer, Member Personality Disorders Project Reference Group
Matt Ruggiero	Academic, lecturer, researcher, private practitioner, Member of the Personality Disorders Project Reference Group
Nathan Gibson	Chief Psychiatrist, Western Australia
Pauline Cole	Psychiatrist, Member of the Personality Disorders Project Reference Group
Sharon Lawn	Professor, College of Medicine and Public Health, Flinders Human Behaviour and Health Research Unit, Flinders University, South Australia
Sonia Neal	Lived experience counsellor psychotherapist,
Timothy Agnew	Consultant Psychiatrist and Psychotherapist (NHS Highland Personality Disorder Service), Scotland.

WA Primary Health Alliance Executive Managers Dr Danny Rock, Bernadette Kenny, and Mark Cockayne for their ideas and contribution at various points in the project.

Individuals involved in the co design process

Members of the Lived Experience / Carers Group

Emma, Ruben, Cody and Trish. Maria and Catherine

Members of the Project Reference Group

Emma Hayes	Lived Experience Consumer
Trish Owen	Lived Experience Consultant and Consumer
Marie Manfredini	Lived Experience Carer
Carolyn Harders	Lived Experience, Carer
Catherine Holland	Co-Chair, Carer Peer Support Worker
Kelly Clark	Lived Experience Consultant and Consumer
Dr Sian Jeffrey	Co-Chair, DBT Coordinator Senior Clinical Psychologist, Alma St Centre
Dr Helen McGowan	Co-Lead Mental Health Network
Sandra McMillan	Senior Clinical Psychologist, Youth Unit, Fiona Stanley Hospital
Dr Giulia Pace	Child and Adolescent Psychiatrist, Head of Service, Touchstone CAMHS
Judith Packington	Senior Social Worker, Rockingham Kwinana Mental Health Service
Dr Matt Ruggiero	Clinical Psychologist, Private Practice and Lecturer Curtin University
Dr Elizabeth Webb	DBT Coordinator, Senior Clinical Psychologist
Alicia Wilson	Senior Project Officer, Acute CAMHS
Rod Astbury	Co-Lead Mental Health Network
James McCloy	WACHS representative, Bunbury Mental Health Service
Colin Penter	Projects Lead WAAMH
Ashleigh Owen	Mental Health Commission
Linley Ford	North METRO DBT program
Pauline Cole	Psychiatrist, DBTeen project, private psychiatric hospital (Marian Centre)
Adam Frawley	Clinical Nurse Specialist Mental Health Emergency Centre, Royal Perth Hospital
James Healey	Acting Mental Health Team Leader/Psychologist 360 Health
Liana Marrone	Senior Policy Officer, Mental Health Commission
Emma Timms	Senior Policy Officer, Mental Health Commission

Additional participants who took part in the co-design process

- Andy Kazim, Anglicare WA
- Ross Wortham, YACWA
- Rod Astbury, MH Network
- James Healy 360 Health & Community
- St John of God Midland- Donna Buckingham(CP)
- EMuY- Melanie Newton (CP)
- Youth Reach South- Serena (SW) and Brett (Nursing)
- Youth Link- Craig Nicholls (CP)
- Youth Axis- Kyla Penfold (CP)
- Hampton House- Amanda Helliwell (Nursing)
- Rockingham Kwinana MHS- Maree Stirling (CP)
- Sally Gambda, aboriginal mental health worker
- Tahlia, clinical professional
- Ivan, clinical professional
- Jo, clinical professional
- Marie, service professional
- Alyssa, clinical professional
- Jennie, clinical professional
- Elizabeth, disability support coordinator
- Sam, community mental health
- Naomi, clinical professional
- Lee Lee, counsellor
- Un-named Mental Health Nurse in clinical situation
- Unnamed individual with lived experience of BPD
- Unnamed individual with lived experience of BPD
- Unnamed individual, recovering consumer
- Rob, carer

Agencies and groups who contributed to stakeholder engagement discussions

- Associate Professor Michael Wright, Curtin University of Technology
- Professor Helen Milroy, University of Western Australia & Commissioner National Mental Health Commission
- WA Primary Health Alliance Executive Managers Dr Danny Rock, Bernadette Kenny and Mark Cockayne
- Members of the Mental Health Network Multicultural Sub-Network Steering Committee
- Members of the Mental Health Network Forensic Mental Health Sub- Network Steering Committee
- Members of the Mental Health Network Older Adult Mental Health Sub-Network
- WA Country Health Services (WACHS) stakeholders
- Aboriginal service providers and stakeholders
- Rural and remote non-government mental health organisations
- Members of the Mental Health Network Youth Mental Health Sub-Network

Appendix 5:

As part of the process of developing the Model of Care a variety of reports and documents were commissioned or prepared. While these documents are not included in this Report they are available on request. Content and findings from the reports are included in this Report.

Smith, P and Kaleveld, L, (2020), Personality Disorder: A Literature Review, prepared on behalf of the Western Australian Association of Mental Health for the Personality Disorders Project Reference Group, Perth WA, 2020.

Wellington, K and Clark, K, (2020), Co-Design Plan- PD Service Model Co-design Report & Co-Designing a Service Model for Personality Disorders in Western Australia Co-Design Process Documentation.

Summary Report of the findings of a Stakeholder Engagement process undertaken to inform the development of the Model of Care for Personality Disorders

Summary of a Service Mapping Process undertaken to inform the development of the Model of Care for Personality Disorders.