

A Model of Care for Personality Disorder in Primary Health Networks (PHNs):

Findings from three consultation workshops to inform the planning and commissioning of Primary Mental Health Care services to better meet the needs of people living with personality disorder.

31 January 2019

Michael Hartup, Associate Investigator
Research Officer, SANE Australia and the Anne Deveson Research Centre

Bonnie Vincent, Associate Investigator
Head of Policy and Engagement, SANE Australia and the Anne Deveson Research Centre

Elise Carrotte, Associate Investigator
Research Officer, SANE Australia and the Anne Deveson Research Centre

Dr Michelle Blanchard, Principal Investigator
Deputy CEO, SANE Australia
Director - Anne Deveson Research Centre

Prepared by SANE Australia for the National Mental Health Commission.

SANE Australia
PO Box 226
South Melbourne
Victoria 3205
info@sane.org

Table of Contents

Foreword	3
Executive Summary	4
Background	5
Workshop Participation and Structure	6
Participants	6
Structure	7
Analysis	8
Workshop Findings	9
Barriers and Enablers to Accessing Care for Personality Disorder	9
Proposed Service Design Values and Principles for Treating People with Personality Disorder in Primary Care	11
Proposed Stepped Model of Care for Personality Disorder in Primary Care	12
Priorities for Investment for Personality Disorder in Primary Care	22
Proposed Service and Program Suggestions for PHN Stepped Care Commissioning	22
Concluding Statements	25
Consultation and Co-design	25
The Importance of Training and Education	26
Service Design for Personality Disorder	26
Appendices	26
Appendix One: Acknowledgements	26
Appendix Two: Glossary	28
Appendix Three: Evidence-based treatment for personality disorder	29
Appendix Three: Workshop ‘Stepped Care’ Activity	30
Appendix Four: Workshop ‘Priority Investments’ Activity	31

Foreword

The National Mental Health Commission supported SANE Australia to build on the recommendations from the Spotlight Report '*Understanding how best to respond to the needs of Australians living with personality disorder*' through consultation within selected Primary Health Network regions around understanding the role of stepped care planning and commissioning for this underserved group.

This report presents the findings of three workshops run within PHNs to explore a stepped care model for people living with personality disorder in October and November 2018.

This report exclusively captures the views of workshop participants which included consumers and carers with lived experience of personality disorder, clinicians, service providers and PHN staff. The workshop facilitated knowledge sharing across these distinct perspectives. As a result, this project informs the development of principles to enable a co-designed and consumer focused approach to service planning and commissioning.

Therefore, the report findings are inclusive of service and program suggestions which cover all types of evidence including established, anecdotal and emerging evidence. This broad inclusion champions the knowledge of those with lived experience of personality disorder as experts in informing the services which best meet their needs.

In implementing the findings from this report, PHNs are encouraged to undertake additional co-design activities, including with people with lived experience of personality disorder in their area to understand the local context. PHNs are also encouraged to further investigate the existing evidence base supporting the suggested services.

Maureen Lewis

Acting Chief Executive Officer.
National Mental Health Commission
January 2019

Executive Summary

Around 6.5% of Australians are believed to be living with personality disorder, a mental illness which involves pervasive and persistent patterns of thoughts, emotions, and behaviour that lead to impairment and distress. Personality disorder is a highly stigmatised mental illness, and many people living with this condition have reported significant challenges in accessing the care they need. This project explored involved facilitating consultation workshops within three PHNs; it brought together consumers, carers, clinicians, service providers, and PHN staff to propose a stepped care model that better meets the needs of people living with personality disorder.

The participating PHNs were WA Primary Health Alliance, Central and Eastern Sydney PHN, and Central Queensland, Wide Bay, Sunshine Coast PHN. During the four-hour workshop, participants explored conceptions of what stepped care looked like for them, identified priorities for investment for personality disorder, mapped the services currently available within each PHN area, discussed gaps, unmet need, and areas for improvement in the existing stepped care model. The workshop also involved a range of small group activities where participants shared their experiences of the barriers to accessing care and treatment for personality disorder, and developed descriptions of potential programs and services for personality disorder in primary care.

The workshops generated a wide range of data incorporating the experience of all participants, including those with a lived experience of personality disorder. Specifically, the data generated during the consultation workshops was collated against four key areas: *barriers and enablers*, *service design values and principles*, *a stepped model of care*, and *suggestions for PHN stepped care commissioning* for personality disorder in primary care.

A range of barriers and enablers were uncovered with regards to access to treatment and support which covered seven key themes – service and program design, training and education, entry and discharge from services, comorbidity, cost and funding, geographic location, and knowledge of the system. Based on the broad range of qualities participants believed to be integral to good, effective service design and delivery, four proposed service design values and principles for personality disorder in primary care were developed: focusing on *inclusion*, being *collaborative and consumer focussed*, using an approach that is *flexible and adaptable*, and embedding the concept of *continuity of care*.

Drawing on the workshop discussions, this report also proposes a stepped model of care for personality disorder in primary care. It unpacks each step of the model – well population, at-risk groups, mild, moderate and severe mental illness – and details the stepped care need for personality disorder. This report then proposes actions to be taken by PHNs. Building on the priorities for investment activity which uncovered service design and options, advocacy, and training and education as key areas of focus, the report also details a range of suggestions for PHN stepped care commissioning. These suggestions include treatment options, crisis management, education and training opportunities, and ideas for providing additional psychosocial support.

The consultation workshops highlighted the importance of targeted engagement and co-design activities by PHNs. Addressing issues around service and program design, as well as the training and education of clinicians and service providers was identified as key to ensuring that the needs of those living with personality disorder are met. Promoting ‘culture change’ around how people living with personality disorder are treated and perceived by services also emerged as an urgent priority for PHNs and the broader mental health sector.

Background

In November 2018, SANE Australia published a ‘Spotlight Report’: *Understanding how best to respond to the needs of Australians living with personality disorder*, funded by the National Mental Health Commission. This report included a literature review and an environmental scan that included an exploration of key evidence-based approaches for treatment and access to services in Australia. The report also presented results from a qualitative study with Australians living with personality disorder and their carers¹. It examined their experiences with evidence-based approaches to prevention, early intervention, treatment and support for recovery and relapse prevention. Of note, the environmental scan identified that there are few specialist personality disorder services operating in Australia. Most of these are located in capital cities and involve privately funded dialectical behaviour therapy (DBT) clinics. Many participants also reported difficulties accessing services that are timely, low cost, evidence-based, and that meet their needs. For more information about this research, please refer to the Spotlight Report². A list of evidence-based treatments for personality disorder can be found in Appendix Three.

The Spotlight Report also explored the role of Primary Health Networks (PHNs) in supporting people living with personality disorder. Since 2016, the Australian Government commenced mental health reforms in primary care to provide a flexible funding pool to PHNs to commission appropriate mental health services to meet the needs of their region. Through this flexible funding, PHNs are able to provide adequate ‘gap filling’ services for people living with complex and severe mental illness, such as personality disorder. Consistent with the expectations of the Fifth National Mental Health and Suicide Prevention Plan (The Fifth Plan), PHNs – working with state jurisdictions – are expected to implement a ‘stepped care’ approach to providing mental health support. The stepped care model involves a hierarchy of interventions, from least to most intensive, which are matched to individual needs. It is a core component of the Australian Government’s mental health reform agenda, utilised as a central building block for service commissioning and regional planning by PHNs.

This project aimed to gain a better understanding of how PHNs are organised to work with people living with personality disorder and their carers. In collaboration with three PHNs, the project involved workshops which focussed on developing a stepped care model specific to the treatment of personality disorder. This project was designed to be exploratory; it was conducted to explore and develop an initial understanding of how PHNs work with people affected by personality disorder. However, it is hoped that the three specific PHN contexts investigated may illuminate similar experiences amongst other PHN contexts and provide suggestions to all PHNs around the planning and commissioning of services for personality disorder in primary care in their region. PHNs are encouraged to undertake further co-design work with those living with personality disorder to determine the appropriate services to commission in their area.

The National Mental Health Commission and SANE Australia specifically acknowledge and thank:

- Those with lived experience of personality disorder and their family, friends and carers who provided input into the development of this model through participation in the workshops
- The three PHNs who hosted the workshops and supported the project with their expertise and resources³.

¹ A glossary can be found in Appendix Two.

² The report is available online at sane.org/images/NMHC_SANE_PD_Report.pdf

³ A full list of acknowledgements can be found in Appendix One

Workshop Participation and Structure

The three PHN consultation workshops took place in the following locations, timed to ensure the highest level of engagement from their selected participants:

WA Primary Health Alliance (WAPHA)⁴

Wednesday 31st October 2018, Perth WA

Central and Eastern Sydney Primary Health Network (CESPHN)

Wednesday 7th November 2018, Mascot NSW

Central Queensland, Wide Bay, Sunshine Coast Primary Health Network (OURPHN)

Friday 9th November 2018, Gympie QLD

Participants

Each workshop engaged 18-20 participants, with a wide representation of consumers⁵, carers, clinicians, service providers and PHN staff. SANE recommended a split of four consumers, four carers, six clinician/service providers, and six PHN staff in each workshop. A breakdown of participant rates is included in the table below.

Table 1. Number of participants

	PHN Staff	Clinicians/ Service Providers*	Consumer	Carer	Total Participants
WAPHA	5	10	3	2	20
CESPHN	3	11	3	1	18
OURPHN	3	11	8	0	20

* Clinicians/Service Providers included psychiatrists, psychologists, GPs, nurses (psychiatric and general), program directors, emergency department workers, case managers, and social workers.

Please note that some clinicians and service providers also had lived experience and therefore spoke from both perspectives. Generally, consumer and carer voices were the most unified in each workshop. Some clinicians and PHN staff offered views that incorporated both their own perspective as well as the perspective of people living with personality disorder they interacted with in their professional capacity.

The limitations in participant demographics should be noted, particularly that the number of participants who identified as carers was limited. This was, in part, due to the limited availability of carers due to their caring role during the recruitment phase. In addition, the discussions that occurred during the workshop did not tend to focus on the experiences of Aboriginal and Torres Strait Islander populations and those from cultural and linguistically diverse populations. However, future workshops in similar settings should provide more options for participation to ensure a broader range of participants can provide their own perspectives and experiences.

Each participating PHN had a different level of experience in providing services specifically for people living with personality disorder, with some already having commissioned programs in place.

⁴ WAPHA is an alliance of three separate PHNs: Perth North, Perth South, Country Western Australia (WA).

⁵ Please note: the term 'consumer' is generally used when discussing the workshop participants. Other references use the language: 'people living with personality disorder'.

- **OURPHN** has a range of existing services. This included Artius Health (triage and intake service) and Partners in Recovery (providing services and support for those with complex mental health needs) working directly with those in the community with lived experience of personality disorder. They were also currently in the process of reviewing models of care in order to deliver more targeted DBT programs.
- **CESPHN** has a range of services in place including DBT groups, suicide prevention programs and headspaces. These services specifically targeted those people with moderate level presentations of personality disorder, a service gap CESPHN referred to as the 'missing middle'. These included a range of DBT services that worked with specific groups such as young people, AOD, and hospital and community settings.
- **WAPHA** also has a range of programs available for those experiencing complex mental illness, with a focus on developing services for young people. They were also in the process of commissioning services targeted towards those living with personality disorder.

All PHNs worked with diverse groups, including a variety of distinct culturally and linguistically diverse and Aboriginal and Torres Strait Islander populations. The catchment areas for both WAPHA and OURPHN also incorporated large rural and remote populations.

Structure

Workshops ran for approximately four hours and included the following activities:

- **Activity One** involved participants discussing with one another how they understood stepped care, and specifically how they understood the phrase 'right care, right place, right time'. The activity was designed to start participants thinking about the principles of stepped care within a big-picture context, exploring the concept of 'right care, right place, right time' for the treatment and care of people living with personality disorder and their carers.
- **Reflection One** involved asking participants to consider one thing they would invest in for personality disorder within primary care. The activity was designed to reveal immediate priorities for investment in the treatment and care for personality disorders.
- **Activity Two** was the core workshop activity. This involved using a wall inside the workshop space to map the services available within each PHN, the gaps and unmet need, as well as areas of opportunity and those in need of improvement. Using the Department of Health stepped care model as a foundation, this activity was used to brainstorm and unpack specific requirements for people living with personality disorder, and to populate a stepped care model. See Appendix Four for what this stepped care model looked like visually for participants.
- **Activity Three** allowed participants to directly share their own experiences of the barriers to accessing care and treatment for personality disorder amongst their peers. The activity was designed to ensure that all participants felt comfortable voicing their experience, had their experience heard by their peers, and also to ensure any barriers not picked up in the wall activity were captured.
- **Activity Four** involved participants developing their own suggestions for potential services. The activity was designed to pick up ideas from the previous activities, adding another level of detail around example services and programs that could be commissioned by PHNs within the stepped care model.

- **Reflection Two** again involved asking participants to consider one thing they would invest in for personality disorder within primary care. The activity was designed to reveal how participating in the workshops may have changed or cemented their priorities for investment in the treatment and care for personality disorder.

Analysis

After the three workshops were completed, the data generated was collected and organised into themes. Documented across four actionable areas, a consultation draft report was then circulated to participating PHNs as well as the project's advisory committee for review. Feedback was then compiled and reflected in this report.

Workshop Findings

The following section outlines data gathered as part of the consultation workshops to propose a potential stepped care model for personality disorder. *Barriers and enablers* to access are covered first, before outlining the *values and principles* needed for the design and delivery of services for the treatment and care of people personality disorder. A *proposed stepped care model* for personality disorder in primary care is then presented, followed by a range of suggestions for services and programs that PHNs might commission.

Barriers and Enablers to Accessing Care for Personality Disorder

Cutting across the stepped care model, there are significant barriers in place that prevent people from accessing treatment and support in primary care. While much of the discussion within the workshops focussed on what was inhibiting access and the fragmentation of the system, discussion also turned towards some positive actions that could enable access.

Workshop participants had the opportunity to share their varied perspectives, with consumers and carers focussing on their experience of access to treatment and support. PHN staff and clinicians shared what they understood to be some of the limitations of working within the current service system. The enablers presented in the table below represent what workshop participants believed would contribute to more effective treatment and access to supports. It should be noted that some of the identified barriers and enablers also reflect the broader mental health service system and may be pertinent to a range of diagnoses.

The *Proposed Stepped Model of Care for Personality Disorder in Primary Care* in this document endeavour to address these barriers and enablers.

Table 2. Barriers and Enablers to Accessing Care for Personality Disorder

Item	Barrier	Enabler
Service and program design	<ul style="list-style-type: none"> - Personality disorder is disadvantaged in 'patient flow' - Lack of evidence for some treatments - Services that do not follow guidelines - Services with strict inclusion and exclusion criteria limiting access - Punitive service design - Limited availability of DBT within public system 	<ul style="list-style-type: none"> - 'Alternatives' while on waitlists - Inclusive design (specific population needs met) - Utilising trauma-informed care - Improved 'bedside manner' - Warmth and trust in relationships with people with lived experience - Consistent access with consistent clinicians delivering services - Greater peer support options - Collaborative process between consumers and clinicians - After-hours support for consumers and carers
Training and Education	<ul style="list-style-type: none"> - Lack of clinician knowledge about diagnostic criteria and treatment options for personality disorder - Stigma from mental health workers - Stigma from general health workers - Gaps in DBT training and quality - Consumers not acting on referrals - Staff using inappropriate language (disrespectful, stigmatising etc) - Discounting of lived experience expertise 	<ul style="list-style-type: none"> - Attitude and behaviour change education for health professionals - More personality disorder specific training for clinicians (including as part of undergraduate courses) - Training for teachers in schools in recognising personality disorder symptoms and helpful coping strategies (may be DBT-based) - Coping strategy training embedded into workforce training (outside of

Item	Barrier	Enabler
Entry and Discharge from Services	<ul style="list-style-type: none"> - Risky behaviours from some people living with personality disorder (e.g. aggression) - Consumers 'pinballed' from one service to another - No accommodation options post-discharge - Lack of follow up - Prohibitive eligibility criteria for services - not meeting specific requirements for treatment 	<p>mental health services; may be DBT-based)</p> <ul style="list-style-type: none"> - Integration with other services (housing, employment, AOD) - Wrap around services (incorporating both clinical and non-clinical support services) - 'Warm handovers' to ensure limited impact on care quality and recovery - Improved discharge planning - Follow up support - Greater flexibility in eligibility criteria
Comorbidity	<ul style="list-style-type: none"> - In context of mental health and substance use difficulties, not being sure where to present – drug or mental health services? - Physical health issues not routinely addressed - Only one issue treated at a time - Difficulty managing interplay of multiple diagnoses 	<ul style="list-style-type: none"> - Ensure people are not excluded from mental health services because they have a drug problem (or vice versa) - Understanding and acknowledging relationship between diagnoses - Focus on intensity and duration of treatment
Cost and funding	<ul style="list-style-type: none"> - Affordability of services - expensive and unsustainable for people living with personality disorder - Services changing due to funding - Staff retention 	<ul style="list-style-type: none"> - Greater funding for more psychotherapy sessions in community - Access to bulk-billing services - More longitudinal funding allocated - Greater subsidies for intensive programs
Geographic location	<ul style="list-style-type: none"> - Access to care depends on location – 'Postcode lottery' - Stigma, particularly in rural locations - Difficulty in accessing specialist services (and specialist services not available everywhere) 	<ul style="list-style-type: none"> - Ability to access care outside of catchment area - Transport support to access care - Improved alternatives to face-to-face services (e.g. Skype, online services) - Training rural-based psychologists in schema therapy or other evidence-based options - Increased outreach training and support
Knowledge of the system	<ul style="list-style-type: none"> - GPs with limited knowledge about service options - Consumers and clinicians not being familiar with system - High knowledge about the failings of the system for consumers leading to hopelessness and anxiety 	<ul style="list-style-type: none"> - Centralised resource outlining service options within PHN - Training to ensure GPs better informed about options and evidence base'

Proposed Service Design Values and Principles for Treating People with Personality Disorder in Primary Care

When discussing the various aspects of an effective system to meet the needs of people living with personality disorder, a range of themes emerged during the workshops around core values which could support treatment and care in Primary Care settings.

Not directly linked to one specific stage of the stepped care model, they are proposed as a set of universal values that could underpin the whole system and help address some of the greatest service access challenges faced by those with lived experience.

The following four service design values and principles are presented to guide PHNs as they commission new services. PHNs are encouraged to adopt these, or similar values and principles, when designing and delivering programs and services. Inherent within all of these values and principles is the notion that they are utilised to design services and programs that are free of stigma and discrimination. Implementing these values and principles may help ensure that services meet the needs of people living with personality disorder and support the sustainability and quality of service delivery.

Please note that in addition to these specific values and principles that arose from the workshops, more general guidelines for treatment of people living with personality disorder can be found via Project Air and the National Health and Medical Research Council⁶. Additionally, some PHNs have established their own stepped care principles which may complement the values proposed for personality disorder.

1. Inclusive

Services across the health system do not exclude or discriminate against people with personality disorder. Services cater for all presentations of personality disorder, not just those deemed socially or behaviourally acceptable. People are always treated humanely with understanding, respect, tolerance and care. No aspect of a program or service is punitive in any way. Criteria for accessing a service is not prohibitive and does not shut out or restrict a person from accessing care when they need it.

2. Collaborative and Consumer Focussed

Collaboration with people with lived experience of personality disorder is key to ensuring services are consumer focussed and responsive to needs. People living with personality disorder are engaged in co-design and are key decision makers in the design and delivery of services. Lived experience participation across the stepped care model not only provides opportunities for meaningful engagement, but also guarantees more effective, sustainable services. Treatment and support is individualised and goal-focussed.

3. Flexibility and Adaptability

Services are adaptable and offer flexible entry options that meet the needs of people living with personality disorder at different levels of severity. Services offer choice to consumers, are recovery focussed and offer lifestyle interventions and supports. Consumers have access to evidence-based interventions in the community that prevent them needing to present to emergency departments as the only alternative.

⁶ Project Air Treatment Guidelines available here:

<https://www.projectairstrategy.org/guidelines/index.html>

National Health and Medical Research Council guidelines available here: <https://nhmrc.gov.au/about-us/publications/clinical-practice-guideline-borderline-personality-disorder>

4. Continuity of Care

Wherever possible, consistency within the treating health care professional team is maintained to ensure trust and warmth is built with people living with personality disorder. People living with personality disorder have regular contact with the same set of clinicians and service providers throughout their engagement with services and programs. When staff leave their roles or additional expertise is required, time is spent to conduct a ‘warm handover’ to ensure limited impact on care quality and recovery. The needs and voice of carers of people living with personality disorder and their important role in the continuity of care is acknowledged.

Proposed Stepped Model of Care for Personality Disorder in Primary Care

The following proposed stepped model of care for personality disorder in Primary Care was developed drawing exclusively on ideas shared during the three PHN workshops.

It was agreed with participating PHNs that the stepped care model as described in the *Department of Health PHN Primary Mental Health Care Implementation Guidance* should be the foundation for understanding what a stepped care approach could look like for personality disorder. The stepped care model as suggested by the Department of Health details five steps, based on severity - *well population, at-risk groups, mild mental illness, moderate mental illness, and severe mental illness*. The model suggests appropriate mental health treatment and support for each step, what services are relevant, the associated workforce requirements and other system changes that may be needed.

The proposed model amalgamates what services workshop participants identified as being currently available and working well within their PHN area across the stepped care stages, as well as ideas for services that could be added or improved to address gaps and unmet need.

A note for PHN commissioning and implementation

The below table includes both clinical and non-clinical interventions for personality disorder. The inclusion of whole-of-system suggestions below reflects that the community is often not aware of who is providing or funding services, including what PHNs are funded to provide. It should be noted that some recommendations may be best implemented through the current State and Territory funding models, including within community mental health services, as well as through private providers and NGOs. However, these suggestions have been retained in the model to highlight the necessity for PHNs to consider these needs in the design and commissioning services and to ensure integrated service delivery that supports holistic care. It is acknowledged that needs extend beyond the health sector for people living with personality disorder and their carers.

It should be noted that PHNs utilising this information to inform the commissioning of services would need to consider funding through the *PHN Primary Mental Health Care Flexible Funding Pool* streams (including psychological therapies for underserved groups, low intensity mental health services and services for people with severe mental illness) as well as funds available through the psychosocial support/continuity of care measure (NPS) and AOD funding for interventions related to comorbidities, for example. In particular, in addressing service gaps in severe presentations (including step up/down into emergency departments and acute services), joint regional planning activities between PHNs and LHNs represent an opportunity for co-commissioning for the treatment and care of people with personality disorder.

The following table provides considerations for strengthening the stepped model of care in primary care specifically for personality disorder. The table proposes suggestions to all PHNs to inform future planning and commissioning of services to better meet the needs of

people living with personality disorder. It is not intended to be instructional, but rather to act as a guide for PHNs based on local need and available funds.

Proposed Stepped Model of Care for Personality Disorder in Primary Care

- The following table provides considerations for strengthening the stepped model of care in primary care specifically for personality disorder.
- The table proposes suggestions to all PHNs to inform future planning and commissioning of services to better meet the needs of people living with personality disorder.
- Please note that not everything in this model may be actionable in Primary Care settings, but outlines considerations to guide developing and commissioning services within the PHN remit.

Table 3. Proposed Stepped Model of Care for Personality Disorder in Primary Care

Stepped Care Stage	Stepped Care Need for Personality Disorder	Possible Action for PHNs*
<p>Well Population</p> <ul style="list-style-type: none"> - Promotion - Prevention - Early intervention - Access to information - Self-help resources 	<p>Health promotion activities which may contribute to reducing risk factors related to personality disorder:</p> <ul style="list-style-type: none"> • Schools - including primary school self-harm interventions, increasing availability of school psychologists/mental health nurses, teacher training in emotional dysregulation and bullying prevention. • Parenting - classes for parenting in other settings (e.g. workplaces), addressing emotional neglect by parents, parenting programs in hospitals and parent-child programs such as circle of security • Post-natal depression prevention • Domestic violence prevention • Adolescent education e.g. validation skills • Improved child protection systems • Increase community training in emotional CPR⁷ and Mental Health First Aid • Community programs promoting emotional wellbeing 	<ul style="list-style-type: none"> • Promote awareness of personality disorder in PHN commissioned child and adolescent focussed services • Strengthen links with NGOs, community and education sectors to promote multi-sectoral approaches

⁷ Emotional CPR is similar to CPR but is focussed on assisting others through emotional crises using three steps: C = Connecting. P = emPowering, and. R = Revitalizing.

Stepped Care Stage	Stepped Care Need for Personality Disorder	Possible Action for PHNs*
	<p>Access to Information and Self-Help Resources for Personality Disorder, for example</p> <ul style="list-style-type: none"> • Spectrum (VIC) website • Project Air • BPD Foundation website • BPD Community • Head to Health website • NEAMI – optimal health • SANE Australia • Orygen Youth Health • headspace • Online skill development in behavioural modification and problem solving • Local community support groups 	<ul style="list-style-type: none"> • Increase public awareness of personality disorders' aetiology and symptoms, and provide myth-busting to reduce stigma • Disseminate listing of resources to PHN staff, service providers, community partners, and primary care networks
<p>At-Risk Groups</p> <ul style="list-style-type: none"> - Intervention for early symptoms or previous illness - Alternatives to face-to-face service 	<p>Low Intensity Services (LIS) and other services online and via phone, which people living with personality disorder and their carers have found useful including:</p> <ul style="list-style-type: none"> • Smart phone apps including: <ul style="list-style-type: none"> ▪ Smiling Mind ▪ Headspace ▪ CALM ▪ Breathe • E-mental health services through headspace • DBT skills and strategies online (YouTube clips) • Telehealth (1800 Respect) • After hours helplines such as Lifeline and Suicide Callback Service • ARAFMI/Carers QLD (or state equivalent) • Orygen Youth Health <p>Improvements to:</p> <ul style="list-style-type: none"> • Primary care consumer pathways 	<ul style="list-style-type: none"> • Where appropriate to need and severity, promote access to alternatives to face-to-face services (online and phone) for early intervention, or to help support recovery • Ongoing education of GPs on Primary Care service offerings for personality disorder presentations

Stepped Care Stage	Stepped Care Need for Personality Disorder	Possible Action for PHNs*
	<ul style="list-style-type: none"> • Health professionals' knowledge of local services • Interventions targeting early psychosis • Other interventions specific to the treatment of personality disorder 	<ul style="list-style-type: none"> • Promotion of intake lines • Strengthen role of pharmacists in early intervention and recovery for people living with personality disorder
	<p>Addressing at-risk populations in school settings including primary school self-harm interventions, increasing availability of school psychologists/mental health nurses, teacher training in emotional dysregulation and bullying prevention</p> <p>Access to support and self-help resources during recovery, for example:</p> <ul style="list-style-type: none"> • WRAP – Wellness Recovery Action Plans and other individualised self-directed personal wellbeing plans (including early warning signs, safety plans) • Recovery peer support (for example Pearl - Peer Engaged Assisted Recovery Lifestyle – which offers a ‘warm call’⁸ line) • Recreational Interests (Art therapy, creative tools) • Lifestyle programs – e.g. diet and exercise programs • Mind Recovery College (recovery focussed courses delivered by lived experience teachers) 	<ul style="list-style-type: none"> • Continue provision of local headspace with participation of local schools <ul style="list-style-type: none"> ▪ Ensure they are meeting the needs (have clinicians with specialised training in personality disorder) ▪ Integrated with local schools (e.g. outreach programs, school speakers, and school counsellors know to refer to headspace) • Ensure each primary and secondary school has, at minimum, a wellbeing coordinator • Strong links with child and adolescent mental health services (CAMHS) and social services • Develop specific strategies to increase access to peer and psychosocial supports for people with personality disorder, • Promotion of particular services made available through the NDIS • Promotion of self-directed wellbeing planning

⁸ Warm call lines are alternatives to ‘crisis lines’ where the call is taken by a peer worker

Stepped Care Stage	Stepped Care Need for Personality Disorder	Possible Action for PHNs*
<p>Mild or Emerging Mental Illness</p> <ul style="list-style-type: none"> - Lower intensity services 	<p>Skill-building for GPs in Personality Disorder</p> <hr/> <p>Early entry to skill-building programs (DBT and other evidence-based approaches)</p> <ul style="list-style-type: none"> • Pre-interviews • Access to free/low-cost groups • Programs available in some headspaces • Skills-based approaches targeting emotion dysregulation <hr/> <p>Seeking alternatives to medication or more holistic approaches for personality disorder (see also At-Risk above) including:</p> <ul style="list-style-type: none"> • Exploring more Low Intensity Services (LIS) options for personality disorder • Linking people with Peer Support Groups (e.g. 'Compeer' – buddy program) • Promoting the role of community sector in managing mild presentations • Conversational models/trust building addressing abandonment 	<ul style="list-style-type: none"> • Upskilling all GPs, including assessment and referral for people with personality disorder • Improve general practice capacity to manage and support treatment and care for personality disorder • Utilise special interest GPs as champions and consult them during service planning • Encourage personality disorder specialisation in GP training programs <hr/> <ul style="list-style-type: none"> • Invest in skills-building programs for mild presentations (including those for adolescents and adults) • Promote available groups and skills-based resources, including through non-government organisations (NGOs) <hr/> <ul style="list-style-type: none"> • Improve pathways to early access to available services • Help address long waiting periods for community health options by providing alternatives
<p>Moderate Mental Illness</p>	<p>Availability and choice of services at the appropriate level of intensity for moderate presentations including 1:1 therapy and peer support</p>	<ul style="list-style-type: none"> • Investment in increasing access to appropriate levels of evidence-based services to prevent escalation to crisis (the 'Missing Middle')

Stepped Care Stage	Stepped Care Need for Personality Disorder	Possible Action for PHNs*
<ul style="list-style-type: none"> - Service access to evidence-based interventions 		<ul style="list-style-type: none"> • Increasing capacity and role of peer workforce in personality disorder treatment and care • Promote trauma-informed care • Promote use of guidelines for people working with personality disorder (e.g. Project Air, NHMRC)
	<p>Access to DBT and other specialist programs, and other specialist services and supports for personality disorder</p> <ul style="list-style-type: none"> • DBT, including DBT 360 program, DBT incorporating peer workers, DBT for specific population groups and settings – young people, AOD, hospitals, community settings • Short waitlists • Implement learnings from existing open dialogue trials (Project Air Wide Bay, St Vincents Sydney) • BPD-specific psychological intervention groups • Co-facilitated (clinician and peer worker) DBT support groups • Schema therapy 	<ul style="list-style-type: none"> • Increase DBT and other specialist service offerings for personality disorder within the public system and reduce waiting times/lists • ⁹PHN clinician training in individual DBT interventions • Ensure services and practices are non-punitive and work to reduce seclusions • Follow DBT best practice, following protocols where possible even where the program is shorter or less intensive
	<p>More inclusive services, and referral to appropriate services. Examples include:</p> <ul style="list-style-type: none"> • Not rejecting high risk presentations for being ‘too high risk’ 	<ul style="list-style-type: none"> • Provision of ‘safe spaces’ in the community E.g. Crisis Cafes • Review inclusion criteria for services to ensure options exist for those with high need, including comorbidities

⁹ Note: a list of specialist services currently available across Australia for personality disorder is listed in the Spotlight Report for reference, largely in a private hospital setting with some community-based services

Stepped Care Stage	Stepped Care Need for Personality Disorder	Possible Action for PHNs*
	<ul style="list-style-type: none"> • High risk presentations not having access to community support (non-clinical) • Not excluding due to self-harm <p>Availability of Psychosocial supports for people living with personality disorder including:</p> <ul style="list-style-type: none"> • Employment assistance programs • Improved links to social supports <p>Private system: Availability of more Medicare sessions offered through Better Access initiative (10 sessions per calendar year)</p> <ul style="list-style-type: none"> • More affordable (if accessing the private system for more support) • More appropriate level of intensity of care 	<ul style="list-style-type: none"> • Improve risk assessment practices • Equip community-based services to better manage risk • Promote 'No wrong door' policy • Reduce referrals to inappropriate services • Following trauma-informed care guidelines¹⁰ <p>Improved access to psychosocial supports (including options through National Psychosocial Support Service measure)</p> <ul style="list-style-type: none"> • Training in personality disorder for professionals working within the NDIS to better understand needs and persistence/enduring nature of condition <p>Advocate to increase the number of sessions people with personality disorder presentation can access through Medicare, especially for comorbidities</p> <ul style="list-style-type: none"> • Promote available financial supports
<p>Severe Mental Illness</p> <ul style="list-style-type: none"> - Access to the right stage of care to maximise recovery and prevent escalation - Wrap-around coordinated care 	<p>Improvement in treatment and practices within Emergency Department/Accident & Emergency including:</p> <ul style="list-style-type: none"> • Better treatment from staff of people with personality disorder including not refusing access to services/ED admission on the grounds of being 'attention seeking' and treated with contempt • More beds in inpatient facilities 	<ul style="list-style-type: none"> • Work proactively with LHNs/Emergency Departments to improve service practices and standards including for humane, respectful and non-judgmental treatment of people presenting with personality disorder in crisis • Improved mental health assessment in A&E • DBT Skills Training of Health Professionals within hospital settings

¹⁰ Phoenix provide a range of training opportunities as well as guidelines: <https://www.phoenixaustralia.org/for-practitioners/practitioner-resources/>

Stepped Care Stage

Stepped Care Need for Personality Disorder

- Remove restraint practices in ED
- Better response times
- More effective long stays

Possible Action for PHNs*

- Improved discharge process back to GPs/Step Down
- Alternative Transport options to/from ED
- Support for carers and family role in crisis
- Through state/territory regional planning activities advocate for:
 - Good practice in ED management (e.g. St Vincent's - 30min responses/collaborative teams)
 - Police/paramedic response and training for personality disorder
 - Improved communication in ED between Mental Health and general/clinical nursing
 - Dedicated carer/peer workers on wards

Appropriate after-care services and follow-up:

- Activities that incorporate normal daily life (walking, art etc.) as preparation for healthy discharge
- After hours options provided - Lifeline suicide attempt survivor debrief - peer-to-peer validation (8-week course), Lifeline Hawksbury to Harbour

- Commission after care and post discharge services that meet the needs of people living with personality disorder
- Availability of Psychosocial Services
- Strategies to improve workforce retention and morale of staff to ensure passionate, committed care teams in aftercare/post-discharge

Examples of services included:

- Sub-acute and respite services (e.g. 'Open Borders', Hampton Rd Freemantle)
- Housing Support Service/PHN Link into Stream 4, care coordinate in community, maintain contact (2-3 months)
- Hospital Alcohol Drug Service Brisbane – detox, critical distress

Stepped Care Stage	Stepped Care Need for Personality Disorder	Possible Action for PHNs*
	<ul style="list-style-type: none"> ● CHIME (Connectedness, Hope, Identity, Meaning, Empowerment) – referral after crisis presentations (3-6 months) <hr/> <p>Alternatives to Emergency Department presentations, including:</p> <ul style="list-style-type: none"> ● Gold Card Clinic – no questions asked, quick access to psych support (brief intervention service for people presenting to ED following deliberate self-harm) ● Safe, overnight spaces with some DBT. for those who cannot access ED (bed shortages etc) ● Consumer friendly design - No 'white rooms' 	<ul style="list-style-type: none"> ● Commission community-based alternatives for crisis presentations
<hr/> <p>Broader Policy and System Change Advocacy</p>		
<ul style="list-style-type: none"> ● Personality disorder to be taken seriously and prioritised; acknowledging that functional impairment can be 'enduring' ● Advocate for more sessions under the MBS for psychological therapies for people living with personality disorder ● Provide personality disorder education across social services, justice and homelessness ● Seek greater resources for PHNs to improve integration between services, including step up/down from acute services ● Advocate for multi-agency policy change to address issues of trauma and social disadvantage that may underpin personality disorder presentations ● Advocate for humane and respectful treatment in all mental health services ● Agreed data sets to provide a baseline for personality disorder prevalence and appropriate planning of service coverage (The last national survey that included data for personality disorder was published in 'Mental Health and Wellbeing: Profile of Adults, Australia, 1997'¹¹) ● Seek reforms to Commonwealth funding to secure contracts beyond one year to ensure continuity of care 		

¹¹ Report available here: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4326.01997?OpenDocument>

Priorities for Investment for Personality Disorder in Primary Care

Through a voting activity, workshop participants had the opportunity to recommend which service or program PHNs should prioritise in their commissioning investment decisions. Participants were asked twice, at the beginning and end of the workshop, to consider what one thing they would invest in for the treatment and support of people with personality disorder.

Themes that emerged during the first investment vote were:

- The importance of advocacy, greater training and education
- Focussing on early intervention
- More choice in available services (including alternative services in crisis situations)
- Greater treatment options.

The themes that emerged later in the day included:

- Improved training and education, particularly for health professionals
- More specific or alternative services and/or enhanced treatment options.

A complete list of priority investment suggestions can be found in Appendix Five, for PHNs further consideration. These identified investment priorities largely informed the following programs and services, as developed by workshop participants.

Proposed Service and Program Suggestions for PHN Stepped Care Commissioning

The following eleven services and programs arose out of the final workshop activity, which sought to propose the types of services/service solutions PHNs could consider commissioning for the treatment and care of people with personality disorder in primary care.

Workshop participants chose one of the ideas from the stepped care model discussions and worked in small groups, with a mix of consumers, carers, clinicians, service providers and PHN staff to add more detail to the service components. Discussing both improvements to existing services and potential new services for their PHN area, the activity also encouraged consideration of the associated workforce needed to deliver the services.

PHNs are strongly encouraged to undertake further co-design activities as well as their own research related to evidence-based approaches to inform final commissioning decisions.

1. Dialectical Behavioural Therapy

Stage in Stepped Care Model: Well to severe

Addresses these barriers: Isolation and lack of education, communication with staff/supports, lack of training and supervision of staff and NGOs, lack of funding for weekly individual sessions for clients in DBT, lack of funding for ongoing groups for best practice model

Service description:

The program would involve a range of skills training groups with a 12-week, 6-month, or 12-month option (the 12-month option would have both open and closed programs in order to be flexible).

The programs would include individual therapy options and phone coaching, and would operate as a 'one-stop-shop' for all support needs specific to BPD such as therapy, skill development, support work, creation of a safe space, access and referral to apps and other useful technology, etc. Staff would receive training on how to deliver the service as well as ongoing supervision. NGOs could be used to support skills training and assist in care co-ordination.

The program would also incorporate peer workers and peer groups as well as other interagency partnerships in order to support with the development and review of recovery plans. People with

living with personality disorder who have severe needs would have access to ongoing coaching (e.g. via a crisis line) and trained clinical staff. There would be additional services targeted towards specific populations including Aboriginal and Torres Strait Islander Australians, people with intellectual disabilities and DBT groups in rural areas.

2. Prevention: DBT Skills in Schools

Stage in Stepped Care Model: Well to at-risk

Addresses these barriers: Reduce the need for services in the long term, provide age appropriate care, address limitations in social wellbeing at school, provide improved access to health services, combat stigma, address lack of educators with knowledge around mental health issues and services

Service description:

The program would be universal, targeting all students and parents. There would be the capacity to expand interventions to an identified at-risk cohort. Access to psychological support would also be improved. Teachers and parents would be taught to identify students that could benefit from a referral to the school psychologist. Teachers would be educated and taught how to adjust methods of delivery to suit the capacity of students and to weave in a stepped-care model that provides students at risk with a higher level of care.

The programs would be supervised by mental health professionals to ensure they deliver what is needed (in line with the Acute Childhood Experiences trauma measure), and are in line with legal and ethical guidelines. There is also scope for innovation in workforce delivery of such a program (e.g. psychology students could assist in schools)

3. More Training and Support for Both Clinical & Non-Clinical Staff

Stage in Stepped Care Model: All stages

Addresses these barriers: Lack of respect, trauma-informed practice, and provision of care that is detrimental and could potentially lead to withdrawal from services

Service description:

All staff would have face-to-face contact with people living with personality disorder. They would have training in personality disorder, trauma-informed care, and suicide prevention training. They would also receive training around cultural sensitivity that is specific to mental health, as well as LGBTIQ inclusiveness (mental health-specific).

4. Hospital and Health Service Staff Training

Stage in Stepped Care Model: Severe/moderate

Addresses these barriers: stigma, care and treatment, improving therapeutic relationships

Service description:

Training would involve education for staff ambulance service, police service, health service and mental health service staff. Staff would receive mentoring and supervision from trained peer workers. As part of the training, a standardised protocol for care would be developed, as well as a feedback process for complaints and compliments. The initiative would also include regular mandatory refresher and upskilling training, as well as offer brief interventions and additional mental health first aid training.

5. Gold Card Clinics (training and programs)

Stage in Stepped Care Model: Flexible, based on health service needs/demographics

Addresses these barriers: The need for consistent programs, regular training of staff and access to good training that is evaluated by people living with personality disorder.

Service description:

Such a service would provide opportunities for early intervention, skill development and DBT training. It would allow for individual therapy and the dissemination of skills-based information. All clinicians, carers and support workers would need to complete the Project Air training program. They would also need to adapt in order to meet the needs of people living with personality disorder, so that the care offered would be flexible and would allow for inpatient, outpatient and 'ad hoc' DBT, in line with guidelines and standard programs.

6. Telehealth

Stage in Stepped Care Model: Moderate to severe

Addresses these barriers: Distance has been a major barrier, along with time, location, cost and the need for anonymity

Service description:

This would be a care management phone program available for people living with personality disorder who have severe, complex mental health needs, whose needs are managed through primary care (with a GP referral and a Mental Health Care Plan). The program would allow people living with personality disorder to be monitored and supported and only referred to acute services when they are at high risk. The program could be delivered by registered mental health nurses with additional training in trauma-informed care and DBT skills.

7. Family and Carer Support

Stage in Stepped Care Model: All stages

Addresses these barriers: Lack of funding for family connections and carer support, lack of consideration for working families and carers and exclusion of families and carers, and the support they provide from consumers' care plans

Service description:

This initiative would involve the creation of a family and carer reference group that would help to govern all stages of care across PHN commissioned services. More information about these supports can be found in the aforementioned Spotlight Report.

8. Peers and Mentors

Stage in Stepped Care Model: All stages

Addresses these barriers: Regional area has no peers or mentors with organisations, no study options to become a lived experience worker/peer worker (nearby urban area has it up and running). Difficulty finding out how to get access. Lack of advocacy for change from those in the community with a lived experience.

Service description:

Peer workers would be available to have regular contact with people living with personality disorder, after hours and while in crisis. They would be able to connect to NGOs/organisations, support GP appointments etc and provide mentoring during recovery stages. It would be run via a peer network that employs peers to support and mentor through each stage and connect people living with personality disorder to their community. It would include regional coverage as well.

Peers would be situated throughout many organisations. They would encourage people to self-advocate as well as act as a middle person or support person ensuring that other clinicians have more understanding from people that have a lived experience. This could also assist in minimising stigma. Peers would require Cert IV in Mental Health Peer Work, trauma-informed care training. The level of support offered would change to adapt to the specifics of the step consumers are accessing support through.

9. Crisis Cafe

Stage in Stepped Care Model: Potentially all stages, but focus would be on at-risk and step-up/step-down points

Addresses these barriers: Emergency department waiting times, community development levels, need to address suicide prevention, gaps and waitlists

Service description:

The crisis cafe would act as a community based, long-term (if needed) safe space that utilises the knowledge of those with lived experience. It would strengthen the community by creating safe and inclusive environments for all, no matter what walk of life they come from. The space would be staffed by people with Cert IV in mental health and those with trauma-informed care training, so it could fill in the gaps in current care models.

10. Safe Space Model

Stage in Stepped Care Model: At-risk to severe

Addresses these barriers: Inability of emergency departments to treat those presenting to hospital, lack of access to appropriate supports that are currently available

Service description:

The safe space model would match the location of the person living with personality disorder presenting to the need. Safe Spaces would be provided at various access points where people are

most likely to access support and treatment. It would include opportunities for risk assessments, information and linkages, and provide an informal lounge area for those requiring a quiet space. After hours (24/7) access to peer workers and clinicians would be offered and clinicians would be trained in triaging, trauma-informed care, suicide intervention skills, distress tolerance and emotional regulation skills.

11. Continuity of Support

Stage in Stepped Care Model: All stages (brief interventions for mild to moderate presentations)
Addresses these barriers: Gaps between services, between service criteria, between 'right time' for people living with personality disorder, and a lack of understanding of the way relationships impact access to treatment.

Service description:

Such a program would involve the creation of a team that follows people living with personality disorder through the different services. This would resemble a community treatment approach, utilising a more relational team that will support and coach people living with personality disorder, similar to a 'doula' team. In addition, the team would provide people with reminders about meetings and appointments as well as provide reminders about treatment options.

Concluding Statements

Personality disorder has a significant impact on the lives of Australians. As evidenced in the aforementioned Spotlight Report, approximately 6.5% of Australian adults meet the criteria for personality disorder. In addition, it is estimated that around 26% of people presenting to emergency departments for mental health issues have personality disorder, while 25–43% of adult inpatients and 23% of adult outpatients meet criteria for borderline personality disorder. In particular, those people living with borderline personality disorder are 45 times more likely to take their own life than the general population. Building upon this initial work carried out in the Spotlight Report, this report has sought to make the case for Primary Health Networks to take specific action in providing access to services that better support people living with personality disorder.

People living with personality disorder often present with a range of complex needs and face unique challenges accessing services and supports in Primary Care. Their needs vary depending on a range of factors, including geographic location, the cost of services, and if they live with other health or mental health conditions. Those with lived experience of personality disorder often have an increased knowledge and experience of the service system, often over many years, including acute awareness of the failings and gaps in the care available.

Addressing issues around service and program design as well as the training and education of clinicians and service providers are also key to ensuring that the needs of those living with personality disorder are met. Enabling a 'culture change' around how people with lived experience of personality disorder are treated and perceived by services has emerged as an urgent priority.

The following will detail some of the main findings from the workshops, and how they can potentially be implemented within PHN regions.

Consultation and Co-design

- The principles of co-design and lived experience participation were utilised in this project, affording opportunities for meaningful collaboration and knowledge sharing. It is recommended that future consultation engage strategies which bring together key stakeholders into the same room to discuss local needs in their PHN region. For a great deal of consumers and carers, this was the first time they had the opportunity to contribute to discussion alongside clinicians and service commissioners. While

future work should always utilise the traditional aspects of expertise as evidenced by clinicians, PHN staff and those who commission services, the lived experience of people living with personality disorder must be positioned alongside this to guarantee the most effective service design.

- PHNs are encouraged to conduct further independent research, particularly on evidence-based care, as they seek to implement suggestions in this report. The findings of this report are intended to be guiding, not instructional.

The Importance of Training and Education

- A consistent theme that arose throughout the three workshops was the importance of training and education, particularly for health professionals. Participants highlighted the need for more education and training opportunities specific to personality disorder, including for GPs and nursing staff and during undergraduate university degrees in psychology.
- Within health care settings, education and culture change for staff related to the values of inclusion, understanding, respect, tolerance and care of those with personality disorder was viewed as a key action.
- Participants also highlighted the need for other professionals who may interact with people living with personality disorder to be better informed as to how to work with them. Training and education opportunities around personality disorder should be extended to those working within education, social services, employment services, and social housing.

Service Design for Personality Disorder

- The most common theme that emerged during the workshops was the inconsistency of services. Services should be more accessible and inclusive with regards to how potential clients enter services. A greater focus should also be placed on working collaboratively with acute services, particularly emergency services around step up/down transitions.
- Warmth and trust in relationships between those with lived experience and clinicians is of high importance, therefore greater focus should be placed flexibility on leniency and time when working with those with lived experience of personality disorder. This could include advocating for more sessions under the Medicare Benefits Scheme for psychological therapies.
- Personality disorders are some of most stigmatised and discriminated against diagnoses. A focus on humane and respectful treatment goes some way to dismantle this stigma. In addition, this report also advocates for personality disorder to be taken seriously and prioritised due to the fact that the functional impairment associated with such a diagnosis can be enduring.

Appendices

Appendix One: Acknowledgements

This project was undertaken with the generous support of the National Mental Health Commission. The authors would specifically like to acknowledge the support of Daya Henkel, Emily Clay and Christine O'Sullivan.

SANE Australia would also like to express thanks to:

- The PHN representatives who assisted greatly in the development and running of the workshops

- The consumers, carers, clinicians, service providers and PHN staff who participated in these workshops
- SANE team members
- Project Advisory Committee members:
 - Professor Andrew Chanen, Head, Personality Disorder Research, Orygen, the National Centre of Excellence in Youth Mental Health; Professorial Fellow, Centre for Youth Mental Health, The University of Melbourne; Director of Clinical Services, Orygen Youth Health
 - Kelly Clark, lived experience representative
 - Nigel Denning, counselling psychologist, Integrative Psychology
 - Phil Edmondson, Chief Executive Officer, Primary Health Tasmania
 - Aaron Fornarino, lived experience representative
 - Professor Brin Grenyer, Professor of Psychology and Director, Project Air Strategy for Personality Disorders, University of Wollongong
 - Jack Heath, Chief Executive Officer, SANE
 - Maureen Lewis, Interim Chief Executive Officer, National Mental Health Commission
 - Rita Brown, Chair, Australian Borderline Personality Disorder Foundation
 - Janne McMahon OAM, Chair and Executive Officer, Private Mental Health Consumer Carer Network
 - Adjunct Clinical Associate Professor Sathya Rao, Executive Clinical Director, Spectrum Personality Disorder Service for Victoria

Appendix Two: Glossary

Lived Experience – Current or former experience of mental illness (in this context, a personality disorder). A person with lived experience may also be referred to as a ‘consumer’ regardless of whether or not they have accessed a service.

Carer – Family, friends, and other people supporting someone living with a mental illness (in this context, they are a carer of someone with a lived experience of a personality disorder). Being a carer is a voluntary role and is not paid employment.

PHN – network of general practitioners, other primary health care providers, secondary care providers and hospitals working together to facilitate improved outcomes for consumers.

Personality Disorder – A condition characterised by pervasive and persistent patterns of thoughts, emotions and behaviour that significantly deviate from cultural expectations and cause clinically significant distress or impairment (American Psychiatric Organization, 2013).

The following specific types of personality disorder are identified in DSM-5:

- Paranoid personality disorder (PPD)
- Schizoid personality disorder (SPD)
- Schizotypal personality disorder (SZPD)
- Antisocial personality disorder (ASPD; ICD-10 dissocial personality disorder)
- Borderline personality disorder (BPD; ICD-10 emotionally unstable personality disorder)
- Histrionic personality disorder (HPD)
- Narcissistic personality disorder (NPD)
- Avoidant personality disorder (AVPD; ICD-10 anxious-avoidant personality disorder)
- Dependent personality disorder (DPD)
- Obsessive-compulsive personality disorder (OCPD; ICD-10 anankastic personality disorder)

Comorbidity – the presence of one or more additional diseases or disorders co-occurring with (that is, concomitant or concurrent with) a primary disease or disorder (in this context, a diagnosis of personality disorder).

Dialectical Behaviour Therapy (DBT) – involves a combination of CBT techniques with skill development relating to mindfulness, distress tolerance, emotion regulation, and interpersonal effectiveness.

Schema Therapy – focuses on allowing people to meet their emotional needs by implementing adaptive coping styles and healing maladaptive schemas (patterns of thoughts and behaviour).

Appendix Three: Evidence-based treatment for personality disorder

(This table is an excerpt from the Spotlight Report)

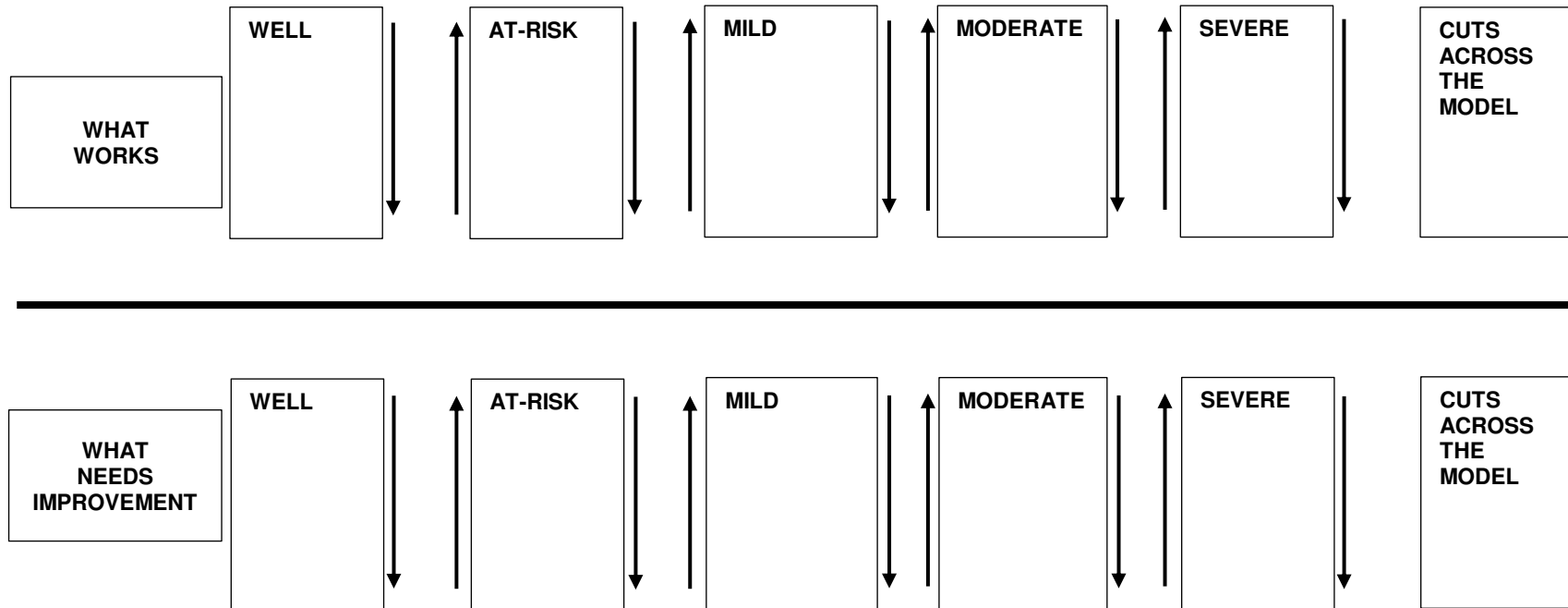
Table 4. Personality disorders psychotherapies supported by Level I (systematic review/meta-analysis) and Level II (randomised control trial) evidence.

Personality disorder	Level I	Level II
PPD	n/a	n/a
SPD	n/a	n/a
SZPD	n/a	n/a
ASPD	n/a ~	CBT; MBT
BPD	DBT; psychodynamic (MBT; transference-focused psychotherapy); schema; CAT; STEPPS	CBT, ACT
NPD	n/a	n/a
HPD	n/a	n/a
AVPD	n/a *	CBT; social skills training
DPD	n/a *	n/a
OCPD	n/a *	Supportive-expressive dynamic therapy; CBT; IPT

~ Meta-analytic evidence supports treatment for conduct disorder, a precursor to ASPD, using CBT and other behavioural interventions, family therapy and group therapy



* Studies combining Cluster C disorders have provided Level I evidence for treatment with CBT, psychodynamic therapy, and interpersonal social skills training

Appendix Four: Workshop ‘Stepped Care’ Activity



Appendix Five: Workshop ‘Priority Investments’ Activity

At the beginning of each workshop, participants were invited to answer the following question in preparation for an activity focussed on unpacking the elements of a good stepped care system as well as exploring areas for improvement for personality disorder and in the system:

 *Based on your reflections of right care/time/place for PD, if you would pick one thing to invest in primary mental health care for PD, what would it be?* 

Participants were also asked a similar question at the end of the workshop.

Results

The following includes a summary of general themes that arose during both pre and post votes. Also included is a list including each item suggested by each participant during each activity.

WAPHA Consultation Workshop

Pre-vote

Topics covered advocacy, training and education, early intervention, services (including alternative services), and treatment options:

- Advocacy (Carer and Consumers)
- Mobile trained teams
- Early interventions
- Education and training in the community
- Trauma-informed care adaptation and training including for peer workers
- Having immediate access
- Staff expertise in creating relational security
- Skills
- Continuity of care – having long term case managers
- Universal mental wellbeing training in school curriculum
- Trained mental health clinicians as care navigators who are mobile and supported by a sound clinical infrastructure
- Telehealth mental health services
- Education about the biological, social, and psychological causes of emotional disorder so it becomes part of general knowledge, like eating well
- Workforce development – early intervention/detection/prevention
- Personality disorder specific training for clinicians that is trauma-informed.
- Sub-acute, residential/respite for people with BPD
- Educate clinicians on trauma-informed care
- Ongoing psychological service, DBT
- Out of hours crisis café (safe space)
- Comprehensive and funded approach to personality disorder across Western Australia that advances the best outcomes for people
- Training for all staff
- Peer workers
- Platform of knowledge (similar to Health pathways)

Post-vote

*Please note that for the workshop at the WAPHA, when participants were asked the question at the end of the workshop, they were asked specifically about investment in early intervention within primary health care for personality disorder).

Topics covered training and education, services (including alternative services), and treatment options:

- Education!
- Crisis café model (out of hours and community based)
- School based programs
- Provide primary health providers with a simple diagnostic tool for identifying personality disorder defined as a perpetuating pattern of maladaptive behaviours
- 40 personal consultations per annum with psychologist under Medicare (or clinical social work)
- More DBT skills groups
- Effective screening and follow up in primary health for mental health
- DBT counselling for primary care consumers
- DBT counselling
- Have mental health specialists and mental health nurses in GP surgeries and schools
- Early diagnosis and treatment
- Educate and support GP's to deliver what is needed
- Telehealth services
- Earlier diagnosis and recognition of BPD/PD
- Regular and unlimited psychologist/Occupational Therapist, social worker sessions
- Break down silos between service systems investing in peer/social/youth workers
- Comprehensive and funded services planned and implemented across Western Australia for people experiencing personality disorder for individuals, carers, and consumers
- Long term education and intervention for children and caregivers following trauma
- 'One stop GP shops' with co-located peer support, mental health and AOD workers
- Support and training for GPs
- Train various professionals to do DBT! And extend MBS sessions beyond 10 sessions
- Improving staff attitudes towards help seeking. Seeing it as a positive rather than stigmatising it.

CESPHN Consultation Workshops

Pre-vote

Topics covered services (including alternative services), research, education and training, and treatment options:

- BPD/PD short term crisis psych dedicated places
- Research
- More training and focus on staff self-care for clinical and non-clinical supports (reduce burnout, better support)
- Training for clinicians that is co-facilitated with a consumer and an 'expert clinician'
- DBT programmes for varying severity of problems
- Trauma therapist
- Supported (funded) referrals i.e. support until appropriate service found
- Credential clinicians with the right experience
- Individual therapy that is adequate and effective
- Early intervention services that are easy to access and easy to meet entry criteria
- DBT (several votes)
- Educate and inform GPs cohort
- Comprehensive support for people discharged from hospital after a short admission
- Emotional regulation groups in schools

Post-vote

Topics covered training and education, services (including alternative services), consultation and engagement, and treatment options:

- Bulk billing psychologists
- Training for staff around psychological knowledge and trauma-informed care
- Clinicians and GPs
- Directory of personality disorder services in the area put together by the PHN
- Educate and inform the public via NGOs and commonwealth-based organisations
- Funding for DBT skills and support groups co-facilitated by peers and clinicians – fund Project Air peers!
- Easy to access early intervention – e.g. short DBT skills courses
- More education for clinicians to reduce stigma
- Individual therapy (with some family if needed)
- DBT
- Forums – consultation
- Education across the board – all clinicians, teachers etc.
- Follow up support for people discharged from hospital after a short admission
- Midwife system – more clinicians
- DBT in schools

- Groups in schools
- Family Connections
- Peer workers

OURPHN Consultation Workshop

Pre-vote

Topics covered training and education, services (including alternative services), and treatment options:

- Clinician education
- Invest in peer support within Emergency Department and alternate models for care in community e.g. 'Living room model'
- Training
- Education to reduce stigma in mental health services
- More psychologist appointments covered/funded
- Broader understanding of BPD
- Health promotion – change language from 'attention seeking' to 'attachment seeking'
- Education and reduce stigma in services
- Individual care plans, reading all patient notes, listening to consumer
- After hours safe space model linked to Emergency Department
- More crisis safe spaces (with trained staff)
- Reducing stigma in the mental health services
- More education for primary health care providers
- DBT groups across the region with 1:1 therapists and 1:1 peer support
- Mindfulness
- Personality disorder specific service with access to DBT and safe space
- Meditation and breathing for first part of call
- Tailored training for allied health professionals so we can achieve personality disorder 'champions'
- Specialised community-based workers to provide intervention – case management
- Safe houses!
- Emotional CPR for everyone in community

Post-vote

Topics covered training and education, services (including alternative services), and treatment options:

- More psychologist appointments available throughout the year (DBT)
- 'One stop shop' for all things PD including DBT skills, carer support, training and education, support staff, safe space, phone coaching, individual therapy
- More education and specialised allied health for PD
- Hub model DBT, safe spaces, and peer support
- Training and education
- BPD centre
- Education

- Facilitators being trained in DBT skills nation wide
- Education within primary health HHS (Hospital and health service), and frontline services
- Clinical education by people with lived experience
- Investment in alternatives to hospitalisation e.g. safe spaces/peer models and building community capacity
- Increased interagency collaboration, memorandums of understanding, and resource sharing to run DBT well
- Safe space alternate to hospital, education and training, improve care, and reduce stigma
- Broader understanding in community of what BPD looks like
- Peer and mentor support and education
- Availability of other options for treatment and recovery instead of the DBT model
- Research and implement other alternatives to DBT
- Specialised education/workers to provide support
- Safe space model with wholistic care allied network involved
- Emotional CPR training
- Safe space model