

Blueprint for Action



NSW Service Plan
for People with
Eating Disorders
2021-2025

Inclusion
Excellence
Collaboration

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Glossary of Terms

TERM	DEFINITION		
AMHS	Adult Mental Health Service		
AN	Anorexia Nervosa		
ANZAED	Australia & New Zealand Academy for Eating Disorders		
ASD	Autism Spectrum Disorder		
ARFID	Avoidant Restrictive Food Intake Disorder		
BED	Binge Eating Disorder		
BN	Bulimia Nervosa		
CALD	Culturally and Linguistically Diverse		
CAMHS	Child and Adolescent Mental Health Service		
CBT-E	Cognitive Behavioural Therapy for Eating Disorders		
C-PTSD	Complex Posttraumatic Stress Disorder		
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition		
ED	Eating Disorders		
FTE	Full-time Equivalent		
GP	General Practitioner		
HASI	Housing Accommodation Support Initiative		
ICD-11	International Classification of Diseases, 11th Revision		
IOI	InsideOut Institute for Eating Disorders		
LGBTI	Lesbian, Gay, Bisexual, Transgender, and Intersex		
LHD	Local Health District		
MFBT	Maudsley Family Based Treatment		
NEDC	National Eating Disorders Collaboration		
NGO	Non-government Organisation		
NICE	National Institute for Health and Care Excellence		
NSW	New South Wales		
OSFED	Other Specified Feeding and Eating Disorder		
PBU	Peter Beumont Unit		
PHN	Primary Health Network		
PTSD	Post-traumatic stress disorder		
SHN	Specialty Health Network		
SUD	Substance Use Disorder		
UFED	Unspecified Feeding or Eating Disorder		
YMHS	Youth Mental Health Service		
		Local Health Districts	
CCLHD	Central Coast Local Health District		
FWLHD	Far West Local Health District		
HNELHD	Hunter New England Local Health District		
ISLHD	Illawarra Shoalhaven Local Health District		
MLHD	Murrumbidgee Local Health District		
MBMLHD	Nepean Blue Mountains Local Health District		
MNCLHD	Mid North Coast Local Health District		
NNSWLHD	Northern NSW Local Health District		
NSLHD	Northern Sydney Local Health District		
SESLHD	South Eastern Sydney Local Health District		
SNSWLHD	Southern NSW Local Health District		
SWSLHD	South Western Sydney Local Health District		
SLHD	Sydney Local Health District		
WNSWLHD	Western NSW Local Health District		
WSLHD	Western Sydney Local Health District		
		Specialty Health Networks	
JH&FMHN	Justice Health and Forensic Mental Health Network		
SCHN	Sydney Children's Hospital Network		
SVH	St Vincent's Hospital		
		Health Pillars	
ACI	Agency for Clinical Innovation		
BHI	Bureau of Health Information		
CEC	Clinical Excellence Commission		
HETI	Health Education and Training Institute		



SECTION 1

Overview

INTRODUCTION

Purpose

This is a compendium document to the *NSW Service Plan for People with Eating Disorders 2021-2025* and should be read in conjunction with it. This document outlines the rationale, key principles and service system framework that underpins the service plan for the improvement in the NSW Health response to people with eating disorders. It builds on the first five-year plan, the *NSW Service Plan for People with Eating Disorders 2013-2018*. NSW Health aims to improve the lives of people at risk of developing or living with an eating disorder and the lives of their families, carers and communities. This will be achieved by embedding the care of people with eating disorders into core business for NSW Health and strengthening the service system response.

This Service Plan, to be implemented over five years, will continue to build and progress on the foundations that were set in the initial Service Plan. It aims to improve health outcomes, improve access to care; improve the quality of care and deliver efficient and effective care. NSW Health acknowledges that Local Health Districts (LHDs) and Specialty Health Networks (SHNs) are at different stages of implementation of the previous Service Plan and therefore will have different approaches to how they implement this Service Plan. The intention of the Service Plan is to outline the principles and service response across the whole of health system for the delivery of health care to this population.

The Service Plan is centrally coordinated and locally driven, considering local population needs. The Service Plan represents NSW Health's plan to deliver services to the target population at both a state and local level. All LHDs are required to deliver services locally where possible; and SHNs including Sydney Children's Hospital Network (SCHN), St Vincent's Hospital (SVH) and Justice Health and Forensic Mental Health Network (JH&FMHN), to their specific populations. Some of these such as Far West LHD and JH&FMHN, will be new to this Service Plan. The Service Plan also outlines strategies to work with partners in care that are external to NSW Health but provide service planning and services that are critical to the care of people with an eating disorder and their families and carers. This includes partnerships with Primary Health Networks (PHNs), General Practitioners (GPs), headspace, private hospitals and private practitioners.

The Service Plan describes opportunities to minimise adverse outcomes while acknowledging:

- the complexity of eating disorders;
- the historic barriers to care; and
- local versus statewide priorities for limited resources.

The Service Plan provides the overall framework for health services in NSW and the basis for LHDs and SHNs to develop Local Implementation Plans and protocols to improve the health response to people at risk of developing or living with an eating disorder, and their families and carers. The Service Plan includes an overview of the status of eating disorders; identifies where people receive care; and identifies the strategic priorities and associated goals over the next five years to improve the health of people at risk of or with a lived experience of an eating disorder. This document showcases examples of existing good practice and highlights innovation across NSW to build success.

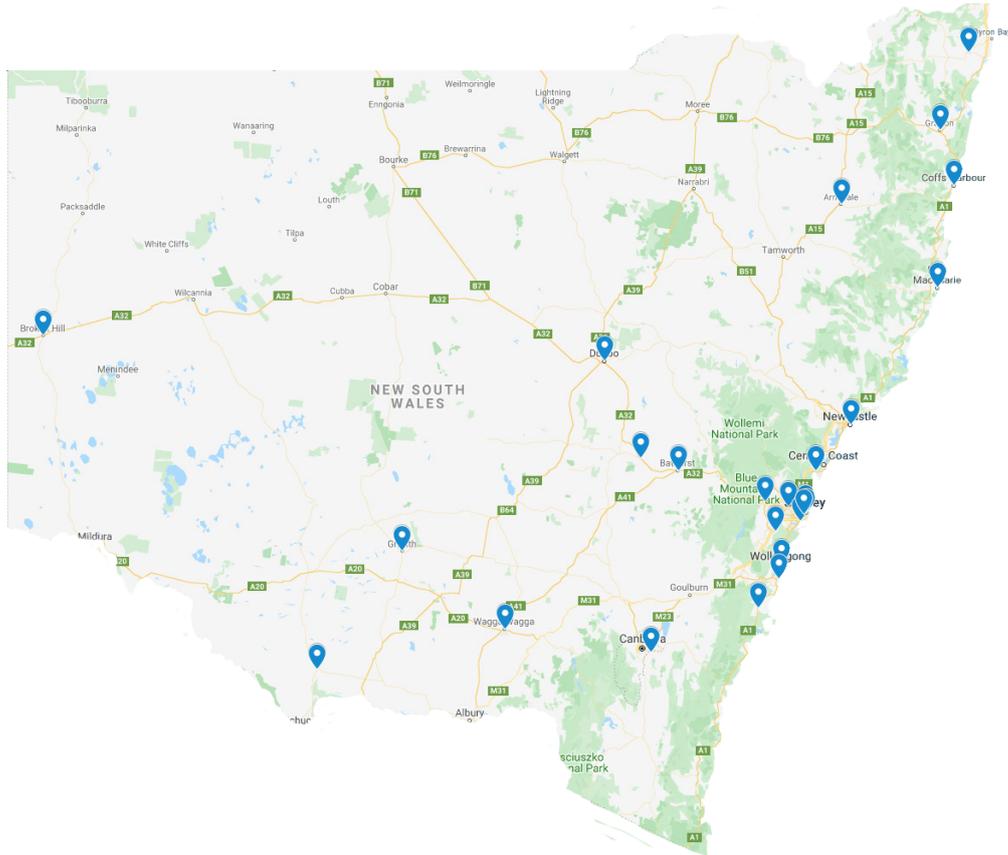
Development of the Service Plan

The Service Plan is funded by the NSW Ministry of Health. The development of the Service Plan was led by the InsideOut Institute for Eating Disorders (IOI), and is informed by the independent evaluation of the first Service Plan, key stakeholder consultations, including people with a lived experience and families and carers, and a statewide consultation process.

The NSW Statewide Eating Disorders Steering Committee advised on the consultation process. The Steering Committee is coordinated by the Mental Health Branch of the NSW Ministry of Health. As part of the consultation process, workshops were conducted in each LHD and SHN across NSW. These workshops were attended by people in key services across the LHD, as well as representatives from local PHNs, people with a lived experience of an eating disorder, and families and carers. Feedback was also sought from other Branches and Pillars of the NSW Ministry of Health.

Approximately 300 people attended consultations workshops across NSW

Figure 1. Location of consultations across NSW



Target Audience

NSW Health acknowledges that eating disorders are a whole of health concern. While eating disorders are a mental illness, there are significant associated medical complications. More than any other mental illness, people with an eating disorder are likely to require services from mental health, medical and allied health services in combination. Often, integrated and simultaneous care is required to ensure that both mental health and medical needs are treated.

People with eating disorders can enter the health system at any entry point to care; and they may have multiple areas of their health impacted by the disorder, which sometimes necessitates treatment from many different sectors of the health service. This requires a broad and far reaching Service Plan. A comprehensive Service Plan will ensure that no matter where a person with an eating disorder enters the health system, they are identified and supported to receive the care they require from the most appropriate service. Some services will be likely to deliver very little direct service provision for people with eating disorders apart from identification and referral, while others will be highly involved in their treatment.

The Service Plan outlines strategies for NSW Health to work in partnership across LHDs, SHNs, and NSW Pillars (ACI, BHI, CEC, HETI); and with external service partners to deliver improved care to people with eating disorders and their families and carers. There are also a number of organisations outside of NSW Health who play a lead role in the health promotion space related to eating disorders, such as Butterfly Foundation, that will form part of the strategic partnerships to carry out this work. Service partners may also wish to use the Service Plan to guide their strategic planning.

Scope of the Service Plan

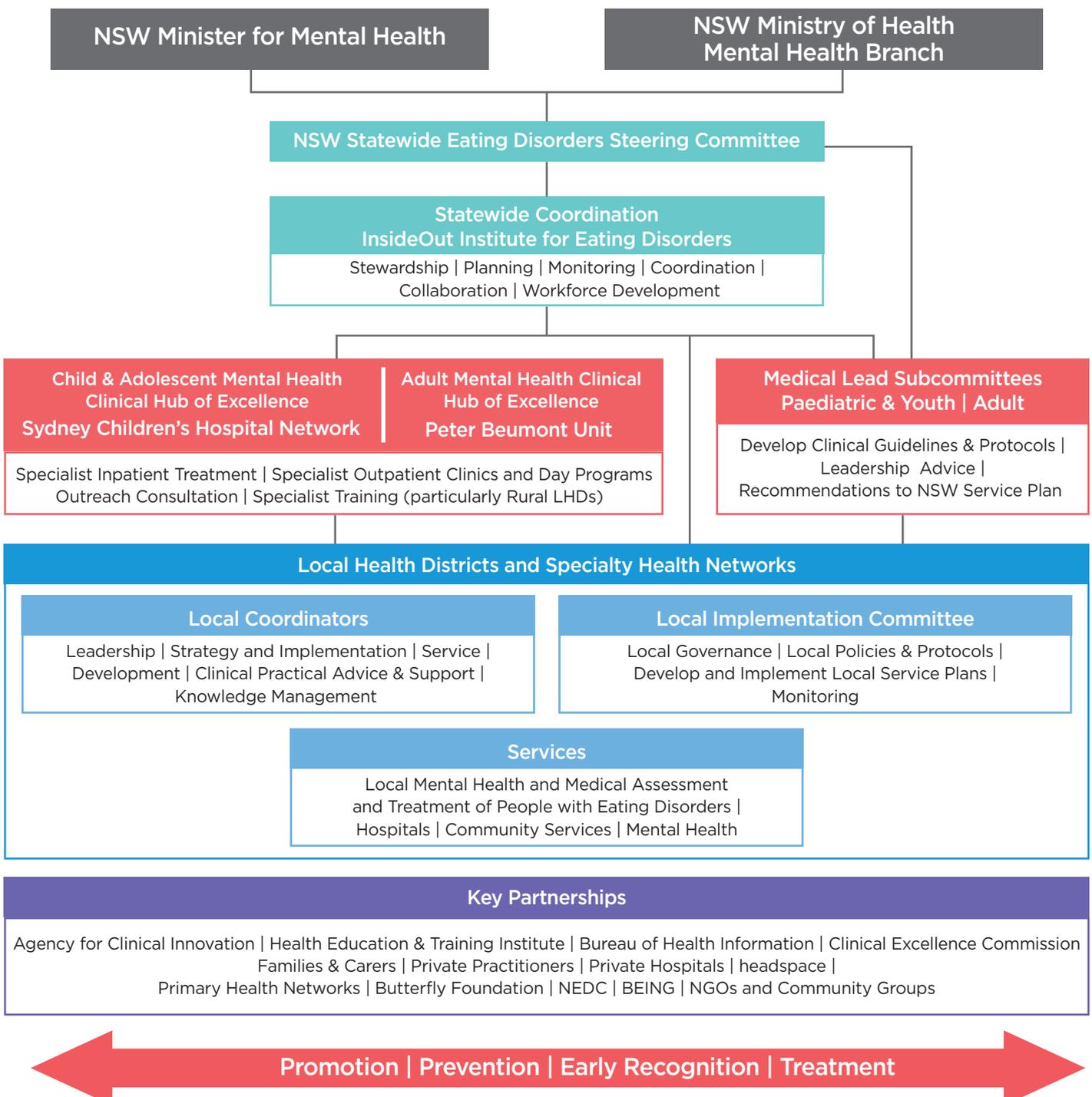
The Service Plan covers the wide spectrum of eating disorders as described in the DSM-5 (excluding Pica and Rumination Disorder) and covers all age groups across the lifespan and all diversity groups. For further information see 'About Eating Disorders Section'. Eating disorders can affect people of any age and services covering the lifespan need to be prepared to identify, assess and appropriately treat the person with the illness. Health Promotion also plays an important role in prevention; therefore, this plan will also have a focus on health promotion and prevention.

While mental health services that currently treat eating disorders will continue to see those with Anorexia Nervosa (AN), Bulimia Nervosa (BN), Avoidant Restrictive Food Intake Disorder (ARFID) and Other Specified Feeding and Eating Disorder (OSFED), there may be others in the health services system who will see people with the other disorders listed. For example, a health service delivering care to people with obesity may provide treatments for any comorbid eating disorder (e.g. Binge Eating Disorder [BED]).

While obesity is not an eating disorder, eating disorders and disordered eating may contribute to the increase in overweight and obesity across the lifespan. It is often misunderstood that eating disorders are only found in people who are underweight. This Service Plan provides an opportunity for services across the spectrum to work together to improve health outcomes across all health sectors.

Operationalising the Service Plan – Governance Structure

Figure 2. Service Plan implementation governance structure



BACKGROUND

What is an Eating Disorder?

Eating disorders are a group of complex mental illnesses characterised by disturbances in thinking and behaviours around food, eating and body weight or shape. The quality of life impacts experienced by persons affected may be significant and wide-ranging, including consequences to psychological, social (e.g. work, family) and medical (or physical) well-being.

In Australia, eating disorders are clinically diagnosed using one of two main diagnostic classification systems for mental disorders: The World Health Organisation ICD-11 and the American Psychiatric Association DSM-5. Whilst both classification systems are widely used across various settings, this Service Plan will refer to eating disorders as defined by the DSM-5.

The DSM-5 Classification System outlines a number of feeding and eating disorders:

- **Anorexia Nervosa (AN)** is a serious and potentially life-threatening mental illness characterised by; persistent and restricted food and fluid intake leading to significantly low body weight and an inability to maintain a minimally normal weight for age and height, intense fear of weight gain, disturbance in body image, and a denial of illness severity.
- **Bulimia Nervosa (BN)** is characterised by repeated binge eating episodes followed by extreme weight control behaviours (e.g. purging, or laxative misuse) to compensate for bingeing. Self-evaluation is greatly influenced by one's body weight or shape. People with BN may be normal weight, slightly underweight or may even gain weight.
- **Binge Eating Disorder (BED)** is characterised by repeated episodes of bingeing, often with a sense of lack of control and marked distress following a binge. People with BED do not engage in any compensation behaviours following a binge, and may be of normal weight, overweight or obese.
- **Avoidant Restrictive Food Intake Disorder (ARFID)** is characterised by persistent problems with feeding or eating which result in a failure to meet appropriate nutritional and/or energy needs. Unlike AN and BN, ARFID is not characterised by body weight/shape disturbances. While most common in infants and young people, may also occur in adults.
- **Other Specified Feeding and Eating Disorder (OSFED) and Unspecified Feeding or Eating Disorder (UFED):** people with OSFED or UFED present with significant clinical symptoms of AN, BN, or BED but do not meet diagnostic criteria. OSFED and UFED may be as severe as AN and BN.
- **Pica** is characterised by the persistent eating of substances that have no nutritional value such as hair, dirt or paint.
- **Rumination Disorder** is characterised by the repeated regurgitation of partially digested food which may then be re-chewed, re-swallowed, or spit out.

Correct identification of an eating disorder is crucial to early identification, early intervention, informing treatment planning and recovery. While core eating disorder symptoms may be present during initial assessments, eating disorder manifestations are highly idiosyncratic and experiences may vary between individuals and over time [3]. The complex, variable, and fluid nature of eating disorder presentations necessitate a multi-dimensional and flexible approach to assessment, clinical diagnosis, and treatment planning within health systems.

Psychiatric and Medical Comorbidities

Eating disorders are a complex, multifactorial convergence of biological, familial, psychological and psychosocial variables [4] and there is great variability in clinical presentation. Complexity increases in the context of other comorbid medical and mental illnesses, presenting a challenge for traditional eating disorder treatments as stand-alone therapies. People with comorbidity tend to have poorer prognosis, increased social and psychosocial impairment, chronic course of illness, and have higher rates of inaccurate diagnosis [5-7].

Medical

Medical complications associated with eating disorders have the potential to affect every organ system including; general health, oral and dental, cardiovascular, gastrointestinal, neurological, endocrinological, dermatological, and metabolic and therefore people with an eating disorder require thorough and close medical monitoring [8].

Services should:

- Take a multi-dimensional and comprehensive approach to assessment, diagnosis, and treatment planning with an emphasis on biopsychosocial formulation [1]
- Consider the role of medical and psychiatric comorbidities in eating disorder presentations
- Deliver treatments in parallel or one-after the other, and should be informed by; the best available evidence, severity and complexity of the eating disorder including comorbidity, the persons level of functioning and personal (and family/carer) preferences where indicated [2]
- Provide joint, collaborative care with a range of appropriate health professionals to support the most effective treatments for people with eating disorders and co-occurring conditions [2]

People with eating disorders can experience a range of nutritional deficiencies/disorders which need to be managed. These range from the effects of malnutrition, to specific vitamin deficiencies, which need to be recognised and treated.

Diabetes is a known risk factor for the development of an eating disorder. Studies suggest that young women with type 1 diabetes are at 2.4 times increased risk of developing an eating disorder than their peers without diabetes [9]. Intensive diabetes management programs, which typically have a concentrated focus on diet and insulin management, are said to be a contributing risk factor for the development of an eating disorder. In a subset of people with co-occurring diabetes and eating disorders, insulin restriction (i.e., reducing insulin doses or omitting necessary doses altogether) is a commonly utilised weight loss strategy. Recurrent insulin restriction places people at a higher risk of medical complications associated with Diabetes and at a three-fold increased risk of mortality [10].

Eating disorders coupled with diabetes are complex presentations to treat, due to the medical and psychiatric complications associated with these two conditions and the way they interact. Little is known about the best treatment approach for this group of at-risk individuals, however evidence-based standards strongly support a collaborative and integrated multidisciplinary approach involving a range of health professionals equipped to manage both conditions together. Clinicians working with people with diabetes should be vigilant for indications or concerns about body weight and shape, unusual patterns of exercise, low calorie meal plans, and unexplained and repeated medical complications.

Psychiatric

People with eating disorders commonly present with psychiatric comorbidity. More commonly, they experience co-occurring psychiatric conditions or symptoms such as mood changes, anxiety, depression, substance use, PTSD, Complex Trauma and/or personality disorders [11, 12], as well as somatoform, dissociative, and impulse control conditions [11].

Hudson and colleagues [12], in their community sample of 18-60+ year-olds, found comorbidities in 94.5% of people with BN; with 80% of them exhibiting symptoms of an anxiety disorder, 70.7% of a mood disorder, 36.8% of a substance use disorder, and 63% of an impulse-control disorder. In their sample, approximately 56% of people with AN, and 79% of people with BED met the criteria for an additional disorder. Psychiatric comorbidity in eating disorders occurs across the lifespan, as indicated by studies of children and adolescents [13-15], and middle-aged and older adults [16-20].

Eating Disorders, Substance Use Disorders and Trauma

A high rate of comorbidity between substance use disorders and eating disorders is well documented [21, 22]. Studies have reported that up to 50% of people with an eating disorder will use alcohol or an illicit substance to problematic levels, compared with 9% of the general population, and that 35% of people who use alcohol or illicit substances to problematic levels have an eating disorder, compared to a 3% prevalence in the general population [23]. In another review comorbidity rates of 17% and 46% were reported, respectively [24].

Eating Disorders can be extremely complex mental illnesses, as is their management. The complexity, severity and risk associated with eating disorders increases dramatically in the context of substance use and may result in several adverse outcomes associated with ED and SUD comorbidity [21], such as:

- Severe medical complications
- Prolonged recovery time from the ED (or SUD)
- Poorer functional outcomes
- Increased frequency and/or severity of psychiatric comorbidity
- Higher rates of suicide and suicide attempts
- Higher mortality rates

People with comorbid EDs and SUDs have higher rates of childhood trauma (i.e. Complex Posttraumatic Stress Disorder (C-PTSD)) and PTSD than any disorder alone [22].

Furthermore, psychiatric comorbidity with PTSD or C-PTSD and eating disorders has been well documented [11, 25]. A study found that 45% of participants with eating disorders had a history of sexual abuse or other types of childhood abuse or trauma [26]. Carter et al. [27] found that 48% of eating disorder unit inpatients reported a history of childhood sexual abuse. In another study, it was noted that women with histories of childhood physical and sexual abuse were three times more likely to develop eating disorder psychopathology than women who reported no abuse [28]. Trauma has also been identified as a risk factor for the development of eating disorder symptoms in children and adolescents, and often persists into adulthood [29]. A controlled comparison study of 10-15-year-old females found that those with an abuse history had higher rates of weight dissatisfaction, increased dieting and purging behaviours, consumed significantly smaller amounts of food when upset, and had higher rates of thin body ideal [30].

Poor treatment outcomes have been observed in people with eating disorders who have experienced childhood trauma [25, 26]. This represents a challenge for the service system and requires a multidimensional and comprehensive approach to assessment, diagnosis and treatment planning that extends beyond standard approaches to care.

Rationale

Eating disorders impact over one million Australians [31]. They are complex mental disorders that result in significant physical impairment and have high rates of mortality [31, 32] and low rates of early detection and intervention. People with eating disorders experience higher rates of comorbid mental health problems than the general population, including depression and anxiety disorders, substance use and personality disorders [33]. They can also experience significant physical comorbidities, such as higher levels of cardiovascular disease and neurological symptoms [34], and are likely to experience stigma and discrimination as a result of their eating disorder. Treatment of eating disorders requires a response to the underlying pathology but also requires complimentary, integrated responses to relevant mental and physical health comorbidities.

While steps have been taken to reduce misconceptions around eating disorders, stigma remains a serious issue. There are widespread inaccurate assumptions about eating disorders (for example, that the illnesses relate to contemporary western societies and cluster in certain socioeconomic groups) which in turn has an adverse impact on treatment responses. Stigmatising views about eating disorders are not limited to uninformed members of the general public; however, they may also be subscribed to by health professionals with limited exposure to eating disorder education.

Historically, eating disorders have been treated in isolation. A late-stage intervention approach has marked the health system, with hospital admissions governing as the 'primary' pathway to care. The difference in treatment costs between therapy delivered early in the illness trajectory and a late stage response, resulting in hospitalisation, is significant [34]. If detected and treated at the right time full recovery is possible.

There is an urgent need to transform the health system from late to early-stage intervention focus and equip it with systems to assess and monitor performance, as well as scalable and effective models of care. While much progress was made in the first five years, the gains are still fragile in many areas of the state. This second phase of service development will help to embed service system change into the future.

A set of guiding principles, strategic priorities and immediate actions will help to achieve this vision.

The progress made to date

The previous NSW Service Plan was ambitious in its scope. It identified the need for large scale system changes for eating disorders requiring a response from the whole health system. In achieving this goal, it is acknowledged that LHDs and SHNs were presented with a significant task. Whole system reform requires time, investment, strong leadership and the appropriate mechanisms in place to support change. It is acknowledged that many LHDs and SHNs are only partially the way through implementing the previous Service Plan, while others are just commencing.

The last five years served as a critical development phase for the integration of eating disorder services across the whole of health. Through dedicated and sustained efforts by LHDs and SHNs, the Statewide Implementation Committee and the InsideOut Institute for Eating Disorders (IOI) much progress against key Strategies outlined in the Service Plan (2013-2018) were made. While implementation is on track, progress is varied between LHDs with some having established formalised clinical pathways to care, and others continuing to progress in their development. Variances in stage of implementation is to be expected between LHDs, as they are diverse in their makeup and have unique challenges and barriers to overcome in bringing about broad systems change.

An independent evaluation of the *NSW Service Plan for People with Eating Disorders 2013-2018* was carried out and completed in early 2018. The evaluation identified key progress and quality and improvements that were made as a result of implementation of the Service Plan.

The first service Plan incorporated 3 strategic priorities. Summary of key progress against each is noted below.

1. The development of local service and workforce development plans for people with eating disorders in every LHD in NSW

- All LHDs developed a Local Service Plan for Eating Disorders in 2016, reflecting key aims and strategic priorities of the NSW Service Plan.
- All LHDs developed local steering committees as the local governance structure to oversee the development and implementation of the local service plan.

- Funding by the NSW government saw the appointment of an Eating Disorders Coordinator in each LHD. Local coordinators have had a pivotal role in planning and overseeing implementation of Local Plans.

2. Support structures and roles to assist LHDs developing and implementing local service and workforce plans

- A Statewide Implementation Committee was established to oversee and guide implementation of the Service Plan. The committee has provided effective leadership for the NSW Service Plan and support for local service development
- Two Medical Leads Subcommittees were established; one for children and adolescents, and the other for adults. They comprise medical and psychiatry leads from most LHDs and SHNs, representing the medical and psychiatric care of people with eating disorders.
- Clinical Guidelines were developed at the state level (e.g. Guidelines for the Inpatient Management of Adult Eating Disorders in General Medical and Psychiatric Settings in NSW; NSW Eating Disorders Toolkit: A Practice-Based Guide to the Inpatient Management of Children and Adolescents with Eating Disorders), and at the district level (including care plans and inpatient admission guidelines).
- Implementation funding supported the development and delivery of targeted statewide training packages to key health professionals across disciplines and settings in all LHDs. See Figures below.
- Health professionals reported an increase in confidence in being able to treat patients with eating disorders as a result of training & supervision/consultation support received.

3. The targeted enhancement of existing eating disorders specialist services

The Ministry of Health provided funding to enhance specialist services provided by the Child and Adolescent Service at the Sydney Children's Hospitals Network (SCHN) and the Peter Beumont Unit (PBU) Adult Specialist Service, based at Royal Prince Alfred Hospital. Funding enhancements were also provided to existing specialist services at Hunter New England, Illawarra Shoalhaven, and Central Coast LHD.

Figure 3. Online training courses completed by NSW Health Professionals up to the end of 2019



Figure 4. Face-to-face training courses completed by NSW Health Professionals up to the end of 2019



The enhancements to specialist services and specialty health networks have enabled the development of diverse and improved clinical programs for the most severely unwell, their families and carers. The Outreach services offered by the specialist services, via their provision of specialist case consultation and training and education to LHDs and SHNs, has been pivotal in increasing workforce capacity and capability and health professionals' confidence in treating very ill people with eating disorders locally.

Current Service Gaps

While substantive progress has been made over the past five years, implementation remains in its early stages and there is yet much work to be done in ensuring the continuance of eating disorders reform. There are both clinical and operational challenges and barriers experienced to varying degrees across NSW requiring further development and focus over the next phase of the Service Plan.

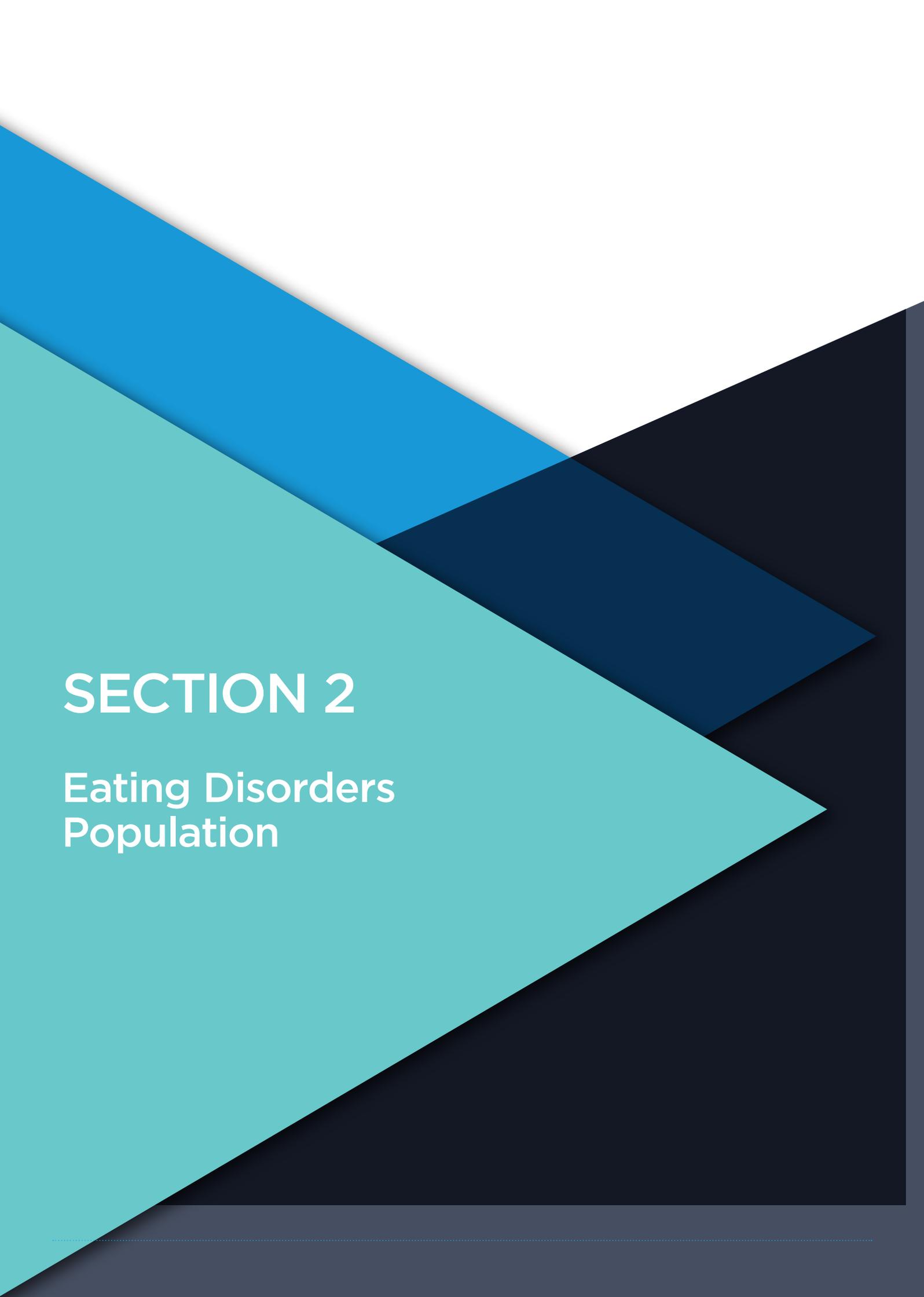
Large scale system change involving the whole of health takes several years and requires a sustained and targeted effort. Strategic effort is required to ensure; maintenance of gains made in the first phase, the embedding of protocols for the assessment and treatment of eating disorders into permanent core health practices, and to address remaining gaps in service delivery and stigma. Data in eating disorders is patchy and will need to be improved to ensure we can measure success going forward.

Most LHDs remain at an early stage of implementation and the changes achieved are still fragile. Inequities in access to care across districts and within LHDs still exist, especially for those who live in rural and remote areas and must continue to be addressed.

Much progress was made in establishing local pathways to inpatient care for people with eating disorders who are in urgent need of medical care. Some LHDs have developed formalised admission pathways while others remain in progress. Some have, or are working towards, developing local policies, guidelines and models of care.

Innovative models of integrated care between medical and mental health services are required to ensure appropriate care for people with eating disorders, including those with comorbidities and complex care needs. Community pathways are still at an early stage of development, with pathways in some LHDs still requiring considerable work.

Promotion and prevention were not part of the previous Service Plan and so this work is at a very introductory stage and will require consideration.



SECTION 2

Eating Disorders Population

NSW POPULATION

According to the 2016 census the population of NSW stood at 7,739,274. Due to lack of good data on people with eating disorders it is difficult to determine accurately the prevalence rate, which can range from four percent to nine percent. The prevalence for each eating disorder varies significantly. For the purposes of this plan we are using the conservative estimate of five percent point prevalence which includes AN, BN, BED and some of OSFED. We do not have prevalence rates for the remaining eating disorders.



Eating disorders affect people of **all ages, genders & backgrounds**



Eating disorders have among the **highest mortality** rate of any mental illness

This means that conservatively about 400,000 people across NSW will at any one time be experiencing one of the most prevalent eating disorders. The two figures below extrapolate this estimated prevalence rate for each LHD.

Figure 5. Metropolitan LHDs predicted prevalence based on 2016 census data.

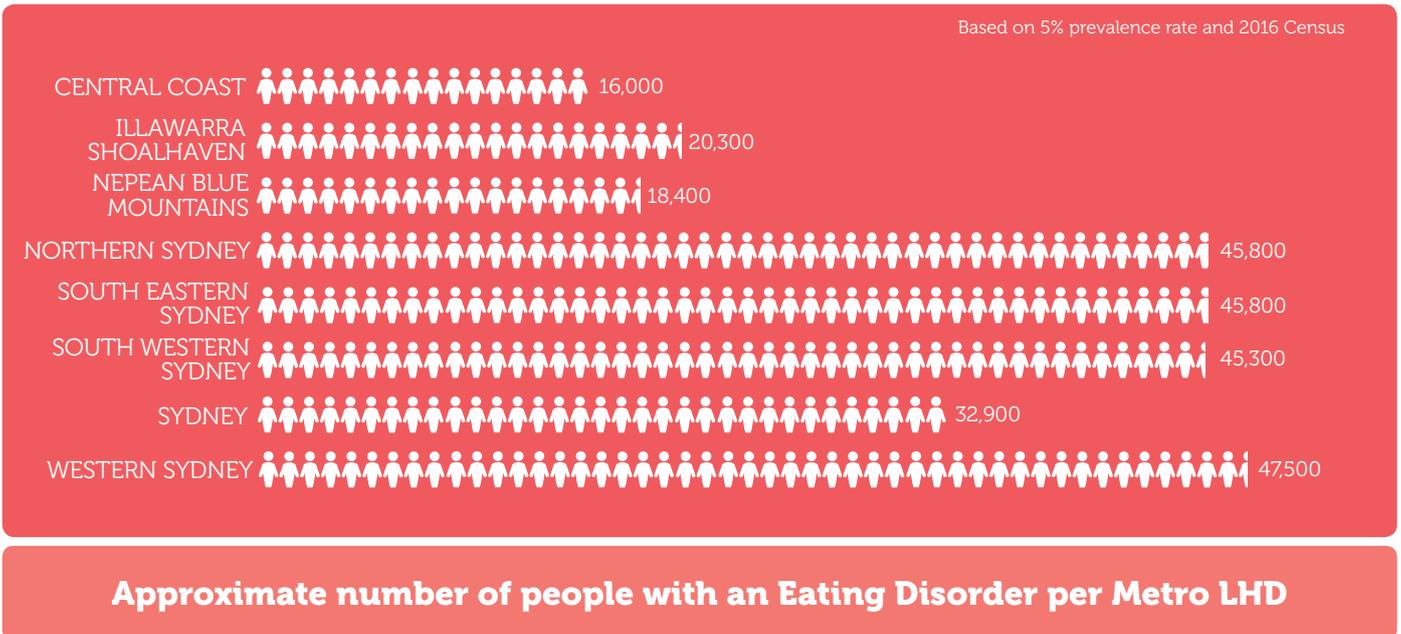
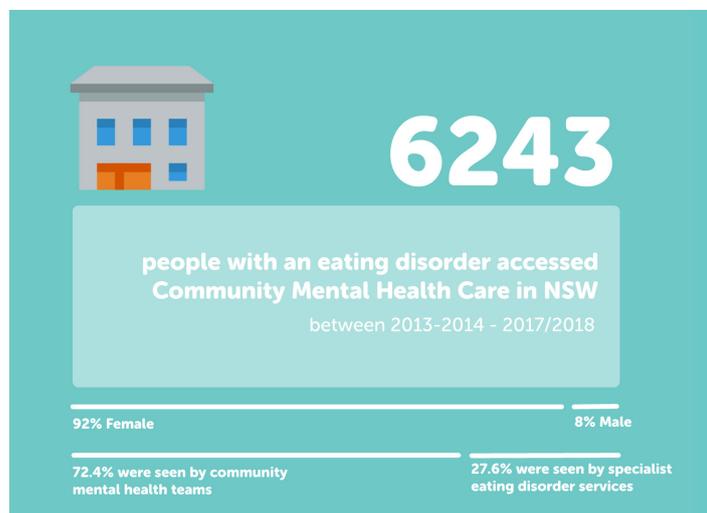
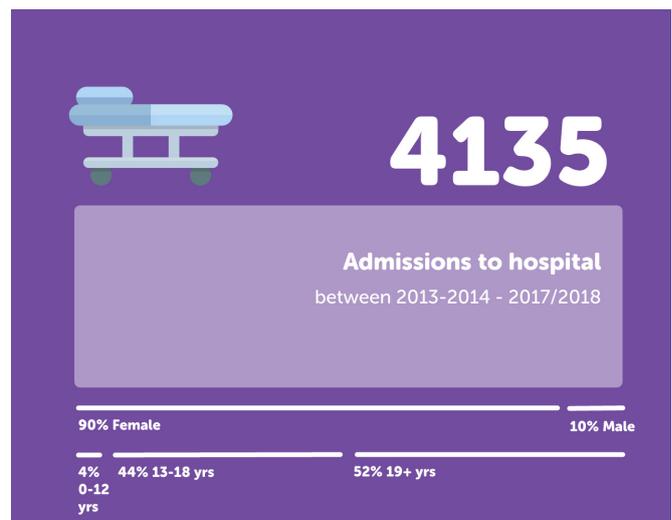
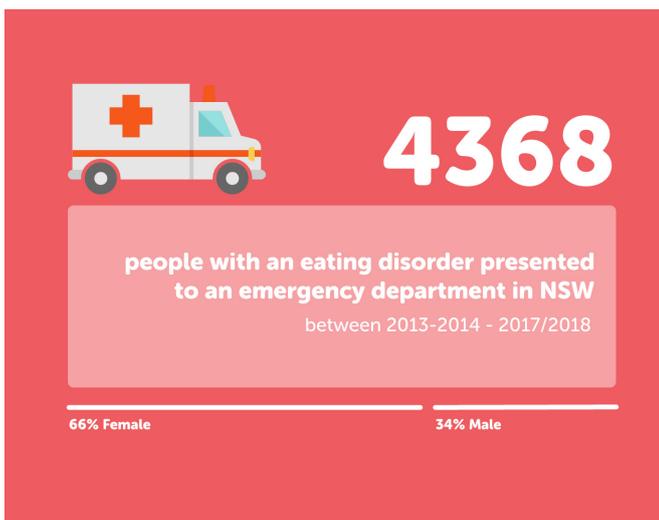


Figure 6. Rural LHDs predicted prevalence based on 2016 census data.



Public Service Usage 2013-2018



EATING DISORDERS ACROSS THE LIFESPAN

Traditionally eating disorders have been considered illnesses impacting adolescent girls and young women, however; it is critical to recognise that the impacts of eating disorders are far more extensive and, in reality, affect a much broader fraction of the community, and in fact occur across genders and across the lifespan.

This supports the need for life span specific competencies in the workforce to appropriately identify, assess and treat. It also requires specific care considerations to be taken in the planning and delivery of eating disorder treatments in accordance with the person's stage of life and associated physical and psychological care requirements. Taking a person-centred approach, this section identifies what should be considered in the delivery of services across the lifespan. The services involved in the delivery of care to the specific age groups should consider the suggestions in their service planning and delivery.

Perinatal

Services should:

- Incorporate screening and assessment for eating disorders in pregnant women and women who present antenatally and postnatally, particularly in women with a previous history of an eating disorder, in health settings where they may present for care
- Ensure appropriate perinatal and postnatal monitoring for women with/or at risk of an eating disorder
- Ensure appropriate multidisciplinary perinatal and postnatal interventions are delivered to those affected

Eating disorders may develop during pregnancy or postnatally in response to changes in weight and shape, or may exist prior to pregnancy [35, 36].

Eating disorders during pregnancy may result in a range of adverse outcomes for the mother and foetus such as risk of miscarriage [37, 38], premature births [39], delivery by caesarean section [40], lower birth weights [41], perinatal death [42], and birth defects [40].

Though eating disorders may occur in pregnant women and during the postnatal period, they largely go undetected and untreated [43, 44]. Given the known risks for adverse outcomes for both mothers and foetus, appropriate perinatal and postnatal monitoring and interventions delivered by a multidisciplinary care team is critical in preventing or reducing obstetric complications associated with eating disorders in those affected, and in supporting vulnerable women and their offspring through reproductive life transitions.

Early Childhood and Primary School Aged (0-11)

Services should:

- Engage in prevention, early detection and management of feeding and eating disorders to prevent risk of protracted illness and associated medical and psychiatric complications
- Strengthen eating disorders mental health care for infants and children under the age of 12 and their families, and address any gaps in service provision
- Establish coordinated and consistent shared care partnerships and referral pathways with a range of children's health services
- Provide education and support to parents, families and carers on feeding and eating disorders
- Engage parents, families and carers as partners in recovery
- Deliver evidence-based eating disorder health promotion in early childhood and school settings

Feeding problems are common in childhood, occurring in approximately 25-35% of normally developing children, and in up to 80% of children with a developmental delay [45]. Disturbances in feeding may result from a range of factors such as developmental disorders or specific medical conditions which impact the child's ability to; latch, suck, chew or swallow; an underlying food intolerance resulting in physical discomfort [46]; or due to an aversion associated with the sensory aspects of food based on the texture, taste, appearance or smell of food [47].

In the DSM-5 the diagnosis of feeding disorder of infancy or early childhood has been renamed to Avoidant Restrictive Food Intake Disorder (ARFID). This type of presentation is relatively common in children, adolescents and adults with pervasive developmental disorders such as Autism Spectrum Disorder (ASD), however, may also occur in people without any conditions affecting normal growth and development. Other disorders common in infancy or early childhood may be Pica or Rumination Disorder.

Many early feeding problems may be transient and resolve without intervention, while in other cases these problems may become more severe and complex, requiring clinical intervention. If unresolved, feeding problems may result in serious medical and psychological complications including failure to thrive, nutritional deficiencies, and growth delays [48].

Prevention, early detection and management are pivotal in addressing eating disorders in early childhood and in preventing associated medical and psychiatric complications. Currently there is limited research on the treatments available for the disorders most likely to occur in this age group.

Child and family, and early childhood health services provided by LHDs across NSW support the development and health of younger children; including services to address psychosocial support, feeding, nutrition and mental health needs and can play an integral role in the early identification and treatment of early onset feeding and eating disorders in this age group.

Service gaps for children under 12. There are gaps in the primary care sector's knowledge and expertise in relation to eating disorders. This can lead to feeding and/or eating problems going undetected and untreated till much further along.

There is great variability in access to CAMHS services across NSW. Some CAMHS services will provide mental health access across the age spectrum, from 0-17 years, whilst others focus their expertise on seeing children over the age of 12, resulting in the needs of primary school-aged and younger children's mental health needs being under resourced. Given the potential for the early onset of feeding and eating disorders, and mental illness more broadly, this disparity requires an urgent response and represents a challenge and a priority for further work.

Adolescents and Young Adults (12-24 years)

Services should:

- Engage in routine assessment and screening of people in this age group, particularly as adolescence is a high-risk period for the development of an eating disorder
- Provide developmentally appropriate interventions, matched to the person's needs
- Address any service barriers or gaps which may inhibit access to care, particularly for those aged 16-17 years
- Ensure continuity of care for adolescents transitioning from paediatric to adult inpatient and community services
- Develop innovative and diverse treatment models suited to young people
- Recognise young people and young adults as a distinct priority population with unique needs, and develop integrative models reflecting this

Adolescence is a peak risk period for the development of an eating disorder [49, 50], and eating disorders represent the third most chronic condition for adolescents, after asthma and obesity [51]. More broadly, adolescence is a high-risk period for the onset of serious mental illness with an increased prevalence of serious mental illness in the older teen years, and higher again amongst indigenous populations and young females [52]. Concerningly, service provision for this age group, particularly older adolescents, is variable across the State.

Findings from Mission Australia's Youth Survey (2012-2016) [52] showed that young people at high risk of mental health problems are more likely to seek help via the internet, telephone hotlines, online counselling websites, and community agencies and magazines. This highlights a need for the development of innovative and diverse options for evidence-based care that provide an alternative to face-to-face interventions and better meet the mental health needs of youth.

- Service gaps for adolescents aged 16-17 years
- *Community treatments*

Traditionally mental health service models are bisected into Child and Adolescent Mental Health Services (CAMHS) seeing people under the age of 18, and Adult Mental Health Services (AMHS) seeing those aged 18 and over. However, as adolescents move towards the age of 16, access to health services in general becomes ambiguous and when they present for medical and or psychiatric care, they are often met with age boundaries and service thresholds dependent on their chronological age, education and living status, and clinical eligibility.

Disparities in clinical thresholds between CAMHS and AMHS, with AMHS thresholds generally being higher, and the differences in models of care between the two, at times results in individuals who were receiving CAMHS interventions not qualifying for AMHS. Similar gaps also exist between primary services treating people with mild-moderate illnesses, and public mental health services that generally see people with more severe presentations. These gaps result in poor continuity of care, and place adolescents at high risk of falling through the gaps. Service transition periods pose a particular risk for young people as this is a common age for onset of eating disorders and disengagement from treatment at this point can significantly impact the recovery trajectory.

Health services tend to be dichotomised in their approach and are either geared towards addressing the needs of children and their families or adults. Very few services are specifically tailored to provide age-appropriate interventions aligned with the needs of older adolescents. Such circumstances result in service provision and treatment approaches that may be ill equipped to meet their developmental needs and may not meet the evidence-base for treatment of young people with eating disorders. The following two services are specifically youth based and can play a very important role in early identification and treatment.

1. Since the late 1990's NSW has provided funding for community-based Youth Mental Health Services (YMHS) across NSW. Another key provider in this space are headspace services which are funded federally. The configuration and purpose of these services for individuals varies with headspace servicing 12-24-year-olds with mild to moderate mental health needs, and public youth mental health services more likely to service between 16-24-year-olds with severe and complex mental health needs. The purpose and make up of these services vary significantly across LHDs, and access is geographically dependant within LHDs that have pre-established youth-oriented teams.
2. Youth Health Services are specialist NSW Health services providing multidisciplinary, primary healthcare to young people. Focusing on engaging disadvantaged young people, they deliver flexible and unique health services to young people in relaxed and comfortable youth-friendly environments. Youth Health Services work in partnership with other government and non-government services, including collaboration with local schools on programs and initiatives

Young adulthood (18-24), like adolescence, is a peak period for onset of an eating disorder. This is a key age for transitions in life relating to the increased susceptibility for mental illness. Research studies, such as the Access Studies funded by NSW Health, have examined access to services for young people and recommend that 'Technology should be fully utilised by health services to promote engagement' of this age group [53].

Service gaps exist for young adults 18-24 years as adult settings are not appropriately designed and delivered in a manner that meets the developmental needs of the adolescent/young adult age group.

- *Inpatient Care*

While most eating disorders treatments occur in the community setting, during times of medical and or psychological risk a hospital admission may be required. Generally, paediatric wards will only admit children up until the age of 16, with 16-17-year-olds often admitted into adult medical wards, where they may be treated with limited age appropriate mental health input. This gap in hospital-based care for older adolescents, and confusion as to where they fit best, is common across NSW. This can result in vulnerable adolescents (with a potential trauma history) not receiving the appropriate mental health care they require, and in an environment that best suits their needs.

To ensure uninterrupted care that meets the needs of the individual, their families and carers, partnerships between child/adolescent and adult providers with a shared understanding between them is required. Addressing the inequalities in services for older adolescents and the service transitions required in the 16-17 year age-range will lead to improved access to health services, a more seamless health care journey for the young person (with less potential for drop out), and better physical and psychological health outcomes for young people and their families and carers.

It should also be recognised that many young people with an eating disorder diagnosis are often developmentally much younger than their chronological same age peers. Therefore, treating these young people in an adult focused environment does not meet what is known to be best practice care for adolescents and young adults.

There is the potential to provide support for the development of youth wards and cohorted age and developmentally appropriate care services, with appropriately skilled and experienced staff to work with this age group. Cohorting older adolescents and young adults together can provide a developmentally appropriate and socially normalising environment for treatment and care; and builds capacity in the mainstream health system to provide developmentally appropriate care for young people.

Adults (18-65 years)

Services should:

- Be aware that eating disorders may be present in adult men and women, and may be a result of first presentation, relapse or severe and enduring illness
- Deliver person-centred holistic interventions aligned with the broader life context
- Use technology and other innovative models of service delivery and design
- Actively work towards reducing stigma associated with eating disorders, and address any other barriers to care

Eating disorders in middle-aged and older adults are generally characterised by one of three profiles:

1. Early onset, non-remitting disorder: including older people who developed an eating disorder during childhood or young adulthood and have an enduring condition who remain persistently unwell for many years. These individuals may have had treatments over the years, and or gone undiagnosed.
2. Early onset, relapse of remitted disorder: these people may have developed an eating disorder earlier in life and been in remission for several years but have experienced a relapse.
3. First onset of disorder: people who have their first episode later in life, with no prior history of eating disorder.

Psychiatric comorbidity is commonly reported in individuals presenting with eating disorders in later life [17-20]. Body image and body dissatisfaction also remains a salient and unremitting issue across the lifespan with no differences in weight and shape dissatisfaction amongst young, middle aged, and older women [54].

Despite the core clinical features of eating disorders presentations across younger and older age groups being the same (excluding amenorrhea), there are distinguishable differences in the psychological determinants precipitating and maintaining eating disorders in adults [55]. Some of the factors associated with the onset of eating disorders in middle-aged and older people include; ageing-related transformations (e.g. wrinkles, weight gain, perimenopause etc.), a cultural context with ideals of a youthful appearance; and changes in familial relationships (e.g. divorce, empty nesting, loss of a spouse etc.) [55].

Due to the stigma attached to eating disorders and the service system structure, many adults with an eating disorder still face significant barriers to accessing care.

Older Persons (>65 years)

Services should:

- Be aware that eating disorders occur in people over the age of 65
- Ensure screening for malnutrition which may or may not be an eating disorder
- Ensure that screening and differential diagnosis of eating disorders are considered in all presentations of ill health, irrespective of the age of the individual
- Deliver individual specifically tailored assessments and management that are congruous with the person's life context and stage of life
- Make efforts to include children, spouses, family and/or carers as collaborators in their care

Eating disorders occur in the elderly (>65 years) however are often overlooked both in clinical practice and in research [56]. As in the case of adults, eating disorders presentations in the elderly may be due to unremitting onset from earlier in life, or due to a variable course of illness with periods of remission interspersed with relapse [57]. Older people living alone and older people in residential aged care facilities are two sub-groups where eating disorders can be complicated by other circumstances. These groups are also more likely to suffer depression and social isolation.

Elderly people may suffer a range of serious health complications secondary to an eating disorder and are at risk of mortality from eating disorders [56]. Often older people with eating disorders also have coexisting medical and/or psychiatric conditions and may be taking a number of medications which may cloud the clinical picture, resulting in the eating disorder being undetected or misdiagnosed.

Other circumstances may also make it more difficult to identify, diagnose and treat eating disorders in the older cohort:

- Lack of available food that is appetizing and nutritious
- Insufficient time/resources for staff/carers to feed or monitor food consumption
- Older people often have multiple health issues and/or are on a range of medications that may disrupt normal eating patterns.

Research on all areas related to eating disorders in older adults is lacking and requires further investigation.

FAMILIES AND CARERS

At a minimum, services should provide families and carers with access and direction to:

- Information and education around the eating disorder, the symptoms, impacts of the illness, stage of illness, and recovery (both verbal and written material)
- Information about the range of services and treatments available for their loved one and themselves, and how to navigate the health system
- Information and education that empowers and supports them to maintain their caring role
- Training and education in skills they may use to support their loved one e.g. during meal support, during times of crisis, following discharge from an inpatient setting etc.
- Recognition of their role in all stages of the illness, and inclusion in discussions around treatment planning and discharge processes
- A response to the family member or carers individual needs, and appropriate referrals. It is often advisable for carers to seek treatment services for themselves
- Emotional support which may include formal counselling, family or couple therapy
- Information about Carer Networks and Support Groups
- An opportunity to provide feedback on carers experiences and service evaluation to inform service improvements
- Open communication about privacy, confidentiality and information sharing

Families and carers play a major and ongoing role in supporting their loved one with an eating disorder to recovery [58, 59]. Often clinicians underestimate the extent to which they can engage with carers without breaching the boundaries of confidentiality, and more work needs to be done with clinicians to improve their involvement of carers as part of the treatment. Carers may be parents, siblings, children, spouses, grandchildren, relatives or friends. The level of involvement for the carer may differ as the ages, developmental status and family dynamic of those affected by the disorder change. The protracted length and serious nature of the illness, along with the all-consuming demands of the eating disorder, place immense financial, social and emotional demands on caregivers. Additionally, the effects are multigenerational with a major impact on siblings as well.

Impact on the Carer

There are significant emotional pressures throughout the entire caregiving process. Caring for someone with an eating disorder can be a very stressful, overwhelming and demanding experience with implications for the well-being of the individual and family. Previous studies have found that carers of people with an eating disorder experience significantly higher levels of stress, challenges and psychological illness than those reported in other groups of carers (e.g. carers of people with psychosis) [56, 57].

It is an extremely difficult adjustment and carers often report that they are unsure how to respond and are concerned that their actions may do more harm than good [60]. It is not uncommon for carers of individuals with an eating disorder to experience feelings of inadequacy and concerns that they will not be able to cope with the protracted nature of the disorder [61]. Some carers have reported feelings of self-blame, patient-blame, a sense of helplessness or overprotectiveness in response to eating disorders [61, 62]. As eating disorders progress, carers often report their own psychological and physiological vulnerabilities, and a sense of powerlessness and helplessness which further undermines their own mental health and wellbeing [60, 62].

Family and Carer support

Family members and carers experience a high level of unsatisfied needs for information about eating disorders and their development, how to cope and manage the eating disorder and sources of informal, social and professional support [61]. Carers have identified they require interventions and resources including; psychoeducation groups, support and therapy by a professional, family therapy by a professional and printed information resources [61].

Families and Carers as Partners in Recovery

Services should:

- Acknowledge families and carers as a valuable resource and support them as partners in recovery
- Positively identify and engage families and carers in all stages of assessment, treatment, discharge planning and recovery processes
- Ensure the provision of family-inclusive care and be considerate and flexible in the different ways families and carers can be involved and supported throughout the treatment journey
- Develop capacity, policies and practices in working with families and carers supporting someone with an eating disorder
- Ensure and encourage family, carer and consumer representative participation in eating disorders governance committees to help shape and design program development, service delivery and evaluation, and quality improvements

EATING DISORDERS IN SPECIFIC POPULATIONS

Rural and Remote Communities

Services should:

- Provide strong leadership in local service planning to improve access to eating disorders health care for people living in rural and remote areas
- Develop Models of Care that allow for flexibility in service design and delivery and enhance access to services for people in rural and remote areas
- Explore and encourage alternative and innovative pathways to care such as Telehealth, or eTherapies that better suit the needs of individuals, their families and carers
- Address any barriers impacting access to timely eating disorders assessment, diagnosis and intervention
- Develop strong partnerships and working relationships with key practitioners, especially GPs and private practitioners

People living in remote and rural areas experience poorer access to a range of health and mental services compared with people living in metropolitan areas, despite the prevalence of people experiencing mental illness being comparable across the nation; with the exception of self-harm and suicide which tend to increase with remoteness.

In addition to the scarcity of resources and services there are other factors which may present as barriers to accessing care in these communities. Fear of stigma, particularly in smaller communities where people may be more easily recognised, may influence help-seeking behaviour. Income issues

combined with lack of access to funded treatment without significant gap fees and access to transport also make it more difficult to access mental health care, especially for people who are physically or mentally unwell, unemployed, living with a disability or from an Aboriginal background.

Of the services available, there is a notable absence of eating disorder expertise among various health practitioners in rural areas thereby leading to barriers in timely assessment, diagnosis and treatment which may result in an increased likelihood of hospitalisation, illness chronicity or, even worse, premature death.

Aboriginal and Torres Strait Islander People

Services should:

- Be aware of the high prevalence of eating disorders in indigenous populations
- Partner and collaborate with Aboriginal leaders and communities, and culturally aligned NGO's to:
 - Develop culturally sensitive and informed eating disorders models of care
 - Identify and support appropriate eating disorders service points, pathways and partnerships
 - Develop culturally sensitive and targeted promotion, detection and treatment responses
- Ensure all approaches to care are trauma sensitive and informed, particularly when considering use of coercive practices

A recent investigation (Hay & Burt in press, ANZAED 17th Annual Conference, 2019) into the prevalence of eating disorders in a general population sample of Aboriginal people found that 25% of survey respondents had an eating disorder, a rate that is much higher than in other Australian people. The survey also found that:

- 5% had full threshold eating disorders (BN or BED)
- 6% met criteria for OSFED & 14% for UFED (in both categories most with recurrent binge eating)
- Aboriginal people had higher levels of over-valuation on weight and shape than any other group

Eating disorders are highly complex with a continually evolving understanding about their manifestation, presentation and treatment. Knowledge related to the particular experience of Aboriginal people, and the role this plays with regard to eating disorders is not well understood due to a lack of research. Research in this area has therefore been made a focus of action under the current Service Plan.

Future research and intervention efforts to address eating disorders in Aboriginal people must be done so within a framework that factors in key areas impacting health outcomes in this population including: inter-relational, historical, social, cultural, economic, environmental, mental and health risk factors that impact on the social and emotional well-being of Aboriginal people.

Persons from Culturally and Linguistically Diverse (CALD) Backgrounds

Services should:

- Partner with Transcultural Mental Health services who may assist in developing and tailoring effective eating disorder health promotion, screening, assessment, intervention and management strategies to suit individuals from CALD communities
- Make strategic efforts to increase health professional awareness of eating disorders in people from CALD communities
- When delivering interventions, make concerted efforts to understand the illness presentation within the individuals personal and cultural context
- Address any barriers (e.g. linguistic, isolation, stigma etc) to accessing eating disorders care
- Ensure all approaches to care are trauma sensitive and informed, particularly when working with refugees

Eating disorders are commonly misconceived as being mental illnesses only impacting western, middle class young females. However, eating disorders occur across all demographic and cultural backgrounds and furthermore, epidemiological data shows eating disorders prevalence in non-Western individuals is increasing [63], and conversely, that treatment rates are lower amongst culturally diverse people [64].

Many first-generation migrants have experienced malnourishment as a result of poverty, displacement and life disruption; significant weight loss is a well-documented risk factor for eating disorders. Anxiety, depression and PTSD [65] are highly prevalent among resettled refugees, with pre-and-post migration stressors and traumatising events [66] being well identified predictors of poor mental health [66, 67]. Second generation refugees (i.e. children of refugees) are at risk of developing

similar mental health conditions to adult resettled refugees, and are at higher risk of developing other behavioural conditions such as eating disorders and problematic substance use [68].

While the population of people from CALD backgrounds represent a heterogenous group, there may be culturally influenced variances in eating disorder phenotypes. Food practices vary across cultural communities, as does the expression and acceptance of mental illness [64]. Cultural variances in the expression of eating disorder symptoms may pose a barrier to identification and inhibit referral and treatment. Australian research demonstrates refugee groups have lower rates of mental health service utilisation compared to the general Australian population [69]; with poor mental health literacy, stigma, and time constraints being some of the identified barriers to accessing care [69].

Very little is known about eating disorders in refugee populations post settlement. Help-seeking, both professional and non-professional, also remains under investigated. Further research into the delivery of culturally acceptable and effective eating disorder treatments to people from refugee and immigrant backgrounds is required.

Health services will need to demonstrate responsiveness in developing targeted and culturally accessible eating disorder health promotion initiatives aimed to improve eating disorders health literacy, and the promotion of early and appropriate health help-seeking when required. The Service Plan will guide health professionals and services to be culturally responsive.

Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) People and Communities

Services should:

- Recognise and specifically include LGBTI people in the development of eating disorders strategies, frameworks, programs and services
- Work towards creating a culturally sensitive workforce that is knowledgeable about eating disorders in LGBTI people and skilled and competent in responding to their specific support needs
- Enhance services and approaches to care by partnering with both clinical and non-clinical LGBTI focused mental health services and sectors that have expertise in working within these communities

While most research on eating disorders has focused on heterosexual individuals, there is emerging evidence that eating disorders disproportionately impact some segments of the LGBTI communities. There are significantly higher eating disorder rates amongst gay and bisexual men compared to their heterosexual counterparts [70], and significantly higher again in transgender individuals compared to their cisgender counterparts [71, 72].

Data reported by the American National Eating Disorders Association [73] indicated 42% of men who identified as gay had an eating disorder. A study found LGBTI youth are at an elevated risk of eating disorders compared to older LGBTI individuals [70], whilst the research on bisexual and lesbian women has yielded conflicting results. Some studies have found lesbian women have fewer eating disorder symptoms than heterosexual women [74, 75], with others finding no differences between the two groups [70, 76].

A number of unique factors may contribute to the development of an eating disorder in LGBTI people compared to their non-LGBTI counterparts. Some include, but are not limited to:

- Fear of rejection or experience of rejection by friends, family and co-workers in revealing their sexuality
- Internalised negative messages and or beliefs about one's self based on experiences of social pressures to conform on issues of sexuality, gender and body image ideals within some LGBTI and cultural contexts
- Experiences of violence and Post Traumatic Stress Disorder (PTSD)
- Victimization through bullying
- Experiences of stigma, discrimination and marginalisation

In addition to these contributing factors, LGBTI people face compounding barriers for accessing culturally-competent treatment and supports [77]. Though initial research demonstrates concerning rates of eating disorders among LGBTI people and communities, there are significant gaps in the knowledge base about eating disorder prevention, intervention and treatment approaches that adequately represent their lived experiences, identities, relationships and needs.

People in the Justice and Forensic Setting

Services should:

- Be aware of the high prevalence of eating disorders within forensic populations
- Carry out routine eating disorder screening and assessment of people in the justice and forensic population, particularly in context of other comorbid mental illness where there is a high risk of eating disorders remaining undetected
- Deliver eating disorder workforce training and development of health professionals working with forensic populations

Surveys undertaken in female and adolescent secure psychiatric settings have found eating disorders to be prevalent among approximately 16% of surveyed patients [78], which is a higher prevalence rate than is observed in the Australian community [79]. Research on females with criminal convictions have also shown an increased risk of AN and BN [80]. Additionally, a recent study indicated that staff working across secure settings have limited experience and training in treating eating disorders both here and internationally [78].

Justice Health and Forensic Mental Health Network (JH&FMHN) have a large Aboriginal population in custody and the number of eating disorders in the Aboriginal population is estimated to be 25 per cent higher rate than in the general population. Particularly when addressing the eating disorders of women and adolescents in this group, the Network will need to be involved/working together with Women's Health, Youth and Aboriginal Health Services.

Referrals to custodial mental health services are often triggered by major mental illness and/or personality disorders, which place individuals at risk of significant self-harm. Primary or co-morbid eating disorders may be missed, unless associated with a rapid decline in overall health. Patients in the Forensic Hospital have primary diagnoses of psychotic illness and major mood disorders. There is also a high proportion of patients with co-occurring personality disorders, substance misuse, and/or cognitive impairment. The identification and treatment of eating disorders can therefore be overshadowed, which may explain why the rates of eating disorder diagnoses in this setting appearing to be very low.



SECTION 3

Service Delivery Framework

OVERARCHING PRINCIPLES TO GUIDE EATING DISORDERS SERVICE DELIVERY

The following key principles that guide service delivery, while relevant to all people with a mental health illness receiving care, have particular significance for people with eating disorders. Ambiguity about treatment may impact care and recovery. Acknowledgement of this as a key barrier, will allow strategies to emerge that enhance patient safety and increase health professional knowledge and confidence.

1. Hope and Recovery Focus

Recovery is possible for all people with an eating disorder, regardless of severity or stage of illness. Emphasis should be placed on service delivery, practice, culture, and language that explicitly promotes hope and optimism for all people impacted by an eating disorder. People should be supported to build on their strengths.

2. Right to Care

Individuals with eating disorders are entitled to the best available care, with timely referrals and access to treatments across health settings, that are person-centred and aligned with their needs regardless of geographic location, age, gender, or cultural background.

3. Dignity and Respect

All persons with eating disorders deserve to be treated with humanity and respect, with a fundamental emphasis on the protection of dignity during all stages of treatment and recovery.

4. Family & Carer Engagement

Unless contraindicated, wherever possible, care for people with an eating disorder should be provided within a framework that enlists families or carers as partners in assessment, treatment and the recovery process. Given the significant impact on family members and carers of people with an eating disorder, support and information for them should be incorporated in all aspects of service delivery and design.

5. Trauma Informed Care & Practice

People with eating disorder may present with psychiatric comorbidity and/or trauma histories, and eating disorders treatments may be experienced as traumatic for the person, families, carers and health professional involved in their care. All people have the right to integrated trauma-informed care and practice that does not traumatise or re-traumatise the person.

6. Holistic Care

Recovery is not only related to the eating disorder, but also to the associated challenges and comorbidities, and other aspects of an individual's life. We value a holistic approach to health, that considers the uniqueness of the individual, and support activities, within and outside of health services, that promote all aspects of health and well-being of people with eating disorders and their families and carers.

7. Person Centred Informed Decision Making

Individuals and their families and/or carers should be provided with information and access to the range of evidence-based treatments which address the specific needs of the person, promotes their recovery and maximises their involvement in decision making. Where possible, individuals have the right to choose from the available range of treatments and support programs appropriate to their needs.

8. Culturally Informed Care

Health care to people with eating disorders should be delivered within a culturally responsive framework that demonstrates appropriate awareness, knowledge, skills, attitudes and an understanding of the individual's history and culture.

9. Collaboration & Integrated Health Care

People with eating disorders have the right to comprehensive and integrated health care that meets their individual needs, and that promotes optimum outcomes for their recovery. This plan supports collaboration with a strong network of stakeholders who work together to drive change and develop responses that meet the needs of people and their families or carers.

10. Developmentally and Clinically Appropriate Care

People with eating disorders have the right to comprehensive, concerted and evidence-based interventions that are developmentally appropriate, trauma informed and fully conversant with their stage of life. Decisions made by health professionals must be informed by the best available evidence.

11. Closest Available to Home and Least Restrictive Care

People with eating disorders and their families and carers should have timely and equitable access to services and supports closest to home whenever possible, especially for children and Aboriginal families. Where possible, treatment should be offered in the least restrictive setting available, that is best suited to the individual's needs and preferences and ensures patient safety and promotes good treatment outcomes.

12. Smooth Transitions and Continuity of Care

Services should work in partnership to facilitate transfer processes that are consistent, connected and coherent and promote an uninterrupted journey to recovery as gaps in services to people with eating disorders can result in serious medical and psychiatric complications. Transitions should be seamless, and most responsive to the individual's health needs and personal context.

EATING DISORDERS SERVICE SYSTEM FRAMEWORK

The following section outlines all levels of care necessary to ensure the provision of appropriate care for people with eating disorders and their families and carers in NSW.

This Service Plan will focus on:

- improving the person and their families and carers journey through the health system;
- establishing mechanisms to support LHDs and SHNs to improve capacity;
- improving capability of health professionals to gain competency and confidence to deliver services locally where appropriate;
- improving access and pathways to high quality evidence-based models of care and treatments; and
- improving partnerships across the service spectrum.

Eating disorders vary in their level of severity and clinical complexity. There are many factors that have implications for determining the best possible place for care of people with an eating disorder, including the nature of the disorder; acuity, severity and complexity of the illness; the level of risk associated with comorbidities; and the physical and mental health complications of the disorders. These also have implications for how services are designed and delivered.

There are several entry points and services within NSW Health that play an important role in identifying, assessing and treating people with eating disorders. Many services who were not engaged in the previous Service Plan but form an important part of the service system are identified in the boxes below.

Emergency Departments

- All hospitals

Inpatient Units

- Intensive Care Units
- Paediatric Wards
- Medical Wards
- Mental Health Wards
- Drug and Alcohol and Specialist Treatment Services
- Maternity
- Residential

Community Health

- Aboriginal Health
- Mental Health
- Aged Care and Rehabilitation
- Antenatal Services
- Child, Adolescent and Youth Mental Health
- Child and Family Health
- Community Dietetic Services
- Dental Services
- Diabetes clinics
- Drug and Alcohol and Specialist Treatment Services
- Early Childhood Services
- Metabolic Clinics
- Older People's Mental Health
- Obesity Services
- Perinatal Mental Health
- Renal Clinics
- School-Link Program
- Violence, Abuse and Neglect Counselling
- Women's Health
- Youth Health Services

Service Partners

Another key focus in this Service Plan is the development of partnerships with external providers. These partners play an integral role in the treatment pathway from prevention to early intervention to treatment. The Service Plan outlines strategies for NSW Health to work in partnership with our service partners to deliver improved care to people with eating disorders and their families and carers. The partners are identified in the box below:

Key Service Partners

- Primary Health Networks (PHNs)
- General Practitioners
- headspace
- Private Hospitals
- Private Practitioners
- Dentists
- Community Managed Organisations that deliver NSW Health funded programs
- Non-government Organisations
- Schools (in particular school counsellors)

Building Specialist Eating Disorders Hubs of Expertise

Eating disorders are often seen as requiring specialist care from a specialist team. This has often created isolation from the rest of the health service, and with extremely limited resources creates a major barrier to care. This reduces the range of services and opportunity for holistic care received and required by people with an eating disorder and their families and carers. Specialised eating disorders services can work to support providers of general services by delivering highly specialised assessment and management advice, facilitating training and education, and contributing to policy and service development as well as the evidence base. It is therefore important that specialised services are available and easily accessible. Building local hubs and spokes of expertise with reach to the specialist services is one potential model for addressing the shortage of expertise.

A key focus of the previous Service Plan was to enhance our specialist eating disorders specialist services for both adult and children and adolescents and to establish local specialist eating disorders hubs or networks. The enhancement to the two specialist services was delivered in the last phase. The Peter Beumont Unit (PBU) for adults increasing to nine inpatient beds and developing a statewide

Outreach service, and the Sydney Children's Hospital Network (SCHN) through its specialist service at Children's Hospital Westmead pilot tested a community-based Child and Adolescent Day Program in partnership with the Butterfly Foundation which is now well established. They also provide outreach support across the state. Strengthening these supports is an integral part of the Service Plan, as is improving the service pathways between the specialist units and the rest of the state and to maintain the outreach support to non-eating disorders specialist services.

There are also a number of key eating disorders services provided in some LHDs, many of which are well established, creating pockets of eating disorders expertise across the state. The long-established comprehensive eating disorders services provided by WSLHD, SLHD and SCHN include inpatient, day patient and outpatient programs. Other LHDs provide community-based eating disorders treatment from long established eating disorders teams. HNELHD received funding under the previous Service Plan to develop an eating disorders day program and their Centre for Psychotherapy also has a long-standing adult eating disorders team. Other community-based eating disorders services exist in CCHD and ISLHD which also support their inpatient settings.

Eating Disorders Coordinators

Another key component of the service delivery framework is the state and local Eating Disorders Coordinators. The previous Service Plan saw the expansion from a Statewide Eating Disorders Coordinator and four Network Eating Disorders Coordinators to include a local Coordinator in every LHD and SHN except FWLHD and JH& FMHN. This phase of the Service Plan has seen the increase from mostly part time Local Coordinators to enhanced funding to support a move to having all Coordinators full-time in recognition of the large role they play in the treatment network. For the first time a Coordinator for FWLHD and JH&FMHN will be funded.

Locally Accessible Models of Care

The development of locally accessible models of care is well underway in LHDs and SHNs across NSW. A key focus of this Service Plan is to continue to develop these models and to ensure implementation. There is undoubtedly a need to appropriately manage increasing demand and to prioritise service provision.

Improving the Service System

The emphasis for this Service Plan is on improving services across the spectrum of care for people with eating disorders and their families and carers. This will be achieved by ensuring that people receive appropriate care at all levels of the health system and by having a workforce that have competence in delivering care in their part in the service delivery pathway, increasing access to specialist services for those with complex needs.

NSW Health acknowledges the challenges to deliver comprehensive care to people with eating disorders and their families and carers. The integration of medical and mental health care is integral to delivering care to people with an eating disorder. New models of integrated care across medical and mental health are being developed and are a key focus of this Service Plan.

There are several elements that compose a service delivery framework. They include:

- Service setting
- Treatment interventions
- Staffing
- Partnerships
- Coordinated care

Service Settings across the Spectrum of Care

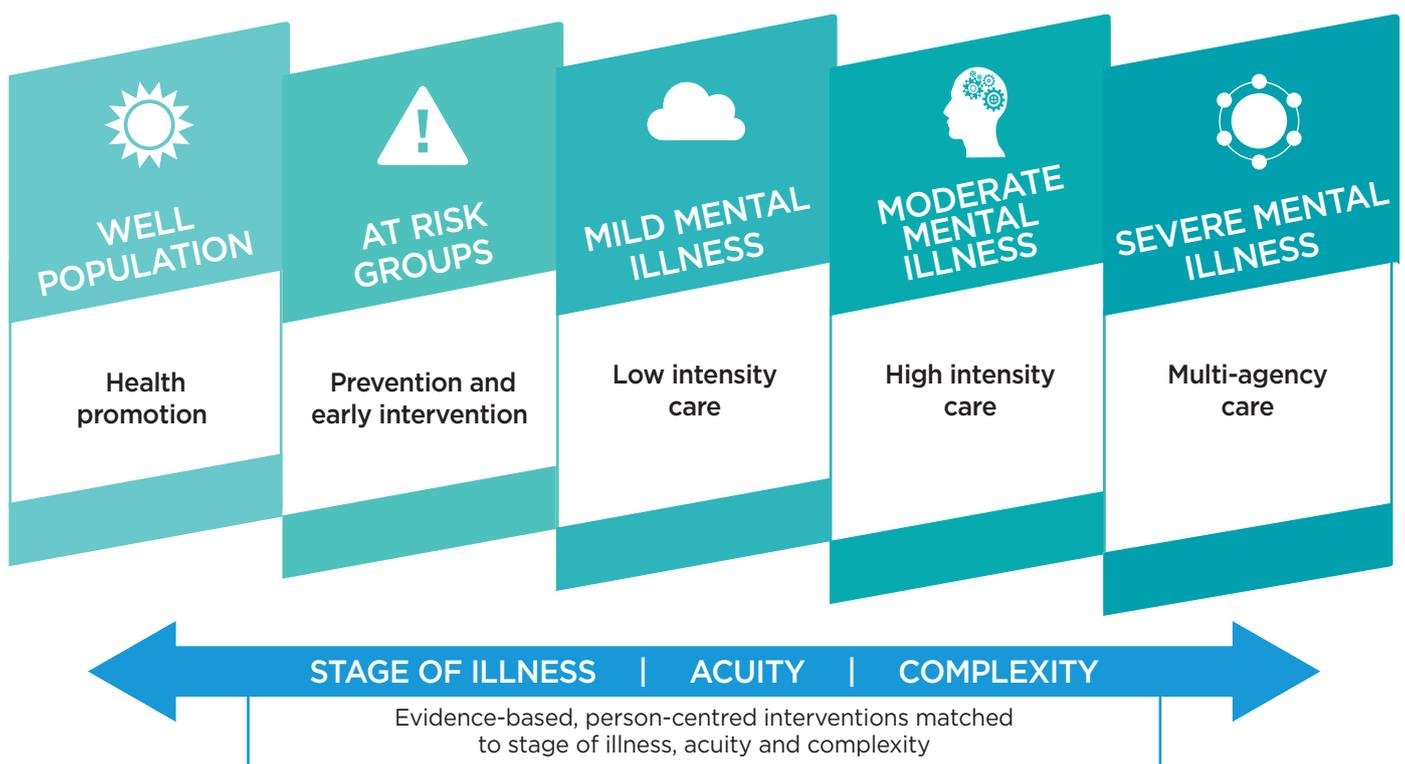
Health care is delivered in a stepped care model often provided in different health settings providing different levels of intensity of care based on acuity and severity.

A comprehensive spectrum of care may be delivered directly by LHDs/SHNs or through clear cross-district agreements. In comprehensive services, these service components are not discrete and care transitions are characterised by continuity in care planning and delivery, which improves risk management.

Entry into the health system can occur at any level of care and it is common for people with eating disorders to experience care at each of the different levels at some point during their treatment journey through the system.

- Primary Care
- Community-based Care
- Day Programs and Intensive Outpatient Therapy Programs
- Residential Eating Disorders Centre
- Inpatient Care
- Specialist Inpatient Care
- Emergency Care

Figure 9. Stepped Model of Care



An ideal care model provides for a seamless treatment journey and transition through the different levels of care. The relationship between these levels of care varies significantly with some services providing more than one level of care, reducing the risk of falling through the gap when transitioning between care levels. To work effectively it requires clear referral pathways between the services, clear roles and mechanisms for consultation, collaboration and review. This will ensure that people do not fall through the gaps when transitioning between levels of care and from child and adolescent to adult services. Transition between services pose a significant risk for deterioration in health status for people with an eating disorder.

Primary Care

The foundation of eating disorders care across the lifespan is community-based care. Primary Care providers including GPs, headspace, private practitioners, dentists and NGOs have a significant role to play in the provision of health care to people with an eating disorder, their families and carers. The health care system relies on the primary care sector to identify and enable early intervention. The PHNs play a major role in the commissioning of mental health services in the primary care sector and the development of Health Pathways, therefore playing a pivotal role in improving pathways to care.

General practitioners are a critical partner in the delivery of community-based care. While they play a critical role in the early identification, they also have a special role in medical monitoring and management of people receiving community mental health care due to the significant medical complications that arise from eating disorders.

headspace services play an important role in early detection and early intervention. LHDs already have a strong relationship with local headspace services and this can be utilised to ensure clear pathway exist.

With the introduction of eating disorders specific Medicare items, mental health allied health private practitioners and dietitians will play an increasingly important role in the delivery of care to people with eating disorders in the community. Private practitioners see a range of people with eating disorders from mild to very severe and complex depending on their skills and experience. Practitioners need to understand and support people to access higher intensity (step-up) care within the LHD when their clients become either medically unstable or require more intensive mental

health care. Developing relationships with local private practitioners will be an important role for local public health services.

Dentists can also play a key role in identification and early intervention. Oral health prevention and timely access services can support patient care. They also play a role in ongoing care for people with an eating disorder, in particular there are a number of dental and oral throat complications in people with BN.

There are several community managed NGO's that provide support to people with mental illness in collaboration with NSW public mental health services and through PHNs. This Service Plan will focus on the role these organisations play in the service delivery system for people with eating disorders.

Community Based Care

Community based care involves identification, assessment, case management, care coordination, treatment, consultation and engagement in recovery and maintenance. NSW LHDs and SHNs provide a comprehensive range of community health services (identified on p. 38) which all have a role to play in the delivery of services to people with eating disorders and their families and carers. Which type and level of community service required is dependent on level of severity and/or complexity and may involve several services delivering collaborative care due to the complexity of the presentation. The significant contribution to care of all of the providers at the community level is recognised, many who deliver care without any specific training in eating disorders.

Dietitians in public Community Health Centres or clinics play an important role in the identification and as part of the multidisciplinary treatment team for eating disorders in the community.

Drug and alcohol and specialist services can play an important part in screening, identification and referral for people with comorbid mental health, alcohol and other drug and eating disorder issues.

Community Mental Health, including AMHSs, CAMHSs and YMHSs play an integral role in the treatment of people with eating disorders. The first Service Plan saw the widescale roll out across NSW of training in evidence-based treatments to community mental health, Maudsley Family Based Treatment (MFBT) for children and adolescents to CAMHS clinicians and Cognitive Behavioural Therapy for Eating Disorders (CBT-E) for youth and

adults to CAMHS, Youth Mental Health and Adult Mental Health clinicians. Community mental health teams can effectively support people with eating disorders to manage symptoms through providing evidence-based interventions and case management with support from specialist eating disorders services. Rural and regional LHDs often have limited resources and capacity to provide comprehensive community mental health management. This remains an ongoing challenge that must be addressed. Community treatment orders can only be managed by public mental health services, so they play a key role in managing care for people who require this level of intervention.

SCHN, WSLHD, SLHD, CCLHD, HNELHD, ISLHD and NSLHD provide eating disorders outpatient treatment through their eating disorders services. This level of local expertise remains a gap across much of NSW.

While the introduction of specific Medicare items for eating disorders is an important new development it must be remembered that not everyone will be able to afford this care and private practitioners may not be able to work with people with more complex or severe illness. There is still a very important role for public mental health services in delivering psychological treatment to people with eating disorders.

Day Programs and Intensive Outpatient Therapy Programs

Day programs and Intensive Outpatient Therapy Programs in the community offer a sub-acute level of care in a less intensive environment than a hospital inpatient admission. These programs can be used as either a step-up or step-down stage in the transition from hospital to community with a fairly high level of intensity required and can be designed to address treatment barriers.

WSLHD opened the first public health day program in NSW in 2003. The previous Service Plan funded a pilot day program for Children and Adolescents to be provided by SCHN, and a new adult day program in HNELHD. Both programs are now well established. CCLHD and SLHD also provide long standing programs at this level of intensity and have moved recently to deliver a more tailored needs based Intensive Outpatient program. This intensity of service provision remains a gap elsewhere in NSW.

Consideration needs to be given to utilising innovative intensive outpatient therapy models and utilising service settings that may be more cost efficient but as effective as day programs e.g. interventions in home settings, an assertive outreach model which may cost less than day programs.

Residential Treatment Centre

The Federal government has provided NSW funding for the establishment of a Statewide community based Residential Eating Disorders Centre in NSW. NSW Health will provide funding for the staffing and ongoing costs of the Centre. The statewide Residential Treatment Centre to be established will allow people with eating disorders access to specialist services in a home-like setting as a step-down from inpatient hospitalisation following medical and nutritional stabilisation, and/or a step-up from day programs or community based care in cases where a more intensive approach to care might be required.

The statewide Centre remains in early stages of planning and development, however once established aims to provide 24/7 wrap-around evidence-based eating disorders interventions that are highly specialised, multi-faceted (i.e. addressing all aspects of illness recovery within a framework that is responsive to individual needs), and delivered within a multi-disciplinary framework, thereby allowing residents access to dietetic, medical and psychotherapeutic care.

This service will fill a critical gap in the stepped continuum of care and will provide people with eating disorders and their families and carers increased options for accessing treatments in a way that meets their individual needs. This NSW Residential Centre will be one of six similar eating disorders residential treatment centres to be established across Australia.

Inpatient Care

Inpatient care is required for more acute presentations where people often present with an acute metabolic crisis and/or acute behavioural and psychosocial deterioration, including food refusal or self-harm behaviours. Inpatient services include general medical, mental health or specialist units. Where inpatient care is provided by generalist medical then input should be sought from a senior psychiatrist, physician and dietitian.

Medical admission due to medical instability at minimum needs to provide the capacity for refeeding with daily biochemistry monitoring, as well as more intensive nursing care. The first Service Plan specifically focussed on improving inpatient medical care and pathways into medical wards across the state. The outreach support from both specialist services has supported the development of greater skill and confidence of staff in medical wards across NSW to admit patients with eating disorders. There is still considerable variability across the state in the ability of hospitals to respond and will remain a focus of this Service Plan.

While most mental health treatment will occur in the community there may be a need for a mental health admission. Most mental health wards are not equipped to treat patients who require refeeding but there are some units across the state that are developing models of care to address this issue. There are barriers that require attention to change this including improving the confidence and skills of mental health staff in understanding and managing the needs of people with eating disorders and the associated risks.

An inpatient admission can also occur for reasons other than an acute psychiatric presentation or acute medical stabilisation. A planned admission may occur when a person is not responding to a lower level of care and a step-up in treatment is required. As a step down from medical stabilisation some LHDs have developed pathways into mental health rehabilitation wards. This forms part of the stepped care service model.

Regardless of which type of unit the admission is to, mental health and medical health must work in an integrated model of care to deliver the most effective and best treatment option to people with eating disorders. Building an integrated medical – mental health inpatient unit would be the next step up from an integrated model of care within existing services and will require careful consideration as innovative models of care are required to break down the barriers between the silos in health.

For people who are medically compromised as a result of malnutrition or who have significant suicidal ideation it may be necessary to initiate an involuntary admission under the *NSW Mental Health Act* or a *Guardianship Act*. The use of the Act for people with eating disorders, in particular AN, has been widely misunderstood and a focus of this service Plan is to continue to work with the NSW

Mental Health Review Tribunal to clarify its use and ensure its appropriate use in relation to people with eating disorders. The appropriate use of involuntary treatment measures is a focus for workforce development.

Eating disorders treatments, particularly inpatient admissions, can be a highly stressful, distressing and sometimes traumatic experience for the patient, families and carers and all involved. Admissions for refeeding can be long and protracted, sometimes lasting up to months. Interventions may involve the use of involuntary treatment or the delivery of treatments that are at odds with the patient's wishes. It is not uncommon during stages of medical acuity, for restrictions to be placed on patient's physical activity for safety and recovery. Most inpatient admissions for refeeding now occur in general medical wards that are not purpose built, nor have adequate resourcing to provide opportunities for patient stimulation outside the scope of medical care. Factors such as these may result in a sense of loss of agency and increased psychological distress for the patient, family and carers. Relationships may be strained when families and carers are required to engage in decision making on behalf of their loved one, or during the delivery of interventions and support at home.

Eating disorders also have the potential to impact health care professionals delivering care and may evoke difficult emotions in the context of transference and countertransference issues. Clinical supervision is essential for all practitioners working in mental health, and particularly with clients with complex presentations. It is important for health professionals to be aware of these issues and be sensitive to individual, families and carers experiences of treatments administered and the settings in which they are delivered. Health services should take care in the lessening of any negative impacts where possible.

Specialist Inpatient Care

Specialist inpatient care plays an important role in providing treatment to people with more severe and complex illness and supporting non-specialist services to increase competence and confidence in service provision. Originally the only access to inpatient care was through the eating disorders specialist hospital units. With more hospitals gaining competency and confidence across the state, the specialists hospitals can treat more complex presentations.

Inpatient admission to specialist services is limited by bed numbers. As such, refining the pathways to the eating disorders inpatient specialist services remains limited as they can face challenges to meet the demand across NSW. Refining the pathways between the tertiary hubs, the local LHD services and the private services will be a key strategy in this Service Plan.

The eating disorders specialist services also support non-specialist services to manage less severe and complex presentations, enabling other services to develop the skills and expertise to treat people with eating disorders. Developing supportive structures to ensure the specialist services continue to play this role continues to be a focus of this Service Plan.

Emergency Care

The main entry point for people with an eating disorder into inpatient care is through the emergency department. Typically, people present in either a medical or psychiatric emergency, although it will be unlikely that 'eating disorder' will be the person's presenting complaint. It is critical that Emergency Departments and ambulance paramedics are able to identify the illness and the accompanying significant risk, as diagnostic overshadowing of medical or psychiatric symptoms may mean the underlying eating disorder is missed. The lack of pathways into inpatient wards from emergency departments can result in people with eating disorders spending a considerable amount of time in emergency departments. The number of presentations to emergency departments of people with a diagnosis of eating disorders who stay longer than four hours in emergency remains a significant issue with approximately 43% spending longer than four hours. While progress has been made in some LHDs and Specialty Networks in identifying pathways from emergency departments this must remain a key focus of this Service Plan.

Workforce

The emphasis on building workforce capacity and capability in this Service Plan will facilitate the inclusion of people with eating disorders in mainstream health services and enhance capacity for continuous improvement within specialised services. The support of health staff delivering care is critical to effective implementation of the Service Plan.

The Service Plan emphasises having the Right People with the Right Skills in the Right Place. Eating disorders commonly occur concurrently with other psychiatric and medical conditions in people already accessing the health and mental health system. It is important for health professionals to be aware of how these conditions will interact and what treatments might then be required. People with eating disorders also usually require the input of health practitioners from various clinical backgrounds, with particular knowledge and skills. Both the high level of mental and medical comorbidity found in people with eating disorders and the complexity of treatment support the need for greater awareness and competence in the identification and response to people with an eating disorder among multiple branches of the health system.

Provision of the full range of interventions from prevention to specialist care requires multidisciplinary expertise from a range of professions including:

- mental health clinicians including psychiatrists, psychologists; mental health nurses, social workers, occupational therapists; peer workers, community/cultural mental health workers; Aboriginal mental health workers;
- medical specialists such as general physicians and paediatricians and from a range of speciality areas (e.g. endocrinology, gastroenterology, cardiology);
- nurses;
- allied health clinicians including dietitians, physiotherapists;
- drug and alcohol clinicians;
- general practitioners; and
- the health promotion workforce.

There are 11,137 medical, 45,796 nursing and 9,898 allied health FTE employed by NSW Health. While it is acknowledged that not everyone in the system requires eating disorders training there is a substantial workforce that require some knowledge and skills to ensure appropriate treatment and care delivery occurs across the service spectrum.

NSW Health recognises the challenge for staff who are less knowledgeable and experienced with this client group. Targeted workforce development is essential for successful implementation of the Service Plan at the local level. A more comprehensive plan to address the capacity and capability of the NSW Health workforce to deliver care to people with eating disorders is a key strategy of this Service Plan. The Eating Disorders Workforce Plan will outline in more detail how this will be achieved.

Partnerships

Partnership models for integration of medical and mental health are critical to the success of the Service Plan. The Eating Disorders Medical Leads Sub-Committee along with the Eating Disorders Coordinators and local implementation committees will be responsible for developing new models of care to deliver more effective care to meet the needs of people with eating disorders.

Partnerships across the paediatric and adult services is also critical for the success of the Service Plan. This gap between the services has been raised as a significant gap in service delivery for people with eating disorders. This is not unique to young people with eating disorders but poses a significant risk to access to care for this particular population as this is the most significant age of onset.

General practitioners remain a key partner for a shared care arrangement when people with an eating disorder are receiving care in the community, whether it be from a public health service or a private practitioner. Improving the pathway between general practitioners and other service providers is an important strategy in this Service Plan. Primary Health Networks will also play a role in supporting workforce development and access to stepped-care primary care services through their services.

Some services have established excellent arrangements for referral pathways and shared care partnerships with private clinicians including headspace clinicians, paediatricians, psychiatrists and other specialist mental health workers in private practice and this experience is critical to the continuum of care for people with eating disorders. This is more easily achieved in metropolitan locations with higher concentrations of private practitioners. Recent changes in referral and access arrangements for specific private mental health services and dietitians, with new items included in the Medicare Benefits Schedule, provide potential opportunities for innovative collaboration. A key focus of this Service Plan is to strengthen the public private partnerships to deliver seamless care across the service spectrum.

Partnership models for mobile outreach, intensive community-based interventions, and HASI-like supported accommodation programs will be examined in developing models for working with people with eating disorders.

For some of our rural LHDs cross-border agreements with other states are required to ensure people with eating disorders and their families and carers receive treatment as close to home as possible.

Prevention and Health Promotion Activities

Prevention and health promotion activities require a wider focus beyond direct clinical care, including general advocacy; education and training for other professionals; specialist contribution to universal, selective and indicated community-based interventions; capacity building; joint service development and collaborative partnerships.

Obesity in children and adolescents has increased dramatically and may have negative impacts on their social and mental well-being into the future (The Health of Children and Young People in NSW, 2014). There are many groups that promote positive body image, good nutrition and appropriate messages around dieting. While the Service Plan does not address obesity directly, it does acknowledge that it is a major population health concern. Health promotion services working together with eating disorders specialists will ensure that public health messaging does not inadvertently increase susceptibility to developing an eating disorder. Research demonstrates when the focus of obesity prevention and intervention is on a healthy lifestyle, rather than weight, it does not predispose people to developing eating disorders (Golden, Schneider & Wood, 2016). Working together makes sense.

Consideration should be given to using social media platforms to promote and advocate healthy bodies and counter 'negative body image' issues.

REFERENCES

1. Hay, P., et al., *Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of eating disorders*. Aust New Zealand Journal of Psychiatry, 2014. **48**(11): p. 977-1008.
2. guideline, N., *Eating disorders: recognition and treatment*. 2017.
3. Hay, P., et al., *Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of eating disorders*. Australian & New Zealand Journal of Psychiatry, 2014. **48**(11): p. 977-1008.
4. Kent, A. and G. Waller, *Childhood emotional abuse and eating psychopathology*. Clinical psychology review, 2000. **20**(7): p. 887-903.
5. Bodell, L.P., T.A. Brown, and P.K. Keel, *The impact of bulimic syndromes, mood and anxiety disorders and their comorbidity on psychosocial impairment: what drives impairment in comorbidity?*. European Eating Disorders Review, 2012. **20**(1): p. 74-79.
6. Hughes, E.K., et al., *Eating disorders with and without comorbid depression and anxiety: similarities and differences in a clinical sample of children and adolescents*. European Eating Disorders Review, 2013. **21**(5): p. 386-394.
7. Pollack, L.O. and K.T. Forbush, *Why do eating disorders and obsessive-compulsive disorder co-occur?* Eating behaviors, 2013. **14**(2): p. 211-215.
8. Report, A.f.E.D.A. *Eating Disorders: A guide to medical care*. 3rd Ed. (2016). ; Available from: <https://www.aedweb.org/resources/publications/medical-care-standards>.
9. Jones, J.M., et al., *Eating disorders in adolescent females with and without type 1 diabetes: cross sectional study*. Bmj, 2000. **320**(7249): p. 1563-1566.
10. Goebel-Fabbri, A.E., *Diabetes and eating disorders*. Journal of diabetes science and technology, 2008. **2**(3): p. 530-532.
11. Brewerton, T.D., *Eating disorders, trauma, and comorbidity: Focus on PTSD*. Eating Disorders, 2007. **15**(4): p. 285-304.
12. Hudson, J.I., et al., *The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication*. Biological Psychiatry, 2007. **61**(3): p. 348-358.
13. Fisher, M.M., et al., *Characteristics of avoidant/restrictive food intake disorder in children and adolescents: a "new disorder" in DSM-5*. Journal of Adolescent Health, 2014. **55**(1): p. 49-52.
14. Norris, M.L., et al., *Exploring avoidant/restrictive food intake disorder in eating disordered patients: A descriptive study*. International Journal of Eating Disorders, 2014. **47**(5): p. 495-499.
15. Ornstein, R.M., et al., *Distribution of eating disorders in children and adolescents using the proposed DSM-5 criteria for feeding and eating disorders*. Journal of Adolescent Health, 2013. **53**(2): p. 303-305.
16. Beck, D., R. Casper, and A. Andersen, *Truly late onset of eating disorders: a study of 11 cases averaging 60 years of age at presentation*. International Journal of Eating Disorders, 1996. **20**(4): p. 389-395.
17. Kally, Z. and E.J. Cumella, *100 midlife women with eating disorders: A phenomenological analysis of etiology*. The Journal of General Psychology, 2008. **135**(4): p. 359-378.
18. Mynors-Wallis, L., J. Treasure, and D. Chee, *Life events and anorexia nervosa: Differences between early and late onset cases*. International Journal of Eating Disorders, 1992. **11**(4): p. 369-375.
19. Peat, C.M., N.L. Peyerl, and J.J. Muehlenkamp, *Body image and eating disorders in older adults: a review*. The Journal of General Psychology, 2008. **135**(4): p. 343-358.
20. Scholtz, S., L.S. Hill, and H. Lacey, *Eating disorders in older women: does late onset anorexia nervosa exist?* International Journal of Eating Disorders, 2010. **43**(5): p. 393-397.
21. Gregorowski, C., S. Seedat, and G.P. Jordaan, *A clinical approach to the assessment and management of co-morbid eating disorders and substance use disorders*. BMC Psychiatry, 2013. **13**(1): p. 289.
22. Killeen, T., et al., *Exploring the relationship between eating disorder symptoms and substance use severity in women with comorbid PTSD and substance use disorders*. The American Journal of Drug and Alcohol Abuse, 2015. **41**(6): p. 547-552.

23. Addiction, N.C.o., S.A.a.C. University, and U.S.o. America, *Food for Thought: Substance Abuse and Eating Disorders*. 2003.
24. Harrop, E.N. and G.A. Marlatt, *The comorbidity of substance use disorders and eating disorders in women: Prevalence, etiology, and treatment*. Addictive behaviors, 2010. **35**(5): p. 392-398.
25. Kong, S. and K. Bernstein, *Childhood trauma as a predictor of eating psychopathology and its mediating variables in patients with eating disorders*. Journal of Clinical Nursing, 2009. **18**(13): p. 1897-1907.
26. Rodríguez, M., V. Pérez, and Y. García, *Impact of traumatic experiences and violent acts upon response to treatment of a sample of Colombian women with eating disorders*. International Journal of Eating Disorders, 2005. **37**(4): p. 299-306.
27. Carter, J.C., et al., *The impact of childhood sexual abuse in anorexia nervosa*. Child Abuse Negl, 2006. **30**(3): p. 257-69.
28. Rayworth, B.B., L.A. Wise, and B.L. Harlow, *Childhood abuse and risk of eating disorders in women*. Epidemiology, 2004. **15**(3): p. 271-278.
29. Rorty, M., J. Yager, and E. Rossotto, *Childhood sexual, physical, and psychological abuse*. Am J Psychiatry, 1994. **151**(8): p. 1122-1126.
30. Wonderlich, S.A., et al., *Relationship of childhood sexual abuse and eating disturbance in children*. Journal of the American Academy of Child & Adolescent Psychiatry, 2000. **39**(10): p. 1277-1283.
31. Smink, F.R., D. Van Hoeken, and H.W. Hoek, *Epidemiology of eating disorders: incidence, prevalence and mortality rates*. Current psychiatry reports, 2012. **14**(4): p. 406-414.
32. Arcelus, J., et al., *Mortality rates in patients with anorexia nervosa and other eating disorders: a meta-analysis of 36 studies*. Archives of General Psychiatry, 2011. **68**(7): p. 724-731.
33. Braun, D., S. Sunday, and K. Halmi, *Psychiatric comorbidity in patients with eating disorders*. Psychological Medicine, 1994. **24**(4): p. 859-867.
34. Touyz, S., et al., *Treating severe and enduring anorexia nervosa: a randomized controlled trial*. Psychological Medicine, 2013. **43**(12): p. 2501-2511.
35. Tiggemann, M., *Body image across the adult life span: Stability and change*. Body Image, 2004. **1**(1): p. 29-41.
36. Newton, M.S. and L.L. Chizawsky, *Treating vulnerable populations: The case of eating disorders during pregnancy*. Journal of Psychosomatic Obstetrics & Gynecology, 2006. **27**(1): p. 5-7.
37. Micali, N., E. Simonoff, and J. Treasure, *Risk of major adverse perinatal outcomes in women with eating disorders*. The British Journal of Psychiatry, 2007. **190**(3): p. 255-259.
38. Mitchell, J.E., et al., *A retrospective study of pregnancy in bulimia nervosa*. International Journal of Eating Disorders, 1991. **10**(2): p. 209-214.
39. Morgan, J.F., J.H. Lacey, and E. Chung, *Risk of postnatal depression, miscarriage, and preterm birth in bulimia nervosa: retrospective controlled study*. Psychosomatic Medicine, 2006. **68**(3): p. 487-492.
40. Franko, D.L., et al., *Pregnancy complications and neonatal outcomes in women with eating disorders*. American Journal of Psychiatry, 2001. **158**(9): p. 1461-1466.
41. Bulik, C.M., et al., *Fertility and reproduction in women with anorexia nervosa: a controlled study*. The Journal of Clinical Psychiatry, 1999.
42. Deering, S., *Eating disorders: recognition, evaluation, and implications for obstetrician/gynecologists*. Primary care update for Ob/Gyns, 2001. **8**(1): p. 31-35.
43. Harris, A.A., *Practical advice for caring for women with eating disorders during the perinatal period*. Journal of Midwifery & Women's Health, 2010. **55**(6): p. 579-586.
44. Easter, A., et al., *Recognising the symptoms: how common are eating disorders in pregnancy?* European Eating Disorders Review, 2013. **21**(4): p. 340-344.
45. Keen, D.V., *Childhood autism, feeding problems and failure to thrive in early infancy*. European Child & Adolescent Psychiatry, 2008. **17**(4): p. 209-216.
46. Bryant-Waugh, R., *Feeding and Eating Disorders in Infancy and Childhood*. Child Psychology and Psychiatry, 2011: p. 128.
47. Chatoor, I., *Eating disorders in infancy and early childhood*, in *The Oxford Handbook of Child and Adolescent Eating Disorders: Developmental Perspectives*. 2012.
48. Wildes, J.E., N.L. Zucker, and M.D. Marcus, *Picky eating in adults: Results of a web-based survey*. International Journal of Eating Disorders, 2012. **45**(4): p. 575-582.

49. Hay, P.J., et al., *Eating disorder behaviors are increasing: findings from two sequential community surveys in South Australia*. PloS one, 2008. **3**(2): p. e1541.
50. Hay, P., et al., *Burden and health-related quality of life of eating disorders, including Avoidant/Restrictive Food Intake Disorder (ARFID), in the Australian population*. Journal of Eating Disorders, 2017. **5**(1): p. 21.
51. Fisher, M., et al., *Eating disorders in adolescents: a background paper*. Journal of Adolescent Health, 1995. **16**(6): p. 420-437.
52. Australia, M., *Youth mental health report: Youth survey 2012-2016*. Mission Australia in collaboration with the Black Dog Institute, 2017.
53. Robards, F., et al., *Predictors of young people's healthcare access in the digital age*. Australian and New Zealand Journal of Public Health, 2019.
54. Webster, J. and M. Tiggemann, *The relationship between women's body satisfaction and self-image across the life span: The role of cognitive control*. The Journal of Genetic Psychology, 2003. **164**(2): p. 241-252.
55. Gupta, M.A., *Fear of aging: A precipitating factor in late onset anorexia nervosa*. International Journal of Eating Disorders, 1990. **9**(2): p. 221-224.
56. Lapid, M.I., et al., *Eating disorders in the elderly*. International Psychogeriatrics, 2010. **22**(4): p. 523-536.
57. Reas, D.L. and K. Stedal, *Eating disorders in men aged midlife and beyond*. Maturitas, 2015. **81**(2): p. 248-255.
58. Treasure, J., et al., *The experience of caregiving for severe mental illness: a comparison between anorexia nervosa and psychosis*. Social Psychiatry and Psychiatric Epidemiology, 2001. **36**(7): p. 343-347.
59. Harvey, K., et al., *Relatives of patients with severe psychotic illness: factors that influence appraisal of caregiving and psychological distress*. Social Psychiatry and Psychiatric Epidemiology, 2001. **36**(9): p. 456-461.
60. Pépin, G. and R. King, *Collaborative care skills training workshops: Helping carers cope with eating disorders from the UK to Australia*. Social Psychiatry and Psychiatric Epidemiology, 2013. **48**(5): p. 805-812.
61. Coomber, K. and R.M. King, *A longitudinal examination of burden and psychological distress in carers of people with an eating disorder*. Social Psychiatry and Psychiatric Epidemiology, 2013. **48**(1): p. 163-171.
62. Highet, N., M. Thompson, and R.M. King, *The experience of living with a person with an eating disorder: The impact on the carers*. Eating Disorders, 2005. **13**(4): p. 327-344.
63. Soh, N.L.-W. and G. Walter, *Publications on cross-cultural aspects of eating disorders*. Journal of Eating Disorders, 2013. **1**(1): p. 4.
64. Becker, A.E., *Culture and eating disorders classification*. International journal of eating disorders, 2007. **40**(S3): p. S111-S116.
65. Slewa-Younan, S., et al., *The mental health and help-seeking behaviour of resettled Afghan refugees in Australia*. International Journal of Mental Health Systems, 2017. **11**(1): p. 49.
66. Steel, Z., et al., *Association of torture and other potentially traumatic events with mental health outcomes among populations exposed to mass conflict and displacement: a systematic review and meta-analysis*. Jama, 2009. **302**(5): p. 537-549.
67. Steel, Z., et al., *Two year psychosocial and mental health outcomes for refugees subjected to restrictive or supportive immigration policies*. Social Science & Medicine, 2011. **72**(7): p. 1149-1156.
68. Pumariega, A.J., E. Rothe, and J.B. Pumariega, *Mental health of immigrants and refugees*. Community Mental Health Journal, 2005. **41**(5): p. 581-597.
69. Kayrouz, R., et al., *Intergenerational and cross-cultural differences in emotional wellbeing, mental health service utilisation, treatment-seeking preferences and acceptability of psychological treatments for Arab Australians*. International Journal of Social Psychiatry, 2015. **61**(5): p. 484-491.
70. Feldman, M.B. and I.H. Meyer, *Eating disorders in diverse lesbian, gay, and bisexual populations*. International Journal of Eating Disorders, 2007. **40**(3): p. 218-226.
71. Diemer, E.W., et al., *Gender identity, sexual orientation, and eating-related pathology in a national sample of college students*. Journal of Adolescent Health, 2015. **57**(2): p. 144-149.
72. Rieger, E., K. Bell, and J.K. Hirsch, *Eating Disorder Symptoms and Proneness in Gay Men, Lesbian Women, and Transgender and Gender Non-conforming Adults: Comparative Levels and a Proposed Mediational Model*. Frontiers in Psychology, 2019. **10**: p. 1540.

73. (NEDA), N.E.D.A., *Eating Disorders in LGBT (Gay/Lesbian/Bisexual/Transgender) Populations.*, in 2012, National Eating Disorders Association (NEDA).
74. Schneider, J.A., A. O'leary, and S.R. Jenkins, *Gender, sexual orientation, and disordered eating.* Psychology and Health, 1995. **10**(2): p. 113-128.
75. Lakkis, J., L.A. Ricciardelli, and R.J. Williams, *Role of sexual orientation and gender-related traits in disordered eating.* Sex Roles, 1999. **41**(1-2): p. 1-16.
76. Share, T.L. and L.B. Mintz, *Differences between lesbians and heterosexual women in disordered eating and related attitudes.* Journal of Homosexuality,, 2002. **42**(4): p. 89-106.
77. Wales, M.H.C.o.N.S., *Living well: A strategic plan for mental health in NSW 2014-2024.* 2014: Mental Health Commission of New South Wales.
78. Long and e. al, *Are eating disorder patients in secure hospitals getting a fair deal? A survey of prevalence and nature of the problem.* Journal of Psychiatric Intensive Care, 2013. **9**: p. 40-48.
79. Hay, P., F. Girosi, and J. Mond, *Prevalence and sociodemographic correlates of DSM-5 eating disorders in the Australian population.* Journal of Eating Disorders, 2015. **3**(1): p. 19.
80. Yao and e. al., *Risk of being convicted of theft and other crimes in anorexia nervosa and bulimia nervosa: A prospective cohort study in a Swedish female population.* International Journal of Eating Disorders, 2017. **50**: p. 1095-1103.

